

Evaluation of a Web-Based Decision Aid for Depression:

A Mixed-Methods Study

by

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## Dedication

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## Abstract

Decision aids inform and empower healthcare consumers in their treatment decisions in an increasingly complex decision-making context where there are often numerous evidence-based treatment options across which to navigate risk/benefit tradeoffs. Evidence-based depression treatments now span several modalities including pharmacological and psychosocial approaches. Given a complex decision-making task, there is the need for consumer decision aids containing sufficient high quality evidence-based information presented in a balanced way in order to navigate options and make informed, values-congruent decisions. Of concern is the relative lack of decision support materials targeted toward adolescents and young adults (18-25 years of age), especially given high incidence rates of mental health problems and low treatment seeking. The purpose of this study was to examine young adults' evaluations of the content of a new Web-based depression treatment decision aid. Associations between sociodemographic variables and evaluative opinions were also explored. The project involved a sequential exploratory mixed-methods design, consisting of two distinct phases: a qualitative study followed by a quantitative study. Study 1 involved collection and framework analysis of interview data from a sample of 10 young adults with a history of depression treatment. Results indicated participants' high levels of familiarity as well as approval for the clarity, amount, balance, trustworthiness, completeness, and helpfulness of the information. Participants also made numerous suggestions for improvement. These suggestions were vetted by the development team and many were incorporated into a revised decision aid which was then quantitatively evaluated in Study 2 by 175 Introductory Psychology students. Participants in Study 2 rated the content of the decision aid as less familiar than those in study 1, but also had high ratings of acceptability of clarity, amount, balance, trustworthiness, and helpfulness. A gender difference was found in that a larger

proportion of women versus men endorsed the decision aid as portraying a balanced description of treatments. The findings have implications regarding strategies to develop high quality, consumer sensitive information to facilitate informed decision making in young adults. This study differed from most others of its kind in that in-depth consumer evaluation data were gathered one topic at a time versus reliance on global ratings. This provided a finer-grained evaluation of the components of the decision aid. Given that the Internet is increasingly used to search for health information, combined with research indicating acceptability of health websites by young adults, the availability of these materials on the Web may be particularly helpful to support decision-making about treatment for depression for this group.

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## Evaluation of a Web-Based Decision Aid for Depression: A Mixed-Methods Study

### *Overview*

Making the best informed choices for our healthcare is an extremely important, but also increasingly complex and challenging process (Coulter, 1997). This is mainly due to the unprecedented growth in the number and diversity of evidence based treatments for many health problems (Charles, Gafni, & Whelan, 2005), each with its own unique risk/benefit profile across which consumers and their loved ones must navigate (O'Connor, Llewellyn-Thomas, & Flood, 2004). The stress of involvement in these complex decision processes can sometimes lead consumers to defer the deliberation process and the final decision to healthcare service providers without ensuring they are making well-informed, values-congruent choices (O'Connor, 2006).

Although efforts within general medicine to increase consumers' knowledge and participation in health-related decision making have increased in recent decades, much less has been done in the area of decision making in mental health (Wills & Holmes-Rovner, 2006). This includes a mental health problem as prevalent and burdensome as depression (Kessler et al., 2005). Like choices in general healthcare, making choices about treatment for depression is also complex, given that there are several broad interventions with a significant evidence base, including pharmacological and psychosocial approaches or both in combination. Adding to the complexity is that many interventions contain a growing number of subtypes such as medication treatments with varying pharmacological agents and psychosocial treatments with varying theoretical frameworks, therapeutic components, and strategies. Members of the public dependent on health professionals for information about depression treatment may find it difficult to obtain sufficient scientifically supported information presented in a balanced way (Leape et al., 1993). If searching for information on the Internet, they may be overwhelmed by

the sheer *quantity* of information available and also challenged to sift through information of highly variable *quality* (Coulter et al., 2006).

Of growing concern is the relative lack of knowledge of the mental healthcare decision making needs of adolescents and young adults, especially given high prevalence rates (Kessler, 2007) of untreated mental health problems during this period (Dozois & Westra, 2004). This important developmental period between approximately 18 and 25 years of age has been labelled *emerging adulthood* by Arnett (2000, 2004) who points out the influence of increased stress associated with numerous life transitions inherent in this period. Lack of treatment engagement in younger adults is strongly related to lower levels of treatment seeking as compared with older adults (Oh, Jorm, & Wright, 2009). Lower treatment seeking is associated with lower *mental health literacy* (Oh et al.), referring to what people know and believe about mental disorders that aids in their recognition, management, and prevention (Jorm et al., 1997). Hence, young adults may hold negative attitudes toward mental healthcare and they may lack the background knowledge needed to identify depressive symptoms, perceive their severity, and begin to seek information and help if necessary (Jorm et al.). Even though high quality health information resources could help equip younger adults to seek and hopefully obtain effective treatment, significantly less is known about their attitudes toward health information and decision aids than is known about the attitudes of older adults (Oh et al.).

Research demonstrates that providing treatment-related information increases mental health literacy (Jorm et al., 2003) and engagement with treatment (Ogrodniczuk, Joyce, & Piper, 2005) and improves attitudes toward care (Buckley & Malouff, 2005). Specific to the Internet, research shows that high quality websites can increase mental health literacy (Christensen, Griffiths, & Jorm, 2004). However, studies measuring the effects of providing quality

information on treatment engagement and attitudes among younger individuals, whether via a website or other modality, are rare (Oh et al., 2009).

Providing high quality information to consumers and health practitioners is part of an enterprise known as *knowledge translation (KT)* which refers to the dissemination of scientific knowledge to the field where it will be utilized (Bowen & Martens, 2005). Although the above task is complex (Broomer, Franczak, Dye, & McAllister, 2001), KT efforts have been increasingly acknowledged as a key element of effective healthcare (Johnson, Green, Frankis, MacLean, & Stachenko, 1996) and mental healthcare (Kirby & Leon, 2006) for Canadians. Furthermore, evidence suggests numerous benefits at individual- and systems-levels of the implementation of KT strategies in healthcare (e.g., Johnson et al., 1996; Russell, Greenhalgh, Boynton, & Rigby, 2004).

Knowledge translation within the realm of healthcare has been described as a process of providing appropriate information in a timely fashion to decision makers in a format that is most effective in increasing informed decisions (Rock, 2006). Importantly, this endeavor does not occur in a social vacuum; it is embedded in our social/healthcare decision making context and reflects slowly changing attitudes toward decision making (Coulter, 2007). Until approximately three decades ago, the predominant approach in North America to healthcare decision making was *paternalistic* where health service providers played the dominant role. Since then, legislation, government policy, and regulatory bodies of health professions have been transitioning from paternalism to alternative models such as *informed choice* and *shared decision making*, based on consumer advocacy (Haug & Lavin, 1983) and the ethical imperative of patient autonomy (Adams & Drake, 2006). A major part of this transition has involved endeavors to



increase the provision of evidence about healthcare options to various users. Efforts have also been made to increase consumer participation in healthcare decision making (Adams & Drake).

In addition to strategies focusing directly on the consumer/health professional consultation, decision support instruments (decision aids) have become a main method for achieving the above goals (Estabrooks et al., 2001). A decision aid is a tool used to inform and empower consumers in their healthcare decision making where two or more valid treatments exist (Charles et al., 1999). Decision aids exist in many forms, including written pamphlets, interactive computer-based programs, DVDs, and websites; they address a large number of health concerns (Charles et al.). Similar to decision making studies in general, much more research on decision aids has occurred in general healthcare than in mental healthcare (Wills & Holmes-Rovner, 2006).

Due to the proliferation of decision aids in past years and findings of generally questionable quality, there has been a call for greater systematization of the development of decision aids (Coulter et al., 2006; O'Connor, Llewellyn-Thomas, & Stacey, 2005). To address this call, efforts have been made to develop more systematic approaches to decision aid development along with comprehensive quality criteria to guide the development and evaluation of decision aids (Elwyn et al., 2006). These criteria guide researchers as they plan and carry out iterative evaluation procedures in order to increase the quality, acceptability, and usage of decision aids. Additionally, consistent with the principles of informed choice and shared decision making, research highlights the importance of the inclusion of consumers early in the development and evaluation processes (Coulter et al.).

The above highlights the unique needs of young adults in their mental health information/treatment seeking. Also noted are the calls for increased quality of health

information, especially on the Internet, and the involvement of consumers early in the development of decision aids. The purpose of the current study was to contribute to the systematic development and evaluation of a decision aid for use with young adults between 18 and 25 years of age.

The introductory section is organized into two parts: the first part focuses on concepts related to decision making within the context of general healthcare as background to the latter part, which focuses on ideas and issues related to decision making within the context of mental healthcare. Within part one, discussion begins with conceptual models of healthcare decision making and is followed by a discussion of research on the decision-making needs and behaviours of healthcare consumers. This is followed by a brief review of consumer Internet use and quality of information on the Web. A description of decision aids follows, including types of decision aids, their goals and key elements, and includes the introduction of Internet-based decision aids. Finally, decision aid development and evaluation processes are discussed, and a table displays numerous aspects of published decision aid evaluation studies.

The second part introduces the concept of decision aids within mental healthcare with a focus on the information and participation needs of mental health consumers, Internet use for health and mental health information, and the issue of the quality of the information searchers often find on the Web. After this, there is a description of adult depression and its treatment followed by a focus on the issue of the relative lack of research on decision making and decision aids for young adults. This is followed by a discussion of decision aids addressing depression and shows that there is a shortage of relevant web-based decision aids, especially those consisting of high quality, balanced information designed for use by consumers. Lastly, the development of the current decision aid is discussed.

## Healthcare Decision-Making Models

Decision aids have been available in healthcare in some form for many years (Adams & Drake, 2006). However, the last twenty years has seen major growth in the development of patient decision aids, including the type, number, and contexts of their utilization (Charles et al., 2005). It is important to note that the development of decision aids has occurred within the greater context of healthcare decision making and that several decision-making models have been proposed to represent this context. These include the paternalistic model, informed decision making, and shared decision making. One helpful way to understand these models is to compare key aspects of decision making across the models. Two important aspects are: (1) the nature of the consumer/health practitioner information exchange; and (2) the nature of the decision making process (Charles et al., 1997).

### *Paternalistic Model*

Traditionally, health practitioners (often physicians) have been seen as biomedical experts functioning as unilateral decision makers on behalf of healthcare consumers. This is termed the *paternalistic* paradigm (Adams & Drake, 2006). Looking at the paternalistic paradigm from a sociological perspective, consumers are viewed as *patients* occupying the *sick role* and thereby are granted (by practitioners) temporary rights and obligations inherent in that role (Parsons, 1951). For example, healthcare consumers operating as patients in the sick role may be excused from activities related to family and work and are obligated to pursue recovery from their illness, to seek medical help, and to adhere to medical advice. In short, consumers are seen as mainly passive and dependent on their physician as expert (Charles et al., 1997). Within this model, the exchange of information along with treatment preferences is primarily one way:

from physician to consumer. Additionally, the consumer is expected merely to accede to the physician's advice and provide consent for treatment (Emmanuel & Emmanuel, 1992).

Researchers point out some key assumptions that underlie the paternalistic model and how the model has been challenged. For example, Charles and colleagues (1999) note the following: First, prior to the 1980s, it was thought that for any given illness there existed one single best treatment with which physicians were not only familiar but also equipped to provide to consumers. Second, it was assumed that physicians would be consistent in their application of the *best treatment* for consumers. Third, it was thought that physicians, due to their technical knowledge and expertise, were in the best position to evaluate tradeoffs between various treatments and to make the final decision. Fourth, based on their professional concern for protecting the welfare of consumers, physicians had a legitimate investment in each treatment-related decision. Physician control was further legitimized by professional codes of ethics binding physicians to act upon the best interests of healthcare consumers (Lomas & Contandriopoulous, 1994). Charles and colleagues note that the above assumptions led to both physicians' and consumers' expectation that a physician occupied the principal role in treatment decision making.

Since the 1980s, the above assumptions have come under scrutiny. For example, it has become increasingly evident that for a growing number of health problems, no single best treatment exists. Furthermore, due to different types of risk-benefit tradeoffs across an often growing number of treatments for a particular health problem, conceptualizations of the decisional context have become significantly more complex (Coulter, 1997). Given that the consumer, and not the physician, has to experience the consequences of these tradeoffs, the assumption that the physician is in the best position to make the evaluation on a consumer's

behalf was challenged (Eddy, 1990; Levine et al., 1992). Concurrently, research examining the quality of medical care across a wide range of physician services found considerable variation in terms of physician procedures for the same disease, even across small geographic regions (Leape et al., 1993). Findings also indicated that these variations were unrelated to a given population's health status (Leape et al., 1993; Roos, 1984; Roos, et al., 1988; Wennberg et al., 1987).

Rising healthcare costs combined with the increasing concerns about the quality of care led to recommendations that physicians be more accountable to their patients and to the public (Katz, Charles, Lomas, & Welch, 1997). In addition, Haug and Lavin (1981, 1983) noted a gain in popularity of the principles of *consumer sovereignty* and *caveat emptor* (let the buyer beware), which was eventually evidenced in new legislation requiring informed consent prior to the implementation of treatment (Haug & Lavin, 1983). Additional legislation was passed protecting a healthcare consumer's right to be informed about all available options for treatment (Nayfield, Bongiovanni, Alciatti, Fischer, & Bergner, 1994; Ontario Ministry of Health, 1994). *Caveat emptor* and *consumer sovereignty* were also manifested in the growing interest within consumer and physician populations in developing and promoting new approaches to decision making which would entail a more substantial role for consumers in the process (Brody, 1980; Cahill, 1996; Charles et al., 1997a, 1999; Emanuel & Emanuel, 1992).

### *Informed Decision Making*

The informed decision-making (IDM) model is sometimes referred to as the autonomous choice model and is the polar opposite of the paternalistic model. In general, it attempts to shift the focus from the clinician to the consumer and emphasizes and safeguards consumer autonomy (Charles et al., 1999). This model limits the role of the clinician to provider of problem- and treatment-related information so as to aid in the consumer's treatment deliberation and choice.

The model recognizes that, even though patients' values and preferences ought to play a greater role in treatment decision making (Coulter, 1997), health professionals usually have much more of the technical knowledge and expertise. Hence, technical information is said to be located in one member of the interaction (i.e., the healthcare professional), whereas treatment preferences are said to be located in the other member (i.e., the consumer). It has been pointed out that both types of information need to be incorporated if effective care that results in improvements in health status valued by patients is to be realized (Hurley, Birch, & Eyles, 1992; Levine, Gafni, & Markham, 1992). Within the IDM model, this is achieved by augmenting the consumer's knowledge of the potential risks and benefits across the available treatment options. The goal is to enable consumers to make decisions that mirror their preferences as well as the best scientific knowledge available (Hurley et al.).

Whereas in the paternalistic model control of the deliberation process and the final treatment decision resides in the clinician, in the IDM model this control shifts to the consumer. Common to both models, information primarily flows one-way (practitioner to consumer; Charles et al., 1999). What is not present in the IDM model is the clinician's values and preferences (Emanuel & Emanuel, 1992). Therefore, while it has been proposed that the paternalistic decision-making process excludes the consumer, the IDM decision-making process, at least in terms of values, excludes the practitioner (Charles et al.).

### *Shared Decision Making*

Elwyn et al. (2001) define shared decision making as a process involving participation of both consumer and healthcare provider to achieve mutual agreement on a treatment decision. This model focuses on the consumer and considers whether consumers have indeed participated in the decision process from two perspectives: the consumer and the clinician. From the

perspective of the clinician, consumer participation occurs if the clinician has helped the consumer understand all the information, if the clinician clearly understood and incorporated the consumer's values, and if the clinician answered all of the consumer's questions. From the standpoint of the consumer, consumer participation is realized if the consumer was sufficiently involved in decisions regarding the treatment and is satisfied with how the treatment was discussed and decided upon (Elwyn et al.).

Charles and colleagues (1997) propose that there are at least four key characteristics of shared decision making (SDM): (1) it involves a minimum of two participants (commonly a practitioner and a consumer but often others such as family members); (2) both parties make efforts to build consensus regarding the preferred treatment; (3) information is exchanged between parties; and (4) a treatment decision is made and agreed upon by both parties (Charles et al.). In a SDM model, the consumer and practitioner initially consider medical/healthcare treatment evidence and discuss benefits and risks of different treatment/screening options (including watchful waiting). Following this, the consumer is encouraged to deliberate and to take as much responsibility as desired in making an informed choice regarding treatment and its implementation. "In shared decision-making, the practitioner becomes a consultant to the client, helping to provide information, to discuss options, to clarify values and preferences, and to support the client's autonomy" (Adams & Drake, 2006, p. 88).

As opposed to the paternalistic model, both IDM and SDM grant the consumer more control of the deliberation process. However, unlike IDM and the paternalistic model, the deliberation process in SDM is interactional in that it invites both the consumer and practitioner to collaborate about treatment-related values and preferences and to reach consensus about the treatment. Unique to SDM is also the exchange of information: whereas in both the paternalistic

and IDM models the information flow is one way (i.e., clinician to consumer), in SDM, the information flows bidirectionally (Charles et al., 1999). It is important to note that, even though SDM invites consumers to engage in the decision-making process, the model does not *require* full participation and can accommodate consumers who prefer to have the practitioner deliberate and even make the final decision unilaterally (Charles et al.).

Even though SDM has grown in its acceptance in current healthcare, Coulter (1997) noted several concerns voiced by critics of SDM. First, it is argued that many patients have no desire to participate in treatment decisions. Second, it is proposed that communicating uncertainties inherent in medical treatments can be harmful to healthcare consumers. Third, some believe that providing risk/benefit information of all possible treatments is not feasible. Fourth, some argue that an increase in consumer involvement in treatment decision making would likely lead to an increased demand for unnecessary, expensive, or harmful medical procedures (Coulter).

Although understandable, these criticisms have for the most part been answered by research evidence. For example, in terms of a desire to participate in healthcare decision making, O'Connor et al. (2003) surveyed Canadians who had made a complex healthcare decision and found that, after consulting with their physician, 39% assumed an active role in decision making, 23% shared the decision with their physician, and only 6% assumed a passive role. Additionally, research indicates that communicating uncertainties in medical treatment does not lead to increases in potential harm. For example, a recent Cochrane review of the decision aid literature found no increases in anxiety and similar levels of satisfaction and ultimate health outcomes when comparing the use of SDM and decision aids to usual care (Stacey et al., 2012). Though



not exhaustive, the above suggest that SDM and the use of a decision aid do not increase risks of harm for patients.

Another study with a sample of depressed patients found that the use of doctor/patient communication in keeping with a SDM model along with the use of a decision aid resulted in greater patient participation in treatment decision-making and also found no increase in consultation time compared with usual care (Loh et al., 2007). Therefore, communicating risk/benefit information of relevant treatments to consumers was shown to be feasible in this study. In terms of increased demands for expensive, unnecessary treatments or screenings, numerous efficacy trials using SDM and decision aids have shown no such increase (e.g., Street, Voigt, & Geyer, 1995; Whelan, Levine, & Willian, 2004).

Numerous studies have also found that consumers desire much more information than they often receive pertaining to a broad range of screening and treatment considerations (e.g., Hill & Laugharne, 2006; Walker, Vincent, Furer, Cox, & Kjernisted, 2000). Adherence to SDM and utilization of decision aids offer some of the most effective ways of providing that information. In fact, the aforementioned Cochrane review demonstrates that the use of decision aids significantly improves consumers' knowledge of options compared with usual care alone (Stacey et al., 2012).

#### Healthcare Consumers' Decision-Making Needs

Studies of consumers' decision-making needs focus on both their information needs (e.g., Walker et al., 2000) and their participation needs or control preferences (e.g., Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Degner, & Sloan, 1992; Degner et al., 1997). Consumers require sufficient information in order to understand their health condition as well as to make an

informed choice about treatment options. Many also desire at least some level of control over the deliberation process and the final choice (Degner & Sloan).

### *Information Needs*

Healthcare consumers (patients and nonpatients) consistently report a need for information regarding health problems (Hill & Laugharne, 2006) and risks and benefits of treatment options (Stiggelbout & Kiebert, 1997), much more so than health professionals often perceive (Cox, Britten, Hooper, & White, 2007). For example, in a focus-group study of information needs regarding medications (Nair et al., 2002), patients wanted basic information about the treated condition as well as specific information regarding side effects, treatment duration, and range of treatment options available to them. However, physicians and pharmacists in this study tended to question the amount of safety and side-effect information patients desired, feeling that this information might reduce medication treatment adherence (Nair et al.). A study focusing on patients recently diagnosed with inflammatory bowel disease (Bernstein et al., 2011) found that 24% felt dissatisfied with the information provided to them by health professionals at the point of diagnosis. Thirty-one percent and 45% reported feeling moderately satisfied and very satisfied with the information, respectively. In spite of these ratings indicating satisfaction with the information provided, there was general agreement among patients that the amount of information provided to them was inadequate (Bernstein et al.).

Grime and colleagues (2007) reviewed the value and role of written information pertaining to medication and found that patients place a high value on information that supports decision making, especially as the information is tailored to their health condition and is sufficiently detailed (Grime, Blenkinsopp, Raynor, Pollock, & Knapp, 2007). Findings that support patients' desire to be well informed are found in qualitative and quantitative research

addressing numerous general health conditions including cancer (Beaver et al., 1999; Bilodeau & Degner, 1996; Hack et al., 1994), prostate cancer (Wong et al., 2000), and mixed conditions (Nair et al., 2002). The overall findings strongly indicate that most patients desire a breadth of information about their illness as well as characteristics of their treatment options (e.g., treatment duration, effectiveness, and side effects).

### *Participation Needs*

There is substantial research indicating that the majority of consumers desire to participate beyond being well-informed in their healthcare decision making (e.g., Benbassat, Pilpel, & Tidhar, 1998). However, there is some variability in terms of the degree and specific ways in which patients/consumers prefer to be involved, varying across studies, individuals, and health problems.

Studies focused on decision making in populations of breast and prostate cancer patients have shown a preference for a shared/collaborative role (e.g., Degner et al., 1997; Hack et al., 1994; Wong et al., 2000). These studies used forced-choice scales such as the Control Preferences Scale (CPS; Degner, Sloan, & Venkatesh, 1997) to assess an individual's preferred degree of involvement (i.e., passive; collaborative; active). Results indicate that a majority of patients (44% to 60%) preferred an "active-collaborative" decision-making role with their physician. That is, patients preferred to make the final decision after taking the doctor's opinion into consideration. However, preferred roles tended to vary based on several factors. For example, some studies found that younger, more educated patients (e.g., Davison et al., 2002) or non-patient participants responding to hypothetical situations (e.g., Degner & Sloan, 1992; O'Connor et al., 2003) tended to favour more active participation when compared with older, less educated and/or *actual* cancer patients facing real treatment decisions who tended to leave

the final decision with their physician after considering options provided (e.g., Beaver et al., 1999; Davidson, Brundage, & Feldman-Stewart, 1999).

### *Internet Use for Health Information and Decision Support*

The majority of consumers desire information relevant to healthcare treatment decision making and want to participate in decision making. Besides obtaining information from healthcare practitioners, books, or close friends and family, many now turn to the Internet. The following brief discussion focuses on health information in general and not necessarily information contained in decision aids, recognizing that individuals at times find web-based decision aids by conducting general Internet searches for health information (Morris, Drake, Saarimaki, Bennett, & O'Connor, 2008).

Searching for information regarding health is one of the most common tasks performed by Internet users (Bader & Theofanos, 2003). Baker et al. (2003) surveyed U.S. households in 2001 and found that 40% of respondents having Internet access used it to search for healthcare-related information. Approximately one-third of respondents reported that this information affected a decision pertaining to their health (Baker, Wagner, Singer, & Bundorf, 2003). More recent examination revealed a trend for increases in health-related searching on the Internet. Specifically, a survey of 203 U.S. patients found that 77% had accessed the Internet at least once, that 79% of web-users had used the Internet to gather health-related information, and that 73% had incorporated the information into their healthcare decision making (Liszka, Steyer, & Hueston, 2006).

Similarly, research with Canadian samples has also demonstrated increases in the level of the public's Internet usage. The Canadian Internet Use Survey (CIUS, Statistics Canada, 2005) found that 68% of Canadian adults (18 years or older) used the Internet for non-business related

personal reasons during 2005. Ninety percent of the sample accessed the Internet from home and 58% of these home users utilized the Internet to search for information related to health (Underhill & McKeown, 2008). In 2008, the survey was readministered to adults 16 years and over (Statistics Canada, 2008). Results indicated that 78% had used the Internet for personal reasons that year. Additionally, 68% of home users accessed the Internet every day and half of users spent five hours or more on the Web every week. Canadian usage was seen to vary based on several factors such as age and income level. Specifically, 96% of younger respondents (16 - 24 years of age) went online versus 29% of seniors aged 65 years and older. Persons in higher income brackets reported more frequent Internet use (i.e., 91% in top quintile); however, usage in the lowest income quintile has been on the rise (i.e., 47%; Statistics Canada, 2008).

Specific to Internet searches for health information and decision support, one study (Couper et al., 2010) examined Internet use and perceived importance of varying sources of information within a sample of 2575 adults 40 years and up making a variety of medical decisions. Findings indicated generally lower than average use of the Internet (i.e., 28%) with usage varying across types of decisions, from 17% usage for breast cancer screening to 48% for hip/knee replacement. The authors reported that web-usage was higher at younger ages, increasing from 14% among participants 70 years old and above to 38% for those aged 40 to 49 years. Additionally, the greatest importance was reported for information from healthcare service providers, followed by the Internet, family, and friends. A study with a younger sample of 145 university students (18-25 years of age) found that greater than 70% of respondents used the Internet to search for health-related information (Hahlweg et al., 2010). The kinds of information these respondents accessed on the Internet included lifestyle, analysis of symptoms, diseases,

drugs/medications, healthcare system or delivery, alternative therapy, and surgeries (Hahlweg et al.).

Very little research has been conducted to explore Internet usage for accessing decision aids. One author noted an estimate by a high-volume producer of decision aids in North America (i.e., Healthwise) that decision aids were accessed approximately nine million times in 2006, mostly through the Internet (O'Connor et al., 2007). Another study examined if individuals could find decision aids on the Web using the most common general search engines (Morris et al., 2008). Results of this study showed that most first-page results linked to informational webpages regarding the condition. Only 16% of search results linked to a patient decision aid (Morris et al.). The authors concluded that, while some search terms and search engines were more successful than others, few resulted in direct links to decision aids. The above indicates the steady rise of consumer usage of the Internet to search for and access health-related information and decision aids. Given this, concern has also grown as to the quality of the information consumers encounter using this medium.

#### *Quality of Health Information on the Internet*

Evaluation research has revealed concerns about the quality of health and treatment information provided to consumers on the Internet and otherwise (e.g., Cline & Haynes, 2001; Coulter, Entwistle, & Gilbert, 1998, 1999; Raynor et al., 2007). Typical criticisms find information regarding health on the Internet to be inaccurate, incomplete, misleading, ignoring of uncertainties, and based on insufficient evidence (Cline & Haynes; Coulter et al., 1999). For example, in a review of 79 information-quality evaluation studies, it was found that the majority of studies (i.e., 70%) deemed information quality on websites to be problematic, whereas some (i.e., 17%) were neutral in their evaluation, and very few (i.e., 9%) had a positive evaluation

(Eysenbach, Powell, Kuss, & Eun-Ryoung, 2002). A more recent study (Coulter et al., 2006) surveyed the literature for health information regarding several health-related topics (i.e., chronic obstructive pulmonary disease; arthritis; healthy eating/obesity; and measles, mumps, and rubella vaccinations.). This study examined information in formats including the Web and printed materials and found that the quality of patient information regarding these four topic areas is in need of improvement, especially in terms of the accuracy, reliability, and completeness of clinical information (Coulter et al.).

Some authors propose potential solutions to the above problems in information quality including that producers of health information start with information needs defined by consumers, provide treatment information predicated on rigorous systematic reviews, and engage multidisciplinary teams (including patients) in developing and testing the materials (Coulter et al., 1999). Unfortunately, based on more recent reviews, it appears little has been done to accomplish these goals on websites within general healthcare (e.g., Coulter et al., 2006) or in mental healthcare (e.g., Reavley & Jorm, 2010, as discussed in a subsequent section).

### Decision Aids

Decision aids have been defined as “interventions designed to help people make specific and deliberative choices among options by providing information about the options and outcomes that is relevant to a person’s health status” (O’Connor et al., 2007, p. 2). In general, decision aids flow naturally from the shared decision-making (SDM) model and are intended not to replace the clinical encounter, but as adjuncts to counseling with healthcare practitioners (Charles et al., 1997). They are explicit regarding choices and facilitate consumers’ expression of their preferences in clinical situations (McCaffery et al., 2007). Barry (2002) notes that decision aids facilitate SDM in cases where there is more than one reasonable treatment/screening option

(i.e., *decision-making* tasks; Deber, 1994) and allow for a better match between health problem-management decisions and consumer preference. Importantly, they are not designed for situations where one clear scientifically validated treatment or screening procedure is indicated (i.e., *problem-solving* task; Deber). However, it could be argued that even consumers in the latter situation would benefit from utilization of a decision or information aid; even if there is only one valid treatment procedure, there remains a choice between taking that treatment and taking no treatment at all. Consumers may prefer to be well informed even if they decide to take a single treatment option.

Similar to the development of the SDM model, decision aids developed primarily out of public (e.g., consumer) requests for more information about healthcare choices and a desire to increase participation in the decision-making process (Stacey, Samant, & Bennett, 2008). Initial decision aids grew mainly out of concerns about high-risk treatment options often for serious illnesses such as cancer (Charles et al., 1999) but have since been designed to address many other health problems such as asthma, back pain, and acne. More recently, decision aids addressing mental health problems such as depression have also been developed (e.g., Loh et al., 2007) but they are limited in number (as will be discussed).

O' Connor and colleagues (2003) note that, although specific goals of particular decision aids may vary, their *general aims* are to enable individuals to: (1) understand the probable outcomes associated with particular options by providing decision-relevant information; (2) consider the personal value placed on benefits and costs (harms) via a process of preference clarification; (3) feel supported in making the decision; (4) progress through decision-making steps; and (5) actively participate in making decisions about their healthcare (O'Connor et al.).



*Goals for Decision Support and Decision Aids—Ongoing Debates*

There has been some debate about the primary goals of decision aids and how to evaluate effectiveness. Many researchers (e.g., Charles et al., 1998; O'Connor et al., 2003) emphasize what are commonly known as *decision process* variables such as patient knowledge, decisional conflict, satisfaction with the decision, anxiety related to the decision process, and the extent to which a decision was followed through. In fact, much evaluation research on decision aids focuses on these outcomes (see ongoing Cochrane reviews; Stacey et al., 2012; see also Kennedy, 2003). However, other researchers have argued that decision aids should be evaluated more on the basis of health outcomes than decision process variables (Entwistle, Sowden, & Watt, 1998; McCaffery, Irwig, & Bossuyt, 2007). The rationale for a focus on health status outcomes rests on the notion that decision aids are used in the context of a healthcare system aimed primarily at improving patients' health and well-being. In this argument, decision aids should be evaluated in terms of how they contribute to this primary goal. Hence, these authors propose that improving the long-term quality of life (QoL) of a patient trumps aiding the short-term decision process. For example, McCaffrey and colleagues (2007) question the utility of a decision aid if it successfully abbreviates and simplifies a decision-making task and increases the satisfaction with the decision but leads to a poorer long-term health outcome. Furthermore, the authors question a negative evaluation of a decision aid if it protracts and complicates the decision process but eventually leads to improved health outcomes. In the former, they propose the aid has failed; in the latter, that it has succeeded. However, this conclusion is starkly contrasted with many evaluation studies of decision aids (e.g., O'Connor et al., 2009).

The argument to focus primarily on health status outcomes as opposed to decision process variables seems predicated on the primacy of the healthcare system to focus on the goal

of improving long-term patient health and well-being. One of the examples used by McCaffrey et al. (2007) suggests that some patients (e.g., deemed low on treatment adherence) might experience greater improvement in health if a clinician used a more *directive* approach versus a decision aid. In this *clinician-led* treatment decision process, the clinician could justifiably exclude other viable treatments and offer only the single treatment *believed* to have greatest potential for patient adherence and presumably lead to the best health status outcome. The patient would not be offered input into the choice; indeed, the patient would not be made aware that a choice existed. However, this example presumes that a given physician possesses more comprehensive and accurate knowledge of the patient and a level of predictive accuracy than may be realistic. It also disregards a patient's right to be informed and involved in a decision with which he/she will have to live. Hence, this is a clear deviation from informed choice and shared decision making and rather resembles the paternalistic model.

In contrast, Kennedy (2003) acknowledges the lack of inclusion of health status as a primary outcome variable in decision aids research and proposes several reasons for this. First, he notes the likelihood that associations between the use of a decision aid and health status improvement are weak and unlikely to accrue for many years. Hence, researchers would be challenged by the need for very large samples and long-term follow-up. Second, decision tools are most often utilized in situations where there is no one best treatment; therefore, the decision between the options will often be based on a patient's values. Given that the treatments are approximately equal in their efficacy, it would be unlikely to expect a difference in health status as a result of using a decision aid. Third, in the event that there are differences in effectiveness of treatment options, deliberation may be less than straightforward due to certain aspects of each of the options. For example, in cases where the potentially most effective intervention entails a

protracted recuperation period, patients may logically choose a less effective option in order to maintain their lifestyle (Kennedy).

Kennedy (2003) also proposes that using QoL and health status variables as primary measures of effectiveness is problematic because patients may quite rationally choose options for treatment that do not maximize their long-term health status. He notes that our current system allows for this kind of patient autonomy. Even though Kennedy discusses the difficulties inherent in making health outcomes *primary*, the consensus among researchers appears to be that these variables are relevant aspects of how a decision aid can improve patient care. Thus, many see QoL and health status variables as valid *secondary* measures of the effectiveness of a decision aid (e.g., O'Connor et al., 2009).

Although few in number, some decision aid studies have included health status outcomes. Of these studies, most have failed to find effects in both general health and condition-specific health. In terms of general health, small effects were found on generic health and physical functioning variables in one study of men considering treatments for benign prostatic disease (Barry, 1997). Similarly, in two studies of women thinking about treatments for abnormal uterine bleeding, improvements were found in terms of physical (Kennedy, 2002) and emotional (Vuorma, 2003) functioning. In studies of condition-specific health outcomes, only one of seven studies included in the most recent Cochrane review (Stacey et al., 2012) found statistically significant effects. That is, Deyo (2000) found improvement in back pain severity at one year follow up. Thus far, the evidence supporting the ability of a decision aid to impact health outcomes is less than convincing. Hence, the relationship between decision aids and health status may be relatively weak and currently too difficult to capture as Kennedy (2003) proposes.

Even though the above debate persists, many researchers continue to prioritize decision process variables over health status (e.g., Charles et al., 1998; O'Connor et al., 2003; O'Connor et al., 2009). This is consistent with the SDM model and the ethical imperative of informed choice. As such, their primary aim is to help consumers make informed, values-congruent choices. On that note, a well-accepted definition of what constitutes a *good decision* is one that is informed, values congruent, and implemented (O'Connor et al., 1998).

Both decision process variables and health status variables are reflected in the principles described in the Canadian Psychological Association (CPA) code of ethics. Specifically, these are: (1) respect for the dignity of the person, and (2) responsible caring. Decision process variables are strongly implied in the first principle in that the person is an end in him/herself, not a means to an end and it raises the importance of individual self-determination. Simply, a person has a right to be informed about the details of her/his health problem and treatment options, including costs and benefits thereof in order to make an informed choice. People also have the right to responsible caring in that professionals need to offer and provide the most effective and least harmful treatment available. Should a conflict of interest across ethical principles arise, psychologists are instructed to give greatest weight to the first principle. The only exception noted is imminent physical danger (which is technically only an issue in healthcare *problem-solving* situations and not in *decision-making* situations; Deber, 1994).

Based on the above ethical principles, it seems logical that decision process variables take priority over health status variables when evaluating the effectiveness of a decision aid. Delivering services in the way that McCaffrey et al. (2007) suggest in their example requires a reversal of the priorities as laid out by ethical guidelines. Hence, it is proposed that *decision process variables* appropriately comprise key goals of decision aids and are legitimate *outcome*

*variables* in their own right. Finally, the focus on decision process variables has been further legitimized by an internationally agreed upon set of criteria for the quality and effectiveness of decision aids (i.e., International Patient Decision Aids Standards; IPDAS; Elwyn, 2006). These standards focus on outcomes of decision process variables such as patient knowledge and match between patients' values and chosen treatments.

#### *Key Elements of Decision Aids*

Decision aids occur in several formats including decision boards, programs for personal computers, audiotapes, interactive videodiscs, audio-guided workbooks, group presentations, pamphlets, and websites. In keeping with the emphasis on variables related to decision quality or process, O'Connor and Stacey (2005) propose *five key elements* that are commonly agreed upon in this literature.

First, the decision aid should *provide facts* regarding the condition, options, and outcomes pertaining to the consumer's health status. Most of these tools begin with a brief description of the clinical circumstances that have stimulated the individual's need to consider a set of options and potential outcomes. Consumers wish to be informed about the conditions or health problems they face and the common manifestations and potential complications. They also need to be informed about treatment options in terms of what they include, the technique and duration of delivery, and the consumer's involvement in their use (O'Connor & Stacey, 2005).

Second, decision aids should *communicate risk* regarding the probability of particular outcomes and the level of scientific certainty. Outcomes of each healthcare option are described with detail adequate to help consumers understand the experience of such an outcome. The authors note that the evidence should be provided to substantiate claims about these outcomes

drawing from research on quality of life. Presenting probabilities of stated outcomes provides the benefit of helping to create realistic expectations regarding potential outcomes.

Third, decision aids *provide opportunities for the clarification of values* to ascertain the specific benefits, harms, and scientific uncertainties that matter most to the healthcare consumer. Two primary ways of clarifying values are to: (1) use the descriptions of outcomes as vicarious experience by which to judge their value, and, (2) ask consumers to explicitly think about the personal importance of each risk and benefit (O'Connor & Stacey, 2005).

Fourth, decision aids often *provide structured guidance* through the steps involved in collaborating and deliberating with the healthcare practitioner. This is commonly done by delineating to consumers the decision-making steps and presenting strategies for follow-up discussions with their service provider. Steps include: considering personal risks and benefits, clarifying personal values, listing current health habits, listing questions, indicating preferred decision-making role, and indicating present predisposition toward the options. Finally, decision aids should provide a *balanced display* of both positive and negative characteristics of the options (O'Connor & Stacey, 2005).

#### *Web-Based Decision Aids*

Over the past two decades, healthcare consumers have witnessed the increasing development of decision aids based on computers and the Internet which incorporate several features that set them apart from most non-web based decision tools. One reviewer (i.e., Schwitzer, 2010) pointed out four such features that may be included: (1) the presentation of probability data regarding outcomes that is customized to the individual user; (2) the use of videos of patient interviews that convey the experiences of consumers who have faced the diagnosis in the past; (3) the capacity to interact with other people in a social support network;

and (4) the accessibility of the aid to any healthcare consumer having an Internet connection. Given findings of great variability in terms of consumers' desire for information and especially participation in decision making, development of decision aids that allow an idiosyncratic approach to providing information and engagement in decision making is advantageous.

Similar to non-Internet decision aids, web-based decision tools require evaluation of content; however, more unique to web-based decision aids is an aspect of evaluation known as *usability*. Usability refers to the process of ensuring a tool like an Internet-based decision aid works well: that someone of average (or below average) ability and experience can use the tool for its intended purpose with minimal frustration (Krug, 2006). Usability testing of web-based decision aids usually involves having participants work with the aid, performing various pre-determined as well as spontaneous tasks, while being observed by an evaluator. Feedback is gathered, synthesized, and appropriate changes are made to the program. The process usually begins with the developers (known as *alpha*-testing) and culminates in testing with targeted users and/or members of the public (*beta*-testing; Krug). Further discussion of the evaluation of web-based decision aids, especially those for mental health problems, is provided below.

## Developing and Evaluating Decision Aids

### *Theories and Models*

There is a persistent concern about the relative lack of theories and models to aid in understanding *how* decision aids work to support decision making (e.g., Elwyn, Stiel, Durand, & Boivan, 2011). One review focused on the utilization of theoretical frameworks and models in randomized-controlled trials (RCTs) of decision aids (Durand et al., 2008). Of the 50 RCTs reviewed by the authors, only 17 made reference to an underlying theory or model. Of these, 11 included a description of the theory or model; however, the degree to which the theory informed

the development, field testing, and evaluation of the decision aids was often not explicit. The authors note that without reference to underlying theory or models, it is difficult to understand how decision aids do or do not impact the decision-making process and outcomes. Although there are other theories and frameworks relevant to decision aids, the following briefly presents two of the most commonly used theories and frameworks for development and evaluation of decision aids (decision analysis and the Ottawa Decision Support Framework).

*Decision analysis* is derived from *expected utility theory* which was originally postulated by Bernoulli (1954) and further developed by others (Kahneman & Tversky, 1979; Pratt, Raiffa, & Schlaifer, 1964). Expected utility theory and decision analysis are considered *normative* theories in that they specify how a person *should* process information and come to a decision under what are presumed to be ideal conditions (Durand et al., 2008). Expected utility theory was developed to predict the choices people make under uncertainty. It was originally created to describe how individuals make risky choices with monetary implications but has also been used to describe other choice making including choices involving health outcomes (Hellinger, 1989).

Decision analysis was introduced in 1964 (Howard & Matheson) and is the express application of expected utility theory, most particularly as it pertains to the development of *decision trees*. Decision trees have been extensively used in designing decision aids over more than a decade and consist of assigning degrees of cost and probability of particular occurrences and combining them to generate the expected cost of each of a number of courses of action. In the realm of decision aids, patients are asked to indicate the value of each available health option on a numerical scale. Then, the utility levels are multiplied by the probabilities of each outcome for the purpose of identifying the option with the highest subjective utility (Robinson & Thomson, 2000).



### *Ottawa Decision Support Framework*

Over the past two decades, researchers have worked to develop the Ottawa Decision Support Framework (ODSF; O'Connor, 2006; See Appendix A) designed to improve the quality of healthcare decisions. The framework is designed to apply to all who participate in the decision making task, including individual patients, couples, families, and healthcare practitioners.

#### *Conceptual Framework of ODSF*

The conceptual framework for the ODSF derives from several models or theories such as the *expectancy value model*, *decision analysis* (described above), *prospect theory*, the *conflict theory model of decision-making*, and the *theory of reasoned action* (O'Connor, 2006). The expectancy value model (Fishbein, 1975) proposes that persons who are asked to make a choice between two or more options embodying significant benefits and harms are most likely to choose the option with the greatest expected values and success. Prospect theory or framing bias theory (Tversky & Kahneman, 1981) was created as a critique of expected utility theory accounting for the observation that some decision makers behave contrarily to the predictions based on expected utility theory. Prospect theory posits a two-fold process of choice: editing and evaluating. Editing refers to the analysis of the offered prospects and is followed by evaluating, which consists of evaluating the offered prospects and choosing the one most highly valued. Importantly, prospect theory also proposes that the way in which a prospect is described or *framed* affects the choices made by individuals. Research in this area has demonstrated a tendency for individuals to place greater value on losses than gains (Tversky & Kahneman, 1981).

The conflict theory model of decision-making (Janis & Mann, 1977) postulates that the decision making process creates stress, conflict, and uncertainty within the decision maker. The main coping strategy for the decision maker is to search out and evaluate information and/or

alternatives. The theory of reasoned action (Ajzen & Fishbein, 1980) proposes that the determining factors in forming an individual's intention to engage in behaviour include not only the decision maker's attitudes but also the subjective norms of important others regarding the intended behaviour.

### *Components and Definitions of ODSF*

The Ottawa model posits that participants' *decisional needs* affect *decision quality*, which in turn affects *behaviour, health outcomes, and use of health services* (O'Connor, 2006). The ODSF also includes the concept of *decision support*. The concept of decisional needs refers to participants' level of decisional conflict/uncertainty, their current knowledge and expectations, their values, their personal and/or clinical characteristics, their personal support and resources, and the nature of the decision in which they are engaged (type, timing, stage, and leaning). The decision quality construct encompasses aspects such as whether or not the decision was informed and whether or not it was congruent with an individual's personal values. Decision behaviour entails delay or follow-through with the decision making process. Decision types include those focused on clinical options (e.g., screening, testing, treating), number of options, amount of risk/uncertainty, seriousness of outcomes, and irrevocability of outcomes (O'Connor).

The Ottawa model asserts that decision support can improve the quality of a healthcare choice (O'Connor et al., 1998). Decision support entails several points of intervention: (1) providing information regarding the nature of the available treatments along with probabilities for various outcomes and/or side-effects associated with each treatment; (2) helping an individual gain clarification of decisional needs; (3) helping an individual to clarify personal values pertaining to the decision; and (4) providing direct guidance and coaching to aid the

individual in the above. The two modalities for decision support intervention are patient counseling and the use of a decision aid (O'Connor et al.).

The ODSF addresses decision quality and measures it in two ways: (1) *quality of the decision*; and (2) the *quality of the process of decision making*. The quality of the decision is defined as the degree to which the option chosen matches informed patients' values for harms, benefits, and scientific uncertainties. The quality of the decisional process is defined as the degree to which a client is helped to: (a) identify a required decision; (b) be acquainted with the available options and related procedures, harms, benefits, probabilities, and scientific uncertainties; (c) understand the effect that personal values have on the decision; (d) gain clarity about which aspects of the options are of greatest significance to them (e.g., harms, benefits, uncertainties); (e) discuss values with healthcare practitioner(s); and (f) participate in decision making in preferred ways (O'Connor, 2006).

Basing the current study on the Ottawa model offers the advantage of structure. In general, contextualizing the current study within a broader framework of research and intervention provides greater understanding of its place and contribution to the field of decision support; it also guides ongoing conceptualization and planning of future studies with the current decision aid. The ODSF incorporates the concept of decision support to improve decision quality using strategies such as providing information to decision makers. The current decision aid fits into the model as a mechanism for decision support.

#### *Quality Criteria Framework*

The ease with which consumers can access health information has greatly increased due to the availability of the Internet. Unfortunately, research has generally found health information of questionable quality (Coulter et al., 2006). There has been a call for greater systematization of

the development of health information in general (Coulter et al.) as well as for decision aids specifically (Elwyn et al., 2006). To address this call, efforts have been made to develop more systematic approaches to decision aid development along with comprehensive quality criteria to guide the development and evaluation of these tools.

By 1999, there were approximately 15 decision aids, all developed by researchers in academic institutions. Research in 2006 found greater than 500 decision aids, developed by a mix of non-profit and commercial organizations (Elwyn et al., 2006). More decision aids than ever are now available on the Internet (Evans, Elwyn & Edwards, 2004). However, the quality of the information contained in many decision aids has been found to be limited (Coulter et al., 2006; O'Connor et al., 2011). For example, some decision aids do not provide citations for their evidence sources and others are biased in the presentation of information (Elwyn et al.). Efforts to address these issues in decision aids have generated several sets of criteria to guide development and increase the quality and effectiveness of decision aids. One of the most commonly utilized is termed the CREDIBLE criteria (Charnock, Shepperd, Needham, & Gann, 1999) and was used to evaluate decision aids for past Cochrane Collaboration reviews conducted by O'Connor et al. (2003, 2007). However, given growing global interest in decision aids development, researchers have worked to develop an internationally accepted quality criteria framework. This framework is known as the International Patient Decision Aids Standards (IPDAS) Collaboration (Elwyn et al., 2006; See <http://decisionaid.ohri.ca/AZsumm.php?ID=1311> where IPDAS is applied to a decision aid).

IPDAS provides a checklist of 30 items in three domains of quality (i.e., content, development process, and effectiveness) and has been used in the most current Cochrane review (i.e., Stacey et al., 2012) to evaluate the development of decision aids. Since its inception,

researchers have converted the IPDAS checklist into a quantitative measure of decision aids quality entitled the International Patient Decision Aids Standards Instrument (IPDASi; Elwyn et al., 2009) and are currently conducting validation studies.

An example of an IPDAS *content* item is: “the decision aid describes the condition (health or other) related to the decision.” An example of a *development process* item is: “Users (people who previously faced the decision) were asked what they needed to prepare them to discuss a specific decision.” An example of an *effectiveness* item is: “there is evidence that the decision aid (or one based on the same template) helps people know about the available options and their features” (Elwyn et al., 2006). Potential answers to items are: “Yes”; “No”; “Not Applicable”; and “Unknown” (Elwyn et al.). Many decision aids have now been evaluated based on the IPDAS criteria. One example is a decision aid discussed subsequently entitled “OCD: Should I take Medicine for OCD?” This decision aid currently meets 19 out of the 25 applicable IPDAS quality criteria (i.e., 10 out of 14 content criteria; 8 out of 9 development criteria; and 1 out of 2 effectiveness criteria).

### *Evaluation of Decision Aids*

In the earlier stages of decision aid development, it is common to conduct an evaluation of the content of the aid. Table 1 displays a total of 21 related studies and presents information as to the type of decision aid, the participants, methods used, variables measured, whether or not information was reviewed by topic, and the reading level of the information.

Table 1

*Evaluation of Decision Aids*

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
AlFaleh, Al Luwaini, AlKharfi, & Al-Alaiyan (2011)	Web: parents choosing treatment for patent ductus arteriosus for their infant	Mothers (10; 10)	Qualitative interviews; quantitative ratings and knowledge scores	Usability (study 1), knowledge, decisional conflict, amount of information, perceived required time, helpfulness, satisfaction (study 2)	No – overall only	Not reported	Based on ODSF; no mention of IPDAS; revisions based on feedback briefly described; two stages with two unique samples of mothers
Ameling, Auguste, Ephrain, Lewis-Boyer, DePasquale, Greer, et al. (2012)	Video and handbook: renal replacement therapy selection	Adults with renal failure (12; 36)	Qualitative interviews; quantitative ratings and scores	Length of both formats, overall impressions, amount of information, understandability, balance, areas in need of improvement, cognitive gist scores	Yes.	4 <sup>th</sup> -6 <sup>th</sup> grade	Based on IPDAS; not on ODSF (or other framework); brief description of revisions to decision aid based on patient feedback

Study	Type(s)/topic(s) of decision aid	Participants ( <i>n</i> )	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Anderson, Carter, Nattress, Beale, Philp, Harrison, et al. (2011)	Booklet: ovarian cancer treatment choices	Female patients with ovarian cancer (20)	Qualitative interviews; quantitative ratings	Knowledge, decisional conflict, clarity, balance, anxiety, amount of information, format, helpfulness, recommendation	Yes—interview only; not in quantitative study	Not reported	No mention of IPDAS, ODSF (or other framework); brief description of revisions made based on patient feedback; participants liked the simple, small table of textual (no symbols) descriptions of treatment options
Bailey, Lewis, Harris, Grant, Bann, Bishop, et al. (2013)	Brochure: decision aid for inviting parents to participate in fragile X screening study	Pregnant women and recent mothers (118)	Quantitative ratings and knowledge scores	Readability, understandability, approval of appearance, helpfulness of information, aids in informed choice making, trustworthiness, amount of information, choice leaning	No - overall review only	Grade 9	Based on IPDAS and Informed decision-making models; no mention of revisions; measured time to read (mean of 6.2 minutes)

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Chiew, Shepherd, Vardy, Tattersall, Butow, & Leigh (2007)	Workbook: chemotherapy decision aid	Women with metastatic breast cancer (17) and medical oncologists (7)	Qualitative interview; quantitative ratings, written suggestions	Amount and length of information, upsetting nature of information, clarity, helpful for treatment decision, recommendation, control preferences, information needs	No - overall review only	Flesch-Kincaid grade 8	Based on ODSF; no mention of IPDAS; provide a brief description of revisions based on feedback; measured time (45-60 minutes); collected physician opinions also
Cox, Lewis, Hanson, Hough, Kahn, White, et al. (2012)	Pamphlet: treatment choices for surrogates of patients with prolonged mechanical ventilation	Patient surrogate decision makers (53); physicians (58)	Qualitative interview and patient chart review; quantitative scores	Usefulness, anxiety, decisional conflict, physician-surrogate (dis)agreement	No - overall review only	Grade 6	Based on IPDAS; not based on ODSF (or other framework); brief reference to “minor revisions” made but no description



Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Dowding, Swanson, Bland, Thomson, Mair, Morrison et al. (2004)	Computer: treatment choices for benign prostatic hyperplasia and hypertension	Healthcare professionals (8); patients (19)	Qualitative interviews	Ease of use, clarity, usefulness, suggestions for alteration	No-overall only	Not reported	Not based on IPDAS, ODSF (or other framework); mentions revisions made but not described; recorded time on decision aid (means: 49; 55 minutes, respectively)
Emmett, Murphy, Patel, Fahey, Jones, Ricketts et al. (2006)	Computer: mode of delivery after previous C-section	Women (26)	Qualitative interviews	Acceptability of: program content, computer format, presentation of health outcomes, usability, amount of information	No-overall only	Not reported	Based on “United Kingdom Medical Research Framework”; not based on IPDAS or ODSF; no mention of revisions
Frosch, Legare, & Mangione (2008)	Video decision aid and informational brochure: colon cancer screen	Adult patients with no cancer diagnosis coming for screening (207)	Quantitative ratings and knowledge scores	Decision role preferences, knowledge	No - overall review only	Not reported	No mention of IPDAS, ODSF (or other framework), or revisions; ethnically diverse sample of participants

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Hochlenert, Richter, Bludau, Bieber, Blumenstiel, Mueller et al. (2006)	Computer: information tool for patients with chronic pain	Fibromyalgia patients (75; 93% women)	RCT with quantitative ratings and recall scores; qualitative interviews	Usability, informative nature of information, importance, usefulness, acceptable time, satisfaction with decision, decisional conflict, recall of information	No-overall only	Not reported	No mention of IPDAS, ODSF (or other model), or revisions
Hollen, Gralla, Jones, Thomas, Brenin, Weiss, et al. (2013)	Pamphlet and Compact Disc: cancer (breast, prostate, lung) treatment decision making	Adult patients: breast cancer (22); prostate cancer (19); lung cancer (39); supporters (80); physicians and nurses (10)	Quantitative ratings	Ease of reading, usability of balance sheets, time investment; helpfulness for: sorting through much information, weighing choices, talking to doctor and loved ones, arriving at decisions, sense of shared decision making	No-overall only	Not reported	No mention of IPDAS, ODSF (or other model), or revisions

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Sheridan, Flix, Pignone, & Lewis (2004)	Pamphlet: prostate cancer screen	Men recruited from general medical clinic (188)	Qualitative interview; quantitative ratings, self-reported knowledge	Novelty of information, knowledge, interest in screening	Yes. After each of 4 sections	Grade 8	No mention of IPDAS or ODSF (study predates IPDAS and ODSF); no mention of revisions; decision aid divided into 4 parts with changes in interest in screening measured after each part
Sivell, Marsh, Edwards, Mansead, Clements, & Elwyn, (2012)	Web: breast cancer surgery	Women with and without history of breast cancer (25)	Qualitative interviews	Usability of program, usefulness for decision making, supportiveness before and after decision making	No – overall review only	Not reported	Based on IPDAS; no mention of ODSF (data gathered based on theory of planned behaviour); mentions some changes were made for increased usability but no details

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Sundaresan, Turner, Kneebone, Pearse, & Butow (2011)	Booklet: prostate cancer treatment options	Men with prostate cancer in posttreatment follow-up (20)	Qualitative interviews; quantitative ratings	Helpfulness, clarity, balance, format, amount of detail, length, anxiety, understandability	No-overall only	Not reported	No mention of IPDAS, ODSF, or revisions
Wakefield, Watts, Meiser, Sansom-Daly, Barratt, Mann et al. (2011)	Web: prostate cancer screen	Men (22;20)	Quantitative ratings and knowledge scores; qualitative interviews	Length, amount of information, balance, usefulness for decision, satisfaction, recommendation, perceived improvement of knowledge, emotional impact	Yes	Grade 8	Based on IPDAS and ODSF; brief mention that suggested changes were incorporated but no specifics; two stages of review (paper form and online) with the same men
White, Towers, Turner, & Hambridge (2013)	Computer: post-stroke depression screen	Stroke patients (62); clinicians (7)	Quantitative ratings (study 1); qualitative interviews (study 2)	Usability, clarity, importance, acceptability of format	No – overall only	Not reported	No mention of IPDAS, ODSF, or revisions

Study	Type(s)/topic(s) of decision aid	Participants (n)	Method(s)	Variables measured	Review by topic?	Reading level	Comments
Wong, D'Alimonte, Angus, Paszat, Metcalfe, Whelan, Llewellyn-Thomas, et al. (2011)	Booklet: decision aid when considering radiotherapy after lumpectomy	Older women with Stage I Breast Cancer (12; 38)	Quantitative ratings (studies 1 & 2) and knowledge scores; qualitative comments (study 2)	Acceptability of usability, visual appeal, clarity, completeness, helpfulness, recommendation (studies 1 & 2), decisional conflict, knowledge, impact, choice predisposition (study 2)	No-overall only	Not reported	Development based on ODSF; no mention of IPDAS; no mention of revisions

*Note.* ODSF = Ottawa Decision Support Framework. IPDAS = “International Patient Decision Aid Standards” collaboration. RCT =

Randomized controlled trial.

Table 1 exhibits that the types of decision aids range across videos, work/handbooks, brochures and booklets, computer programs, and those based on the Web. Topics vary across treatments and/or screenings such as for renal failure, chronic pain, several cancers, benign prostatic hyperplasia, and hypertension. Topics also include other decisions such as mode of delivery following a previous caesarean section and whether or not parents want to participate in a fragile X screening study. Participants are adults ranging across patients, health professionals, mothers, and those at risk for various illnesses.

Methods used to evaluate decision aids have varied from exclusively quantitative or qualitative methods, with others using multiple methods or mixed-methods designs. The use of more than one method helps maximize the strengths and minimize the weaknesses inherent in either qualitative or quantitative methods alone. The most common variables examined in these studies are consumer perceptions of the information (i.e., clarity, helpfulness, amount, balance) as well as participants' knowledge, decisional conflict, willingness to recommend the decision aid, usability, and perceived length of format. Seven studies mention revisions based on participant feedback; five provide a description of changes. Trustworthiness, novelty, and perceived (or actual) required time to engage (i.e., read, add personal information) with the decision aid material were variables measured in two studies.

An example of an *exclusively quantitative* evaluation of a treatment decision aid is provided by O'Connor et al. (1998) who piloted a decision aid for women considering hormone replacement therapy (HRT) after menopause. The researchers utilized self-report rating scales assessing patient acceptability of the comprehensibility of each informational component as well as perceptions of length, pace, amount, and balance. Authors also utilized a pre/post design to examine decision aid effects in terms of patient knowledge, expectations, values, and decisional

conflict. Finally, they examined patient perceptions of the influence of others on the process of decision making. Results showed that most women found the decision aid acceptable in length and pace, comprehensible, and balanced. Additionally, there was significantly increased general knowledge and more realistic expectations of HRT risks and benefits. Participants also reported that they felt more informed, clear regarding values, certain, and supported in their decision. Changes in preference for treatment occurred only in those who were undecided at baseline (O'Connor et al.).

Dowding and colleagues (2004) utilized *exclusively qualitative* methods to conduct an evaluation of a computerized treatment decision aid for two conditions: benign prostatic hyperplasia (BPH) and hypertension. Researchers conducted individual structured interviews with 8 healthcare service providers and 19 patients while they progressed through the content of the aid. Questions focused on the ease of use of the program, the content of the decision aid (including clarity), usefulness of the tool for the provision of information, and suggestions for improvement. The authors also recorded the time spent on the program. Qualitative analysis indicated overall positive assessment by patients and healthcare professionals of each of the programs; however, mean usage times of 49.4 minutes for the BPH aid and 54.6 minutes for the hypertension aid were deemed too lengthy for use in primary care (Dowding et al.). The authors suggested that the decision aids would be more helpful as information pamphlets for patients to review on their own time.

Emmett et al. (2007) provide an example of an evaluation of two *computer-based* decision aids, in their case regarding mode of delivery following previous caesarean section. Twenty-six women from two UK hospitals participated in this exclusively qualitative pilot study conducted in preparation for a planned RCT. One decision aid was an information-only program

and the other was an information-plus-decision-analysis program. Women were observed and interviewed as they were asked to freely use and comment on the decision aid. The data were analyzed to generate themes relating to the program content, the acceptability of the computer-based design, the presentation of health benefits and risks, the usability of the computer program, and repeat access to the programs (Emmett et al.).

Results of Emmett et al.'s (2007) study showed that women found both aids useful and informative and that the majority of participants appreciated the computer-based format. Women found the utility measurement of the decision analysis program acceptable, although, some had problems completing required tasks. Following this pilot study, the authors reported that the following revisions were made: (1) expansion of the program content; (2) development of a training session to accompany the decision analysis program; and (3) development of an Internet version to allow repeat access to the decision aids.

Hochlenert and colleagues (2006) provide an example of a decision aid evaluation project that used *multiple methods*. Patients with fibromyalgia evaluated a computerized treatment decision aid for chronic pain. This is one of the rare RCTs conducted at an earlier stage of development. Patients were randomly assigned either to a shared decision making (SDM) group (treated by doctors trained in SDM plus access to the decision aid) or an information-only group (treated by doctors untrained in SDM plus access to the decision aid). Variables studied with quantitative methods were decisional conflict and satisfaction with the decision, measured with the Decisional Conflict Scale (O'Connor, 1999) and the Satisfaction with Decision Scale (Holmes-Rovner et al., 2001), respectively. These were administered to both groups immediately following the initial contact. Results indicated no significant differences between groups in terms of decisional conflict or satisfaction with the decision (Hochlenert et al.).



Hochlenert et al. (2006) also posed six evaluative questions to participants following use of the computerized decision tool and addressed: (1) assessment of presented information; (2) usability of computer program; (3) importance of introductory information for handling the computer program; (4) usefulness of this tool in a physician's office; (5) the quality of the layout; and (6) assessment of time needed to use the program. Results indicated that patients valued the availability of a computerized decision tool in a physician's office. The variables examined with qualitative methods (interview questions administered three months after initial contact) focused on changes in attitude, recall of information given at the initial examination consultation, perceptions of the order of information in the decision aid, and suggestions for changes to the content of the decision aid (Hochlenert et al.).

Sheridan and colleagues (2004) conducted a *mixed-methods* evaluation of a new decision aid for prostate cancer screening with a sample of male consumers. Qualitative variables included acceptability and usability of the decision aid which was collected via two rounds of *think aloud* interviews while participants viewed the material. The decision aid was revised based on qualitative data and then evaluated again in the quantitative phase (Sheridan et al.).

Quantitative variables in Sheridan et al.'s (2004) study included three domains of knowledge of prostate cancer screening: (1) knowing the advantages of screening; (2) knowing the disadvantages of screening; and (3) knowing enough to make an informed decision. They also measured interest in screening. Researchers utilized self-report questionnaires to assess the potential influence of each of four component parts of the decision aid on men's knowledge as well as their interest in screening. Questionnaires assessing knowledge and interest were administered at five points: baseline and following review of each informational component. Results indicated significant increases in all three domains of knowledge. In terms of men's

interest in screening, results showed that the decision aid was most influential on those who were undecided at baseline. Additionally, no relationship was found between change in interest in screening and demographic variables (e.g., age, ethnicity) or a prior history of screening. Results also indicated that two-thirds of men felt they gained new information from each component of the decision aid; however, only 10-15% felt the information was influential on their choice (Sheridan et al.).

Each of the methods used to evaluate decision aids has strengths and weaknesses. For example, a quantitative study offers the advantage of being able to more readily collect data from a larger sample (e.g., O'Connor et al., 1998) with findings potentially more generalizable than those of a qualitative study (e.g., Emmet et al., 2007). However, quantitative methods are disadvantaged in that they are more likely than qualitative methods to impose researchers' categorization schemes upon participants via the use of certain questions and rating scales. Therefore, the data may not as closely represent the actual experiences and attitudes of participants as those gathered in a qualitative study. It appears the use of both qualitative and quantitative methods can help capitalize on strengths while minimizing weaknesses of each method. The use of mixed-methods designs offers the additional benefit of a structured framework facilitating a more thoughtful process of combining divergent methods.

Following earlier evaluations, decision aids are commonly subjected to more controlled examinations of potential effects on patients' decision making processes and outcomes. Stacey et al.'s (2012) review provides a good overview of study variables as well as decision aid efficacy across many evaluations of decision aids. The review includes 86 RCTs of decision aids, 63 of which used at least one measure based on the IPDAS criteria. Recall that these criteria focus on attributes of the decision and of the decision process and deem secondary other behavioural,

health, and health-system effects. Pooled findings showed that decision aids outperformed usual care in numerous domains. These include increased knowledge, improved realistic expectations of outcomes, decreased decisional conflict associated with feeling uninformed, decreased decisional conflict associated with a lack of clarity regarding personal values, and improved patient-practitioner communication. Additional domains in which decision aids outperformed usual care include reducing the proportion of passive decision makers and reducing the proportion of patients who remained undecided after the intervention (Stacey et al.).

Stacey and colleagues (2012) also found that complex decision aids increased knowledge more than simple decision aids and found that including probabilities (especially using numbers versus words) in a decision aid impacts accuracy of risk perception. Results also indicated that exposure to decision aids decreases choice of optional surgery and has no seeming adverse effects on health outcomes. Decision aids did not affect anxiety. Similarly, O'Brien et al. (2009) conducted a meta-analysis of decision aids specific to cancer and found that the use of decision aids increases knowledge without increasing anxiety, particularly in cancer *screening*.

Watson and colleagues (2006) examined the impact of a brief decision aid on men's attitudes, knowledge, and intention to have a PSA test. Nine-hundred-and-ninety men aged 40-75 recruited from 11 general practice sites in the UK were randomized to receive either a postal copy of the decision aid and a questionnaire (intervention group) or a questionnaire only (control group). Results showed that men in the intervention group had significantly higher knowledge scores as well as less positive attitudes toward PSA testing than control group men. However, there was no significant between-group difference in terms of intention to test in the following 12 months. The study also measured men's perceptions of readability, detail, and balance.

Results showed that 87% found the decision aid easy to read, 94% felt it contained about the right amount of detail, and 94% felt the information was balanced in presentation (Watson et al.).

Researchers evaluating web-based decision aids have begun to examine associations between how consumers use the decision aid and decision process variables such as informed decision making and knowledge. For example, Joseph-Williams et al. (2010) examined associations between men's use of an Internet decision aid for PSA testing and components of informed decision making. This was accomplished via web-log analysis of users' online behaviours. Web-log analysis provides data including the number of webpages opened as well as the time spent on any given webpage and on the overall website. Men between the ages of 50 and 75 were recruited from 26 general practices in the UK. Aspects of informed decision making were knowledge, favourable attitudes toward PSA testing, and intention to undergo PSA testing. Perceptions of informed decision making were assessed via an online questionnaire.

Joseph-Williams et al. (2010) found large variation in usage resulting in group comparisons based on a median split: "high access users" versus "low access users." The mean time spent on the website was 20 ( $SD = 15$ ) minutes; mean number of webpages accessed was 32 ( $SD = 21$ ) of 60 pages. A significant positive association between usage and knowledge emerged. Significant negative relations were found between usage and favourable attitudes toward screening and between usage and intention to undergo PSA testing (Joseph-Williams et al.).

In summary, published evaluations of decision aids are heterogeneous in terms of type and topic, participants, methods used, and variables assessed. Some of the most common variables are consumer opinions about the clarity, amount, helpfulness, and balance of the information. There were seven studies that reported consumer suggestions for improvement and five offered a brief description of the changes. Only two studies measured trustworthiness,

novelty, and perceived (or actual) required time to engage (i.e., read, add personal information) with the decision aid material. Measuring change in knowledge is less common until the point of conducting an RCT.

### Decision Aids in the Mental Health Field

Similar to other areas of healthcare, mental health has become increasingly complex in terms of the number and variety of treatment options (Patel, Bakken, & Ruland, 2008), indicating a need for decision assistance for consumers (Charles et al., 1999). Decision aids have only recently been developed for use in the mental health field (Wills & Holmes-Rovner, 2006) and very few have undergone formal evaluation (Adams & Drake, 2006). In fact, the most recent Cochrane review contained only one of 86 decision aids addressing depression (Stacey et al., 2012). As previously stated, decision aids are closely tied to the shared decision-making (SDM) model and are designed to facilitate SDM. Aspects of SDM (other than decision aids) have been studied to a greater extent in mental health than have decision aids themselves.

Although the SDM model in healthcare has its origins in the 1950s and began to form a part of healthcare practice and research in the 1960s, practice in the field of mental healthcare has only recently been addressed (Shauer, Everett, delVecchio, & Anderson, 2007). The National Institute of Mental Health (NIMH, 1999) has highlighted the importance of incorporating consumer and health practitioner decision-making processes into intervention research as a main strategy for improving services and treatments in mental healthcare (Wills & Holmes-Rovner, 2006).

Several concerns may have contributed to the relative lag in SDM research in mental health compared with general healthcare. First, the literature has often questioned whether a desire for greater participation in decision making exists on the part of those seeking mental

health services. Second, some authors have questioned the *capacity* of consumers with mental health diagnoses to participate effectively and rationally in their own treatment decisions (Danker-Hopfe, & Helmchen, 2003; Roberts et al., 2002). Third, some have questioned whether a *desire* exists on the part of those seeking mental health services to obtain treatment-related information similar to those with non-mental health diagnoses (Adams & Drake, 2006). Although concerns about decision-making ability exist, a growing body of research supports the capacity and desire of individuals with mental health diagnoses to participate in healthcare choices, often to a greater extent than health practitioners facilitate (Patel et al., 2008).

#### *Information and Participation Needs in Mental Health*

A small number of studies have examined information and participation needs in persons with mental health problems. One study examined the information-seeking and decision-making preferences of psychiatric patients (Hill & Laugharne, 2006). Researchers utilized an adapted version of the Autonomy Preference Index (API; Ende et al., 1989) and administered it to a sample of patients in a community mental health program. Findings indicated a strong desire for information on mental disorder and treatment; however, the extent to which patients wanted to make the final decision varied substantially. Similar to findings in general health, participants from this psychiatric population who were younger and/or employed desired a more active decision making role (Hill & Laugharne).

Similarly, a study focusing on psychiatric inpatients' perceptions of how medication information was provided in a hospital setting found that patients received inadequate information (both verbal and written; Pollock, Grime, Baker, & Mantala, 2004). In this case, the informational deficiency was also recognized by healthcare providers (e.g., nurses, psychiatrists); however, their concerns had to do with potential iatrogenic effects of providing medication

information to patients. These concerns are similar to those reflected by physicians in early debates about the appropriateness of certain aspects of the SDM model in general (discussed previously; Coulter, 1997). Inpatients in this study reported they wanted information on topics such as the diagnosis, the name of the prescribed medication, the dosage, short- and long-term medication side effects, and the potential consequences of treatment refusal (Pollock et al.). Others have examined psychiatric patients' desire for treatment-related information and found that, similar to patients in general healthcare, they too desire much more information than they usually receive (Hill & Laugharne, 2006; Walker et al., 2000).

Adams and colleagues (2007) examined perceived roles and preferences for SDM in a sample of individuals with severe mental illness and found that most participants preferred SDM, particularly when it came to their mental healthcare. Specifically, a significant portion (i.e., 77%) of participants preferred autonomous or shared roles, but only 37% reported experiencing more than a passive role (Adams, Drake, & Wolford, 2007).

Simon and colleagues (2006) were among the first to examine depressed patients' perspectives on SDM regarding treatment. In this study, 40 depressed patients engaged in a semi-structured interview pertaining to doctor-patient treatment decision making. Questions addressed patients' information sources, first contact regarding health concerns, and issues related to treatment decision making. A large majority of patients (i.e., 85%) reported that they and their physicians had shared involvement in treatment choice. The authors reported the results of qualitative analysis which revealed that the first formal contact made by these patients was with their general practitioner; additionally, the majority (i.e., 65%) felt their general practitioners were a vital information source regarding depression and treatment options. Even so, interview data confirmed the common perception of a lack of information about depression and options for

treatment. Respondents desired information on the occurrence of mental disorder, the need for formal treatment, social stigma, and treatment type (i.e., psychotherapy versus pharmacotherapy; Simon, Loh, Wills, & Harter, 2006).

Stacey and colleagues (2008) explored the decision-making needs of patients considering options for depression treatment. This research utilized structured interviews based on the Ottawa Decision Support Framework (O'Connor et al., 1998). Findings revealed a positive relation between the level of certainty about a recent treatment decision and reports of feeling informed, supported, and clear about values regarding risks of options. Other than information provided in discussions with a psychiatrist, nurse, or family doctor, participants identified access to printed information as an important decision-making support need (Stacey, Samant, & Bennett, 2008).

Another study explored the information needs of depressed patients within three months of starting a new antidepressant medication (Garfield, Francis, & Smith, 2004). Qualitative analysis of interviews revealed a common unmet need for information regarding adverse drug reactions. Additionally, information was lacking in terms of treatment duration and concerns surrounding medication dependence and dosage. Patient reports indicated the importance of both the timing (i.e., the point during treatment when information was given) and type of information (e.g., information regarding medication side effects, dependency issues, or predicted duration of treatment; Garfield et al.).

Another study examined the capacity to make treatment choices in patients with schizophrenia (Bunn, O'Connor, Tansey, Jones, & Stinson, 1997). Researchers focused on intentions to either continue or discontinue the use of antipsychotic medication subsequent to receiving education on the issue. Results indicated that almost all (i.e., 87%) participants decided



to continue the medication, and the participants who decided to discontinue medication cited rational reasons (e.g., side effects) for discontinuation (Bunn et al.). Similar results have been observed in other mental health studies (e.g., Roberts et al., 2002).

The above review of research highlights the similarity in information and participation needs across samples seeking general healthcare services and those seeking mental health services. This includes the desire for information pertaining to treatment as well as the desire and capacity to participate in treatment-related decision making.

#### *Effects of SDM and Decision Aids in Mental Health*

A small number of studies have been conducted examining the effects of using a SDM approach with patients accessing mental health services. For example, Loh and colleagues (2007) conducted a study that utilized a decision aid and examined the effects of a SDM intervention in the primary care of depressed adults. Patients in the intervention group consulted with physicians trained in SDM techniques who used a decision aid during the physician-patient consultation and then provided a printed leaflet with information about depression (e.g., symptoms, course, and treatment). Only the SDM intervention group and not the control group (receiving usual care) exhibited improvements both in patient participation in treatment decision-making and patient satisfaction. An important finding in terms of feasibility was that the intervention did not increase consultation time (Loh et al., 2007).

An RCT conducted by Hamann and colleagues (2006) also examined the effects of SDM (including a printed decision aid) compared with routine care for inpatients diagnosed with schizophrenia. They found that patients in the intervention group possessed greater knowledge regarding their condition and higher perceived decision involvement as compared to controls. Additionally, more support for the feasibility of SDM and decision aids was generated in that

patients in the intervention group did not require more time with their doctor than did patients in the control group (Hamann et al., 2006).

As evident from the above studies, SDM and decision aids provide benefits for patients receiving mental health services similar to those in general healthcare. However, more work is required to understand how this population of consumers conceptualizes decision-making participation as well as to identify their preferences for participation in decision making. Research also needs to examine acceptability of various levels of participation and to study decision preferences among more diverse cultural and psychiatric populations (Patel et al., 2008). Furthermore, there is a need to develop and test decision aids in mental health samples utilizing a more systematic approach and measuring them against agreed-upon quality criteria (Holmes-Rovner et al., 2007). Despite wide advocacy for SDM and decision aids, the rates of uptake continue to be low in health and mental healthcare (Wills et al., 2006). Given this, research is needed to develop an evidence base for implementing SDM and decision aids as integral processes in healthcare and mental healthcare (O'Donnel et al., 2006). This includes identifying barriers and facilitators to implementing decision aids in various contexts, as successful implementation appears to hinge on factors such as decision aid attributes, practitioner and patient characteristics, and the specific context of implementation (O'Donnel et al.).

Research with SDM and decision aids in mental health suggest very similar outcomes as found in general healthcare (Patel et al., 2008); hence, it may be that similar concerns and cautions inherent in implementing decision aids exist across general- and mental-health settings and populations. However, it may also be true that unique issues will surface as research continues. For example, concerns may arise regarding the potentially magnified emotional

vulnerabilities of mental health consumers compared with non-mental health consumers in the face of important healthcare decisions.

The fundamental nature of mental health problems highlights the potential for greater vulnerability to emotional distress in populations seeking mental health services. Given this, concern is justified regarding the potential to increase a patient's anxiety in decision making about the care of their mental health. Overall, reviews of decision aids in general healthcare indicate that they do not increase patients' anxiety (O'Connor et al., 2003, 2007, 2009; Stacey et al., 2012). In studies showing increased anxiety with the use of a decision aid, anxiety varied with the type of decision (e.g., decisions involving invasive procedures were associated with greater anxiety; Wills & Holmes-Rovner, 2006). Research should evaluate the impact of decision aids on anxiety and emotional distress in the mental health field. Again, SDM presents an *invitation* rather than a *requisite* for patient participation. It also intends to inform and equip patients for their preferred level of autonomy (Charles et al., 1997); hence, practitioners can be sensitive to patients' needs and thereby also avoid unnecessarily increasing patients' anxiety.

#### *Internet Usage for Mental Health Information*

Consumers often search the Internet for general health information. A modest number of studies have focused on Internet searches for mental health information by the general population. One study (Powell & Clarke, 2006) found that more than 10% of the general population in the UK had conducted Internet searches for such information. The authors noted that participants with higher levels of current psychological distress and those with a history of mental health problems were more likely to have conducted an Internet search for mental health information. Interestingly, only a small portion of the sample (12%) rated the Internet as one of

the three most accurate information sources, compared with a larger portion (24%) who identified the Internet as one of the three sources they would utilize (Powell & Clarke.).

Equally rare are studies focusing on Internet use by those with mental health problems. One such study (Khazaal et al., 2008) evaluated the use of the Internet to search for general health and medical information by 319 patients diagnosed with a psychiatric disorder. Results indicated that 64.7% of patients were Internet users, that most users (68.5%) searched the Internet for health-related information, and that only a small percentage (27%) of users knew and utilized any criteria reflecting the quality of information on the websites (stated objectives of the site, identity of authors, references for the information, sponsor information; Khazaal et al.).

Powell and Clarke (2007) conducted a qualitative investigation of Internet use with a purposive sample of 36 mental health service users with Internet experience. The intention was to explore participants' perceptions of advantages and disadvantages of the Web as a source of mental health information and to explore user motivations and concerns. One of the main motivations for Internet information seekers was to find information about the experiences of other people with similar problems with the main benefits being a sense of universality and a sense of hope for recovery. Benefits of the Web as an information source included anonymity, privacy, and convenience. Interestingly, participants' concerns about the Internet were greater for potential misuse rather than inaccuracy of information. Examples of feared misuse included use of chat rooms on mental health websites to threaten suicide as well as fear that members of these chat rooms may be disingenuous and/or predatory (Powell & Clarke, 2007). Similar to concerns about general health information, concerns about the quality of mental health information on the Internet have grown, especially as web-searches for mental health information have become more commonplace.

### *Quality of Mental Health Information on the Web*

Although relatively less research has been conducted on the information quality in mental health compared with general healthcare, extant studies highlight a similar concern across both spheres. For example, one study focused on the quality of information on a website addressing the treatment for anxiety disorders (Ipser, Dewing, & Stein, 2007). Utilizing the DISCERN assessment tool (Charnock, 1999) and examining 67 websites, findings indicated that information on these websites was of poor-to-moderate quality. Additionally, findings demonstrated associations between certain website characteristics and overall website quality. Specifically, higher quality scores were associated with sites that had a clear statement of purpose and that acknowledged their sources (Ipser et al.).

Reavley and Jorm (2010) conducted a systematic review focused on studies evaluating mental health website-information quality. They examined 31 articles covering disorders of affect, anxiety, eating, substance use, and schizophrenia/psychosis. The largest portion of articles described studies focused on affective disorders. Findings indicated significant methodological variation in site selection and rating schemes, with the authors deeming some of limited validity. Findings also indicated that the majority of studies concluded that information quality was poor, though the authors also reported that the quality of some of the websites with information about affective disorders may be improving.

Another recent study examined the quality of health information contained on the Internet regarding treatment for depression (Walsh et al., 2010). Websites were selected via Google search of “depression for patients” (conducted in July, 2008) as well as websites to which a specialist reported they would refer a patient. A total of 23 websites were evaluated utilizing both the Ensuring Quality Information for Patients (EQIP; Moulton, Franck, & Brady, 2004) and

DISCERN (Charnock, 1999) measures. Both measures assess whether or not a question has been answered or the degree to which a question has been answered. However, the EQIP scale also addresses the design of a website. The authors reported that the study also included an assessment of the readability of the content and focused on four treatment types: psychological, pharmacological, neurotherapeutic, and alternative treatments.

Walsh et al. (2010) reported EQIP scores assessing website quality as adequate or moderate and DISCERN scores indicating that the quality of information on most websites was moderate, with potentially important though not serious deficits. However, when examination focused on key questions that previous research had indicated were important to the public (Walker et al., 2000), many websites did not fare as well. That is, information addressing issues such as the duration and effectiveness of treatment and what happens when treatment is discontinued received lower scores across all treatment types evaluated. Results of the above studies indicate a need to develop mental health information in general as well as that contained in decision aids that is higher in quality and that effectively answers concerns that have been raised by the public.

#### *Examples of Decision Aids in Mental Healthcare*

Decision aids have been developed for mental health problems such as Obsessive-Compulsive Disorder (OCD), Generalized Anxiety Disorder (GAD), Panic Disorder, and depression. The majority of these decision aids are framed as questions or *decision points*. For example, the OCD decision aid entitled: “OCD: Should I take Medicine for OCD?” is a decision aid developed in 2010 by *Healthwise* and focuses on deciding between taking medications and engaging in counseling or therapy (Romito & Weinstock, 2010). The decision aid offers information regarding the nature and course of OCD and describes the treatments. It also allows

a comparison of features of treatment options and has a values clarification exercise as well as a brief quiz about the information covered in the decision aid.

Another example is a decision aid for anxiety disorders entitled “Anxiety Disorders Patient Decision Aid” (Kapczinski, 2003). The decision aid provides a brief general description of anxiety disorders. It also lists three broad treatment modalities: talking (psychological) therapies, medicines, and self-help. Medications are given a brief description while the other treatment options are not described. This decision aid makes no reference to any guiding developmental framework nor any formal evaluation based on a set of quality criteria. A literature search uncovered several studies evaluating effects of depression decision aids (e.g., Loh et al., 2007; Wills et al., 2006); however, the decision aids themselves were not available. The search revealed a small number of web-based decision aids addressing depression which are described below.

#### Adult Depression

Depression consists of an assortment of somatic, affective, and cognitive symptoms including low mood; reduced interest in, and withdrawal from, normal activities; excessive feelings of guilt, worthlessness, or hopelessness; concentration problems; fatigue; psychomotor problems (retardation or agitation); and changes in sleep and appetite. Once these symptoms interfere significantly with social and/or occupational functioning or cause significant distress and continue beyond two weeks, the threshold for major depressive disorder (MDD) has been reached (American Psychiatric Association, 2013).

Depression affects as many as one in four Canadian and U.S. residents in their lifetimes (Kessler et al., 2005; Vasiliadis, Lesage, Adair, Wang, & Kessler, 2007). However, its prevalence is arguably dwarfed by its impact on human life, for depression is seen as one of the most

burdensome maladies in the world (WHO, 2002), with numerous social, economic, and personal costs (Klerman & Weissman, 1992). Murray and Lopez's (1996) Global Burden of Disease study predicts that depression will be the second most common cause of disability in the 21<sup>st</sup> century (second only to ischemic heart disease; Murray & Lopez, 1996). Moreover, some suggest that the prevalence of depression is increasing (Klerman & Weissman; Murray & Lopez). In both Canada (Dewa et al., 2004) and the U.S. (Want et al., 2004), depression has been found to be the main source of disability in the workplace.

*Evidence-Based Treatments for Depression: A Decision-Making Task*

There exists a growing range of evidence-based treatments targeting depression. As will be evident in the following, each treatment often embodies a unique profile in terms of effectiveness, side effects, and risks. This presents the mental health consumer with the task of weighing the tradeoffs across an ever-increasing number of potentially effective options.

*Evidence-based* treatments are currently defined as interventions demonstrating efficacy in one or more randomized controlled trials (RCTs) that compare effects of active treatment to those of a control condition and randomly assign participants to the various groups (Chambless & Hollon, 1998). There is a considerable literature on evidence-based interventions for depression in adults, with numerous well-researched psychological and pharmacological treatments showing broad applicability. Guidelines for the treatment of depression, including summaries of evidence-based practices, have been published by a number of influential bodies including the Canadian Network for Mood and Anxiety Treatments (CANMAT; Kennedy, Lam, Parikh, Patten, & Ravindran, 2009), the American Psychiatric Association (APA, 2010), the Royal Australian and New Zealand College of Psychiatrists (2004), the British Association for Psychopharmacology (BAP, 2008), and the National Institute for Health and Clinical Excellence



in the United Kingdom (NICE, 2009). One of the key aims of these publications is to assist healthcare practitioners and patients in decision making about appropriate treatment based on solid evidence and specific individual situations.

*Psychological and Pharmacological Interventions: Effectiveness*

Cognitive-behavior therapy (CBT) and interpersonal therapy (IPT) are considered to have the best documented efficacy in the psychological treatment of MDD; albeit, CBT has been the more extensively studied in terms of depression. CBT involves identifying maladaptive thoughts and behaviours associated with depression and engaging in strategies to correct them. Reviews of studies of CBT's efficacy for reducing depressive symptoms provide ample empirical support (e.g., Butler, Chapman, Forman & Beck, 2005; Dobson et al., 2008; Lynch, Laws, & McKenna, 2010). IPT focuses on the client's current relationships and immediate social context and aims to intervene in symptom formation and the social dysfunction linked with depression. Although fewer studies have been carried out, a growing literature attests to the effectiveness of IPT as well (e.g., Feijo de Mello et al., 2005; Jarrett & Rush, 1994). The American Psychiatric Association recommends that responders to psychotherapies such as the above continue the successful form of psychotherapy for 16 – 20 weeks after remission to prevent relapse (APA, 2010). This time period is known as the continuation phase of treatment. Logistics such as frequency of visits are left open, except to suggest they be responsive to the client's needs and congruent with clinical judgement.

Many studies have also provided support for the effectiveness of pharmacological treatments for depression. For example, a review by Barbui, Furukawa, and Cipriani (2008) looked at the efficacy of paroxetine, a selective serotonin reuptake inhibitor (SSRI), versus placebo in treating MDD, including 29 published and 11 unpublished trials. Barbui et al. found

that fewer participants in the paroxetine group failed to reach at least 50% improvement in symptoms compared with those in the placebo group. In another review, Deshauer et al. (2008) synthesized the results of 6 classic RCTs of SSRIs and reported similar findings. Deshauer et al. found that patients who continued treatment for 6-8 months were significantly improved, as measured by response to treatment, but they did not have significantly better rates of remission or ratings of treatment acceptability than placebo groups.

Six-to-eight months of medication treatment is recommended as the standard of care for treatment of depression in the current psychiatric guidelines (APA, 2010; NICE, 2009). These guidelines advise that patients who have responded to pharmacotherapy for depression persist with the same medication at the same dosage during both the continuation and maintenance phases. This is because lower-dose antidepressant maintenance treatment has not been proven effective in relapse prevention (APA). The duration of recommended treatment is indefinite for chronic or recurrent depression (APA).

Some studies examine the comparative effectiveness of the various pharmacological and psychological treatments. Numerous studies comparing CBT to other therapies find little difference in efficacy. Specifically, authors report no significant difference between the efficacy of CBT and behavioural activation (Cuijpers, van Straten, & Warmerdam, 2007; Ekers, Richards, & Gilbody, 2008), IPT (Casacalenda, Perry, & Looer, 2002; Ekers et al., 2008; Luty et al., 2007), or antidepressants (Casacalenda et al., 2002; Dimidjian et al., 2006; Ekers et al., 2008). While potentially equal in efficacy, these treatments appear to be more effective than no treatment, as evidenced by Casacalenda et al.'s (2002) meta-analysis of 6 RCTs with control treatment arms, which found equal remission for antidepressants, CBT, and IPT (46%) over control conditions (26%).

A review of pharmacological and psychosocial interventions for depression in primary care reported comparable efficacy for the two modalities (Wolf & Hopko, 2007). Wolf and Hopko concluded that both are favourable in comparison to usual care; however, they did not conduct a meta-analysis because of the heterogeneity of the reviewed studies. Similarly, a review of comparison studies involving treatment of later-life depression concluded that the efficacy of pharmacological and psychological treatments is comparable (Pinquart, Duberstein, & Lyness, 2006). However, Pinquart and colleagues cautioned that smaller adjusted effect sizes may be generated in medication trials as they are more apt than psychotherapy trials to utilize a credible active placebo.

Contrary to these findings, Cuijpers and colleagues' (2008) review of studies comparing the efficacy of psychotherapy and pharmacotherapy concluded that SSRIs were more efficacious in treating MDD than was psychotherapy, and that treatment efficacy was similar across tricyclic antidepressants (TCAs; and other antidepressants) and psychotherapy (Cuijpers, van Straten, Andersson, & van Oppen, 2008). Although the difference was statistically significant, the authors caution against over interpretation of these results given the small effect size ( $d = - 0.16$ ). Cuijpers et al.'s (2008) stringent review only included studies that used an RCT to directly compare a pharmacotherapy to a psychotherapy group. Comparisons included CBT (15), IPT (7), PST (5), other psychological treatments (12), SSRIs (15), TCAs (16), and other medications (6). Although finding an efficacy advantage for SSRIs, the authors also acknowledged that drop-out rates were lower in psychotherapy versus pharmacological treatments, which may exert a long-term impact on efficacy.

Cuijpers et al.'s (2008) acknowledgment of limitations includes the fact that there may be important and unmeasured (in short-term outcome studies) differences between psychotherapy

and pharmacotherapy over the long-term. Also of note, not all individuals are willing to take antidepressant medications given inherent potential side-effects (APA, 2010). Therefore, comparative trials necessitating that participants be willing to be potentially assigned (via randomization) into a pharmacological treatment may omit any individuals unwilling to be assigned to the pharmacological group (Hoffman et al., 1998; Huppert, Franklin, Foa, & Davidson, 2002; Zoellner, Feeny, Cochran, & Pruitt, 2003). The issue of preference for treatment could thus bias the sample in favour of those more content with pharmacological treatment.

Butler, Chapman, Forman, and Beck (2006) conducted an overview of meta-analyses on CBT treatment outcomes for various psychiatric disorders and found large effect sizes ( $d > 0.8$ ) for depression. They concluded that CBT was as effective as behavioural activation and more effective than antidepressants in treating depression. Generating similarly positive results for CBT, Dobson et al. (2008) found that brief CBT is similarly effective in the long-term as continued medication treatment and that CBT's positive effects were as enduring as those of medication, post-treatment. Dobson and colleagues also found that CBT was less expensive than medication over the long-term. On a cautionary note, reviews of CBT tend to assume that it is a standardized treatment across studies; however, CBT, even if manualized, is not delivered in a standardized manner but is tailored to clients' needs and abilities. Given that the particulars of how CBT is tailored are not usually, if ever, provided, it is not possible to replicate the exact treatment that was utilized in a given trial. Therefore, it is important to be mindful of this significant limitation in any synthesis of CBT studies.

#### *Psychological and Pharmacological Treatments: Other Factors to Consider*

Besides effectiveness, there are other factors for consumers to consider including treatment availability, the time it takes for the treatment to begin to take effect, the potential

short- and long-term side-effects of a treatment, potential discontinuation effects, financial cost of treatment, post-treatment maintenance of treatment gains, dependency issues, and potential increase in risk of suicide. Each treatment can have specific properties within various domains, often called a risk or safety *profile*. Another trade-off for consumers to navigate is effort.

Although a benefit of psychological treatments is a relative lack of side-effects, consumers must consider that participation in psychological treatments demands significantly more effort than for medications. Perhaps a patient is too depressed and inactive to believe he or she could invest the required energy into a treatment. In this case, medication may be preferred. Hence, consumers must navigate among the profiles of each treatment in their decision making. This decision making process is further complicated by the fact that a growing literature provides at least some support for the use of combined pharmacological and psychological treatments.

#### *Combined Treatment*

Healthcare service providers sometimes suggest *combined treatment* as a preferred option to one treatment alone (termed *monotherapy*). The evidence is mixed on the benefits of combined treatment. While current guidelines (BAP, 2008) recommend psychological treatment as an adjunct to medication for treatment of severe MDD, a recent mega-analysis reports comparable outcomes for combined medication and psychotherapy versus CBT or IPT alone (Hollon et al., 2005). Findings from other meta-analyses show improved outcomes and retention rates with combined treatment (e.g., Cuijpers, van Straten, Hollon, & Andersson, 2010; Keller et al., 2000; Pampallona, Bollini, Tibaldi, Kupelnick, & Munizza, 2004). Otto and colleagues (2005) suggest against considering combined treatment as a default treatment for depression due to its limited benefit over and above monotherapy. However, Otto and colleagues

do note that combined treatment may well be most beneficial for chronic MDD and/or for relapse prevention (Otto, Smits, & Reese, 2005).

Hollon et al.'s (2005) review comparing monotherapy with combined treatment concluded that antidepressant monotherapies are effective for treatment of depression but only for while they are continued; they do little to decrease risk after their termination. Hollon and colleagues also concluded that IPT and CBT are as effective as pharmacotherapy but that CBT in particular demonstrates reduced post-treatment relapse risk. They also report that continued CBT or IPT further reduces risk and that joining IPT or CBT with medications preserves the specific benefits of the individual treatments. Hollon et al. state that the combination of CBT or IPT with medications may also improve response compared with either treatment alone and that this benefit may particularly apply to those who are chronically depressed.

It appears that the comparative efficacy of pharmacological and psychological treatments is somewhat arguable over the short-term. However, psychological interventions, principally CBT and IPT, may possess more lasting effects and not involve difficulties such as discontinuation symptoms and higher risk of relapse which are linked to termination of pharmacological treatment. In considering studies that do find an advantage for one acute treatment over the other, it is important to discern the clinical significance of these differences, and to consider potential bias in the sample given patient preferences, and the selection bias introduced when participants must be willing to accept both psychological and pharmacological treatment in order to participate in a trial.

#### *Self-Help Treatments*

Although the psychological and pharmacological treatments reviewed are the most commonly employed, they are not the only treatment approaches targeting depression (Vincent,

Walker, & Katz, 2008). For some individuals, self-help is a desirable option. However, self-help therapies are only beginning to generate substantial supporting evidence for their use (e.g., Andersson & Cuijpers, 2009; Cuijpers, Donker, van Straten, & Andersson, 2010). Examples of self-help therapies include self-administered computerized CBT (Kaltenthaler et al., 2006; Spek et al., 2007), CBT-based bibliotherapy (Andersson et al., 2005), and other forms of guided self-help, either alone or as an adjunct to medication treatment (Mead et al., 2005; Salkovskis et al., 2006).

The above illustrates how consumers often find themselves being offered a choice between two or more options of approximately equal potential benefit. In the shared decision-making model, when two or more treatments offered are approximately equally likely to be effective, the consumer is asked to choose an option based on his/her values pertaining to the various other features of each treatment. If the two treatments for depression with the most empirical support (i.e., psychological and pharmacological) as well as a combination of the same are approximately equally effective in treatment of depression, then consumers are encouraged to make a personal decision about which treatment they prefer based on their personal values. This situation meets the definition of a “decision-making” task and calls for the development of effective information and decision tools (Charles et al., 1998).

#### Focus on Young Adults

A growing body of research supports concerns regarding mental health problems and treatment decision making within the specific population of young adults. Epidemiological data reveal that mental health issues are common among this group (Gravel & Beland, 2005; Kessler, 2007), with 12.8% of persons aged 14-to-24 years meeting lifetime criteria for depressive disorders and 28.2% for anxiety disorders (Kessler). Incidence rates of depressive disorders

increase abruptly during this developmental period and peak between the ages of 18 and 24 (Kessler). Without adequate treatment, these disorders are often unrelenting (Dozois & Westra, 2004; Moreno & Delgado, 2000), exerting harmful effects in numerous developmental spheres (e.g., education, career, relationships; Dozois & Westra) during key life transitions.

Although many people with current mental disorders obtain insufficient or no treatment (Collins, Westra, Dozois, & Burns, 2004), treatment seeking is lowest among adolescents and young adults (e.g., Sareen, Cox, Afifi, Clara, & Yu., 2005). Reasons for a lack of help seeking cited by many young people include that they prefer to deal with problems on their own, are afraid to request assistance, or simply put it off (Sareen et al.). Although aspiring toward self-help is commendable and can ultimately result in symptom amelioration, individuals whose self-help efforts prove unsuccessful may benefit from other treatments. Lin and colleagues' (1996) findings from the Ontario Health Study showed that the lowest usage rate of mental health services was for individuals under age 25 (Lin, Goering, Offord, Campbell, & Boyle, 1996); this age group has also demonstrated lower self-perceived need for care (Meadows et al., 2002). Moreover, the most commonly identified obstacle to accessing care is the view that treatment for mental health is unnecessary or ineffective (Christiana et al., 2000; Sareen et al., 2007); and, this is a particularly prevalent attitude among adolescents (Dubow, Lovko, & Kausch, 1990).

Related to observations of lower treatment seeking among young adults is the growing concern about the level of mental health literacy within this group (Rickwood, Deane, Wilson, & Ciarrochi, 2005). *Mental health literacy* refers to what individuals know and believe about mental disorders which helps them recognize, manage, and prevent them (Jorm et al., 1997). Proportionately few members of the public are able to recognize common mental disorders, few know about treatments and/or treatment efficacy, many have negative attitudes toward help



seeking for mental disorders, and few are able to aid others in obtaining appropriate help (Jorm et al., 2006). Contributing factors to lower mental health literacy in young people include a lack of knowledge regarding help-seeking options as well as the social stigma associated with mental health problems and disorders (Jorm, Wright, & Morgan, 2007).

Jorm and colleagues' (2006) review found evidence supporting the role of community-wide initiatives and interventions targeted to high risk populations for the improvement of mental health literacy and help seeking (Jorm et al., 2003). This is consistent with similar research demonstrating that providing treatment-related information increases engagement with treatment (Ogrodniczuk, Joyce, & Piper, 2005; Walitzer, Dermen, & Connors, 1999) and improves attitudes toward care (Buckley & Malouff, 2005; Esthers, Cooker, & Ittenbach, 1998). Specific to the Internet, research shows that high quality websites can increase mental health literacy (Christensen, Griffiths, & Jorm, 2004); however, studies measuring the effects of providing quality information on treatment engagement and attitudes among younger individuals, whether via website or other modality, are rare (Oh, Jorm, & Wright, 2009).

Arnett (2000, 2004) has postulated a theory that the time between age 18 and 25 years comprises a discrete period of development in industrialized societies that he terms *emerging adulthood*. Emerging adulthood typically involves change and exploration as young people search out potentialities and gradually make enduring choices across love, work, and worldviews. Currently, greater proportions of young adults engage in post-secondary schooling and more often put off other life transitions such as entry into full-time labour, leaving the parental home, commencing a marital relationship, and potentially having children (Shaienks & Gluszynski, 2009). In general, young people perceive they have crossed the threshold into

adulthood when they accept substantial responsibility for themselves, make autonomous decisions, and become financially self-supporting (Arnett 2001).

Considering that emerging adulthood is a distinct stage of adult development, it is possible that some attitudes and perceptions are unique to this group. Unique perceptions pertinent to the current discussion may include those regarding health information delivered in varying modes such as books and websites. Research has generated mixed results in terms of links between age and perceptions of the helpfulness of websites pertaining to mental health information. For example, Oh et al. (2009) conducted a national telephone survey with 3,746 Australians between 12 and 25 years of age along with 2,005 co-resident parents. Variables assessed included the perceived helpfulness of several interventions in response to several vignettes (i.e., depression, social phobia, psychosis, and depression with alcohol abuse). The research compared young persons' preferences for a web-based intervention with 3 other interventions: self-help books, counselling, and visiting a mental health service. Results showed that 71% of participants rated websites and self-help books as "likely to be helpful," which was lower than ratings of counselling (i.e., 92%) and higher than ratings of mental health services (65%). Interestingly, age was identified as a predictor of rating a website as likely to be helpful. That is, participants between 18 and 25 years of age were more likely to rate a website as likely to be helpful than participants between 12 and 17 years of age.

Leach and colleagues (2007) surveyed almost 3,998 Australians 18 years of age and up and compared ratings of helpfulness across website, book, and health educator for an individual portrayed in a vignette as having either depression, depression with suicidal ideation, early schizophrenia, or chronic schizophrenia. Considerably more participants rated bibliotherapy (i.e., 66%) and health educator (i.e., 86%) as helpful compared with a website (i.e., 54%). Most

germane to the current discussion is that younger age predicted the likelihood of rating a website as helpful (Leach, Christensen, Griffiths, Jorm, & Mackinnon, 2007). Leach et al. note that findings are qualified by the fact that participants' choices were provided *on behalf of* the individuals in the vignettes, as opposed to what they themselves might prefer. Choices may have differed if participants were indicating their own preferences.

Cunningham et al. (in press) conducted a discrete choice conjoint experiment with 1,035 young adults (18-25) and adults (26-35) regarding preferences to receive information about anxiety and depression for themselves (as opposed to an individual in a vignette). They found that younger age did not predict a preference for information provided on the Internet. The authors note the need to provide information based on empirically derived preferences rather than on demographics such as age (Cunningham et al., in press)

The above discussion reveals some of the unique characteristics and needs of young adults in their mental health information/treatment seeking. Included is their reluctance to request help for mental health problems and their appreciation for privacy if they do seek information/help (both of which are linked to sensitivity to mental health-related stigma). Young adults report a lack of knowledge regarding help-seeking options and in general place a premium on websites for information addressing mental health issues. Given lower income levels at this age, combined with the above characteristics and preferences, it is likely that young adults would utilize and benefit from a high quality, free, web-based decision aid for depression.

#### Web-Based Decision Aids for Adult Depression

Recall that there are few decision aids addressing mental health issues such as depression (Adams & Drake, 2006). In order to obtain a more up-to-date assessment of the number, nature, and accessibility of decision aids for depression, I conducted a Google search on February 23,

2011. Review continued through five pages of Google results of which the final two pages yielded no applicable websites. Use of the search term: “Decision aids and depression” resulted in eight websites advertising a total of seven decision aids for depression. Of these, two were decision aids for childhood depression. One was a clinical trial for a new decision aid being evaluated but unavailable for viewing at that time. This left four decision aids for adult depression. (I conducted another Google search on June 30, 2013 which revealed no new depression decision aids.) One of the websites was from a recent review of available mental health decision resources conducted by the Substance Abuse and Mental Health Services and Administration (SAMHSA; [http://download.ncadi.samhsa.gov/ken/pdf/consumersurvivor/SAMHSA\\_Decision\\_Aid\\_Chart\\_Jan08.pdf](http://download.ncadi.samhsa.gov/ken/pdf/consumersurvivor/SAMHSA_Decision_Aid_Chart_Jan08.pdf)). This website listed of six depression decision aids and included all decision aids from the Google search results.

Of the six listed decision tools in the SAMHSA review, one had to be ordered and there were fees involved (i.e., Health Dialog), another was a clinician’s guide and not for use by consumers (i.e., MacArthur Foundation), another exclusively dealt with pharmacological treatments (i.e., Agency for Healthcare Research and Quality; AHRQ), and another dealt with childhood depression (i.e., Preferred Care through Healthwise).

There were two others most relevant to the current study (i.e., Preferred Care through Healthwise). One is entitled: “Should I take an antidepressant?” (<http://decisionaid.ohri.ca/Azsumm.php?ID=1058>; accessed February 23, 2011). The other is entitled: “Should I stop taking my antidepressant?” (<http://decisionaid.ohri.ca/Azsumm.php?ID=1311>, accessed February 23, 2011). Each of these is framed from the perspective of pharmacological treatments but do include some information

regarding non-pharmacological treatment (e.g., counseling). Of the IPDAS criteria, both of these decision aids currently meet eight content criteria and four development process criteria. Neither meets any of the effectiveness criteria.

Combined with findings of a general lack of high quality health information on the Web (Coulter, 2006), what appears to be missing are interactive, free of charge, and easily accessible (and re-accessible; Emmett et al., 2006; Oh et al., 2009) Internet-based decision aids for adult depression that provide high quality, accurate, and balanced information in terms of *both* pharmacological and psychological interventions.

#### *Development of the Current Decision Aid*

The content of the decision aid was developed to provide high quality information to consumers and to answer questions of interest that consumers identified in past research (e.g., Walker et al., 2000). In order to provide a tool that is most helpful and accurate, the decision aid's development has been guided by the IPDAS quality criteria framework (Elwyn et al., 2006) and has been following the stages as outlined by several authors and researchers (e.g., Dowding et al., 2004; Emmet et al., 2007; O'Connor & Jacobsen, 2003). The development team for the web version was comprised of a clinical psychologist, a clinical PhD student, and two web-designers. Although the development of the current decision aid falls outside of the purview of this study, a brief description of the process follows.

The content of the decision aid focuses on answering questions members of the public have about treatments for depression. Answers to these questions were derived from comprehensive literature reviews (including systematic reviews and meta-analyses) conducted by members of a research team located in Manitoba and Ontario and consisting of young adults and researchers with backgrounds in psychology and psychiatry. A description of this team is

located at [www.depression.informedchoices.ca](http://www.depression.informedchoices.ca). Information on issues such as the cost of treatment, persons providing treatment, and places where treatment could be accessed was gathered from information sources in the community based on the clinical experience of members of the research team. The goal was to provide practical, comprehensive, and balanced information. Descriptions of the characteristics of pharmacological treatment, psychological treatment (e.g., CBT), and combined treatment were included. Self-help options were also included given the high interest in self-help approaches in the public (Cunningham et al., in press).

An earlier version of the aid developed by Dr. John Walker was presented to a working team of health professionals from a variety of disciplines including psychology, psychiatry, and family medicine that was developing material to support primary care providers in Manitoba. Feedback from the team indicated overall acceptability of the completeness and balance of the content. The information aid was distributed to all family physicians in Manitoba. The content of the current version is subject to alteration based on feedback from young adults, healthcare providers, and interested members of the public. Future iterations will also reflect updated literature reviews on treatments for depression.

#### *Developmental Status of the Decision Aid*

It is important to note the iterative nature of the development and evaluation of the current decision aid. The information in the current version of the aid had already undergone preliminary evaluation by a variety of health professionals, resulting in numerous revisions. The information had also been updated due to ongoing literature reviews by a team of researchers. Now that the current studies have been completed, the aid is once again undergoing revisions

based on study findings. There are also future steps planned to continue to gain consumer and health professional input as to the helpfulness of the information in the decision aid.

In terms of the IPDAS criteria, the decision aid had progressed to meet several of the IPDAS *content* and *development* items. For example, the *content* item concerning a description of the health concern (depression) had already been met prior to the proposal of this study; however, the content item concerning a description of what happens in the natural course of the condition if no action is taken was met during the current project. The *development process* item focused on field testing the decision aid with people facing the decision is unmet; whereas the item addressing whether or not users (people who previously faced the decision) were asked what they needed to prepare them to discuss a specific decision has been satisfied. Specifically, a number of researchers (e.g., Garfield et al., 2004; Walker et al., 2000) have surveyed patients with a history of depression treatment to identify the type of information they need to help them decide about treatment. The major IPDAS criterion addressed by the current study fell within the development process domain. Specifically, the goal was to evaluate the decision aid with young adults who had experienced depression and with young adults in the community not selected for having experience with depression in order to determine acceptability and gain their input on its improvement.

## Research Overview

### *Purpose of the Research*

Providing sufficient high quality evidence-based information about depression treatment helps individuals navigate across increasingly complex treatment decisions. In order to improve the quality of information about depression on the Internet and to increase its utilization, Coulter et al. (2006) suggested increased systematization in the development and evaluation of decision

aids based on comprehensive quality criteria (e.g., IPDAS; Elwyn et al., 2006) and the incorporation of consumer input early in the development process. The current review indicates a lack of web-based decision aids for depression with high quality, balanced information including pharmacological and psychosocial treatment information (e.g., Reavley & Jorm, 2010). Also lacking are published studies of evaluations of such decision aids where the evaluative perceptions of young adults are collected and analyzed. Providing sufficient amounts of evidence-based information about depression on a website that has been evaluated by the target group may ultimately help increase informed decision making and motivation to seek treatment among young adults (Jorm et al., 2009).

#### *Research Objective*

The broader purpose of the current study was to address the above needs and contribute to the systematic development and evaluation of a depression decision aid for use with consumers and other members of the public with a particular focus on the information needs of young adults. To that end, we carried out two studies with samples of young adults. Our intent was also to measure participants' online usage of the aid with the purpose of exploring associations between sociodemographic variables and participants' online behaviour in interacting with the decision aid.

#### *Primary Research Questions*

1. What opinions and ratings do young adults provide about the clarity, balance, trustworthiness, completeness, and helpfulness of the information in the decision aid (Study 1 and 2)?
2. What opinions and ratings do they provide regarding the amount of information in the aid (Study 1 and 2)?



3. What level of familiarity do participants report regarding the information in the aid (Study 1 and 2)?
4. What are their suggestions for improving the decision aid (Study 1 and 2)?
5. What contributions do the qualitative data make to a revised version of the decision aid for the quantitative study (Study 1)?
6. How does the amount of time spent on each topic vary across topics, controlling for the number of words per topic (Study 2)?

#### *Secondary Research Questions*

Research has demonstrated relationships between sociodemographic factors and patients' actual behaviour with decision aids. For example, participant factors such as age and educational attainment were related to the amount of information reviewed while using a computerized decision aid in one study (Molenarr et al., 2007). The following questions relate to characteristics of persons interacting with the decision aid:

7. How do participant characteristics (i.e., age, education, gender, current psychological distress, history of depression, history of depression treatment, and parents' education) relate to perceptions of clarity, amount, trustworthiness, balance, familiarity with, completeness of, and helpfulness of the decision aid (Study 2)?
8. How do participant factors (per above) relate to web-behaviour (i.e., time spent on the website and particular topics; completion or noncompletion of survey; Study 2)?

## Overview of the Study Design

### *Mixed-Methods Research: Background*

Creswell (2003) notes that mixing research methods has had a relatively brief history in the social sciences. Researchers such as Campbell and Fiske (1959), in the formative period of mixed-methods research, introduced a strategy of using more than one quantitative method (i.e., “multi-trait, multi-method”) to examine the validity of psychological traits (Campbell & Fiske). Jick (1979) discussed the combination of qualitative and quantitative methods as a means of achieving triangulation, thereby strengthening confidence in study findings (e.g., increasing the ability to attribute variation to individual differences versus to the methods employed to measure the variation; Creswell, 2007).

Further developments occurred during a period (i.e., the 1970s and 1980s) characterized by paradigm debates when researchers such as Guba and Lincoln (1988) asserted that qualitative and quantitative research are each based on different foundational assumptions and, as such, that the logic and internal consistency of each paradigm mitigates against combining them (Guba & Lincoln, 1988). However, researchers like Patton (1981) argued for the preeminence of practical, real-world, concerns over philosophical and epistemological concerns regarding purity of methods. In other words, researchers must be open and able to adapt to, collect, and analyze the kinds of data that are available to them. This forms the basis for the *pragmatic* argument, which has become the foremost argument for mixing methods (Tashakkori & Teddlie, 2003a).

Even though the above debate has not been entirely resolved, during the late 1980s and 1990s, researchers focused more on developing *procedures* for mixing methods and data. For example, Greene, Caracelli, and Graham (1989) analyzed 57 evaluation studies and created a classification system consisting of six study types and discussed design decisions that fit within

each type. Building on developing classifications, researchers eventually developed specific types of mixed-methods designs (Creswell, 2007). Currently, there are numerous authors advocating for, and utilizing, mixed-methods designs (e.g., Creswell, 2003; Ivankova & Stick, 2006; Tashakkori & Teddlie, 2003a), especially where it is evident or expected that an exclusively qualitative or quantitative approach by itself may produce an incomplete picture. In these cases, a mixed-methods design offers the advantage of the clarification of subtleties in findings and cross-validation of findings (Creswell, 2007).

### *The Current Study Design*

The current project is a sequential exploratory mixed-methods design, consisting of two distinct phases: qualitative methods followed by quantitative methods (Creswell et al., 2003), utilizing samples of young adults. Study 1 was limited to persons who had experienced depression and its treatment; Study 2 did not have this limitation. Study 1 involved the gathering, analyzing, and interpreting of open-ended in-depth text data. The primary focus of examination was the opinions of young adults with a history of depression regarding a depression treatment decision aid. The qualitative findings informed a revision of the decision aid (details below), which was then launched in a web survey format in Study 2.

In Study 2, the revised version of the decision aid was evaluated by collecting, analyzing, and interpreting quantitative data with a larger sample of university students between 18 and 25 years of age, not necessarily having a history of depression treatment. Hence, *mixing* of the two distinct methods occurred in the form of *connection* (Creswell et al). That is, the qualitative and quantitative methods are *connected* during the intermediate stage of research by the influence of the qualitative findings on the development of the next iteration of the decision aid. Even though the qualitative phase occurred first and informed the next version of the decision aid to be

launched in the quantitative study, both methods were given equal weight. This was because the quantitative phase was primarily pre-planned in terms of procedures and survey questions and was therefore not fundamentally and significantly impacted by the qualitative phase of the project.

The Ottawa Decision Support Framework (ODSF; O'Connor, 2006) functioned as a guiding model in the decision aid's development and evaluation. Predicating the current study upon the ODSF (with its basis on several theories) will more easily facilitate future hypothesis testing including the examination of effects of the decision aid on decision quality, and will help to provide generalizable findings as to *how* these effects are achieved. The original International Patient Decision Aid Standards (IPDAS; Elwyn et al., 2006) framework was viewed as a practical list of quality criteria to guide the current project in the aim of providing decision and information support based on the overarching ODSF.

#### *Rationale for Mixed-Methods Study*

A mixed-methods design was used as this is a relatively new area of research. Given the lack of decision aids for depression (SAMHSA, 2010), and the limited work on evaluation of decision aids, the evaluation of the decision aid under development constitutes the exploration of a new area of research. Given how little is known about consumers' experiences and opinions in this area, it is beneficial to utilize qualitative methods, as they can provide significantly more in-depth and rich data compared with quantitative methods, essential in the earlier stage (i.e., Study 1) of an exploratory study (Fitzpatrick & Boulton, 1994). Ultimately, utilization of both qualitative and quantitative research methods was intended to increase the comprehensiveness of the overall findings of the project. Figure 1 depicts the phases, activities and products that comprised the current project.

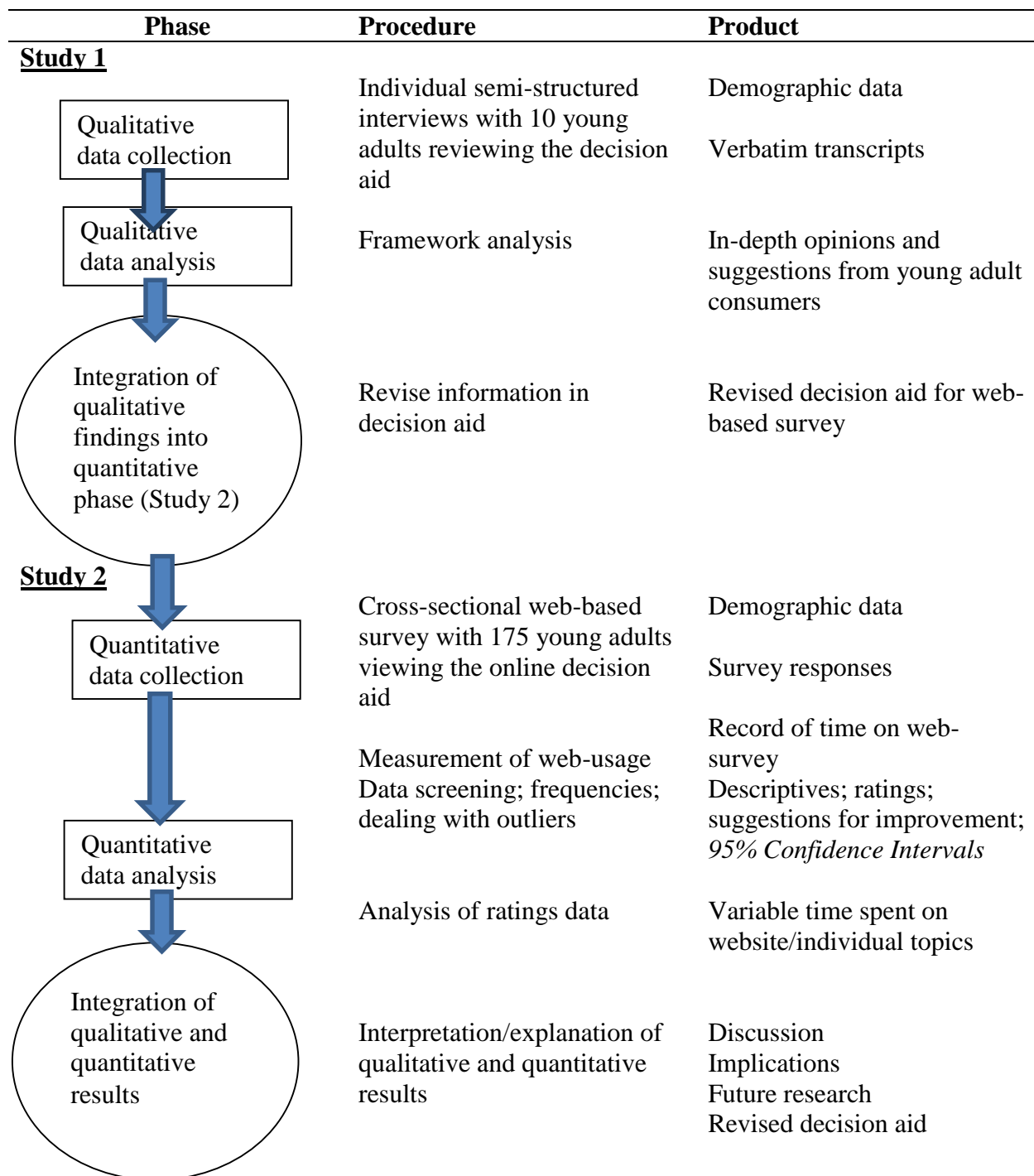


Figure 1. Visual model for mixed-methods sequential exploratory design phases, activities, and products.

## Study 1 Method

### *Participants*

A survey of the decision aid literature revealed that the common range in sample size for evaluating a new decision aid is between 10 and 15 (Dowding et al., 2004; Emmet et al., 2006; O'Connor & Jacobsen, 2003). Most often, it is at this point that data analysis results in redundancy (Lincoln & Guba, 1985). The current analysis reached redundancy after the data of 10 adults had been analyzed; therefore we capped recruitment at 10. We used homogeneous purposive sampling to target adult consumers between the ages of 18 and 25 years (inclusively) who previously faced a decision about treatment for depression. Criterion sampling ensured a balanced representation of men and women (a more detailed description of participants follows in the results section).

### *Measures*

#### *Demographics Questionnaire*

Participants completed several items pertaining to their gender, age, educational attainment, current residence, parents' postal code, and expected debt once their postsecondary education has been completed. They were also asked about a history of depression and pharmacological and/or psychosocial treatment (See Appendix B).

#### *Kessler Psychological Distress Scale--6 (K6; Kessler et al., 2002)*

Participants completed this brief screening measure of general psychological distress. The *K6* is a 6-item scale which asks respondents to rate how often within the past month they felt, for example: "hopeless?"; "nervous?"; "so depressed that nothing could cheer you up?" Response options range on a 5-point Likert scale from "all of the time" to "none of the time". All items were reverse scored and summed to a range of 0-24 (Kessler et al.;

<http://www.integration.samhsa.gov/images/res/K6%20Questions.pdf>). Numerous studies have demonstrated evidence of good psychometric properties possessed by the *K6*. For example, good internal consistency was demonstrated within a U. S. sample (i.e., Cronbach's alpha of 0.89; Kessler et al., 2002) as well as an Australian sample (i.e., alpha of 0.85; Furukawa, Kessler, Slade, & Andrews, 2003). The *K6* has also demonstrated the ability to accurately discriminate between DSM-based clinical and non-clinical cases in numerous studies (e.g., Kessler et al., 2003). Convergent validity was demonstrated by Arnaud et al. (2010) in that the *K6* was correlated (i.e., 0.83) with the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) and correlated (i.e., 0.51) with the Hamilton Depression Rating Scale (Hamilton, 1960).

#### *Mini International Neuropsychiatric Interview (MINI; Sheehan et al., 1998)*

The MINI is a structured clinical interview used by researchers and clinicians to provide diagnoses of DSM-IV- and ICD-10-based psychiatric disorders. The depression and (hypo) mania sections of the MINI were administered to those interested in participating in Study 1 in order to confirm a history of depression and screen out bipolar disorder.

#### *Interview Protocol*

The interview questions derive from a combination of the literatures on decision making in healthcare and from several decision aid evaluation studies. For example, Dowding and colleagues (2004) launched a computerized decision aid and asked patients about the aid's ease of use, content, usefulness, and things to alter. Emmett et al. (2007) conducted a study of two computer-based decision tools and posed questions in terms of the acceptability of the computer-based format, presentation of health benefits and risks, and the usability of the program. Holmes-Rovner and colleagues' (2005) evaluation of a prostate cancer decision aid in plain language

utilized focus groups and asked similar questions regarding the acceptability of content and language, the understandability, and the usability of the format.

One of the central features of qualitative methods is concurrent data collection and analysis (Pope, Ziebland, & Mays, 2000). The plan was to allow emergent processes and findings to shape ongoing data collection (i.e., “sequential analysis”; Pope et al.). Indeed, emergent findings did affect ongoing data collection in several ways (described below).

Preliminary testing of the proposed interview protocol resulted in administration times within the 60-90 minute time range. However, actual administration with participants resulted in significantly longer duration of more than 120 minutes. This was due to the tendency for interviewees to provide substantial personal information on experience with depression and treatment. Also, participants often took time to voice concerns and make suggestions for content that was addressed in upcoming sections of the decision aid. Due to both of the above concerns, consultation with team members led to the decision to eliminate some of the preliminary questions regarding decision-making processes and to provide a printed outline of the decision aid so interviewees could view upcoming topics. These changes were made after the first four interviews.

Data from questions regarding helpfulness and trustworthiness located on individual topics failed to elicit rich data and were removed from each page. These items were instead asked after three sections (i.e., Medications, Psychotherapy or Counselling, and Combined Treatment/Self-Help treatment) for the final six interviewees. The presentation of the Medications section and Psychology or Counselling sections was counterbalanced. The remainder of the decision aid was presented identically for all participants. The two interview



protocols are presented in Appendices C and D; the decision aid outlines are provided in Appendices E and F.

Copies of the Study 1 (Appendix G) and Study 2 (Appendix H) decision aid are provided so that reviewers of this thesis can view the materials that were under evaluation. The current version of the decision aid is now available for viewing at the Informed Choices website (<http://depression.informedchoices.ca/>).

### *Procedure*

#### *Research Setting*

We conducted this research in Manitoba's capital city: Winnipeg, a city comprised of approximately 700,000 people. Over the past decades, the emphasis of mental health treatment in Manitoba has shifted from institution-based to community-based interventions. The delivery of mental health services was devolved to regional health authorities such as the Winnipeg Regional Health Authority in 1997. Consumers have access to a variety of treatment and education resources; however, medication treatment is more accessible than non-medication based interventions such as psychotherapy or counselling.

I conducted recruitment and interviews at the offices of the Mood Disorders Association of Manitoba (MDAM), which is a self-help association co-located with the Manitoba Schizophrenia Society, Anxiety Disorders Association of Manitoba, and the Obsessive Compulsive Disorder Centre, Manitoba Inc. in downtown Winnipeg, Manitoba. MDAM's clients are from diverse sociodemographic backgrounds across the late adolescent and adult age range. Clients have had or are having problems related to mood and these problems vary from intense/crisis level to reduced levels managed well in the community. MDAM provides a number of services including peer support and public education, all of which are provided by staff and

volunteers having personal experience with mood difficulties. In terms of physical space, MDAM is a collection of quiet, warmly decorated offices and cubicles. The staff and volunteers are friendly and helpful. I conducted interviews in a private, out of the way, and very quiet office. Ethical approval for the study was obtained from the University of Manitoba Research Ethics Board.

### *Recruitment*

The director of MDAM introduced me to several MDAM staff and volunteers to coordinate recruitment visits to their self-help groups. Also, a staff member made an announcement on Facebook about the study (See Appendix I), inviting those interested and within our study parameters to make contact about participation. There were no responses to the Facebook advertisement; I completed all recruitment in-person at several of the MDAM youth group meetings, where I explained the study and allowed interested individuals to provide contact information for a follow-up conversation. I provided more details regarding the study utilizing a telephone script (see Appendix J) during individual conversations with each prospective participant, either by phone or in person. I had a Helping Resources sheet ready (though it was never required) during phone and in-person recruitment in the event a potential participant would experience distress during our interaction (See Appendix K). With their verbal consent, I administered the relevant sections of the MINI either on the phone or in person and confirmed each participant's eligibility. In all cases, it was most convenient for participants to attend the interview at the MDAM offices.

### *Procedural Flow of Data Collection*

Using a greeting script (See Appendix L), I welcomed participants to the interview site, described what was required of participants, obtained written informed consent (Appendix M),

and provided the honorarium and a copy of the Helping Resources sheet. Then, participants completed the demographics questions, K6, and I conducted the interview. During the interview, participants viewed the decision aid topics in sequence, answering topic-based questions after each topic as well as final overall questions. Once finished this review/interview, I provided each participant with the Research Feedback sheet (See Appendix N). I audio-recorded each interview and the team had a professional transcriptionist transcribe the interviews. During (i.e., while participants were reading) and following the interview, I used “analytical memos” (Strauss & Corbin, 1990) to record and track ongoing questions, comments, and decisions I made while working to identify categories and themes. These memo data enhanced my understanding of the interview data and in developing a categorization scheme.

#### *Data Analysis*

Study 1 relied upon *framework analysis* (Ritchie & Spencer, 1994, pp. 173-194) which has been developed particularly for applied research including evaluation (Ritchie & Spencer, 1994). This form of qualitative analysis was a good fit for the study’s exploratory, evaluative nature which used an interview that was comprised mainly of repeated questions that provided an initial analytical framework. There are five key stages: familiarization, identifying a thematic framework, indexing, charting, and mapping/interpretation.

During the *familiarization* stage, I immersed myself in the data: listening to recordings, reading transcripts, and reviewing observational notes, with the goal of discovering and listing key ideas and repeated themes. These included information topics and subtopics found to be of varying clarity, completeness, and/or familiarity. The work consisted of capturing conceptually similar meaning units under representative categories. During this stage, I recorded and reviewed ranges of responses to interview questions, and I noted issues important to interviewees.

The key goal of the next stage was to *identify a thematic framework (or index)*. Here I noted key issues, concepts, and themes within the research notes generated in the familiarization stage. These themes and patterns provided the framework within which I could examine and reference the data. The initial thematic framework was based on the interview questions and topics to which they applied. However, I was able to refine the framework based on respondent-generated emergent themes and patterns of particular responses.

*Indexing* refers to a procedure whereby the thematic framework is methodically applied to all of the data (as opposed to selected transcripts). I read and annotated all data based on the categories contained in the thematic framework. I listed categories along with their corresponding codes and coded data into specific categories. I accomplished this by lifting summaries and quotes from the previous phases and organizing into summary tables, based on topic and interview question.

*Charting* involves a set of activities intended to develop an image of the *sum total* of the data. This involved my consideration of the full range of attitudes and experiences within each issue or theme. I then copied data from their original context and reorganized according to the applicable thematic reference. These charts consist of headings and subheadings drawn from interview questions, from the thematic framework, and/or from consideration of the best way to summarize the study results. I created charts for each key topic.

Simultaneous to the above procedures, I engaged in periodic reviews of transcribed data and comparison with developing meaning units, categories, and codes so as to help ensure accuracy; this also functioned as a strategy to increase the credibility and consistency (dependability) of the analysis and findings. These intermittent reviews facilitated ongoing note-taking regarding the developing coding framework and (along with other factors) indicated when

saturation was achieved. Abstraction and synthesis followed the creation of the charts. That is, I studied and further distilled into summary form each annotated passage of text and then entered these summaries into another table. I referenced the original text to facilitate tracing each summary statement back to its source. This facilitated examination and replication of the abstraction and synthesis process. *Mapping and interpretation* constituted the final stage of analysis. I brought together and reported the key characteristics of the data after the data had been sifted and charted based on core themes.

Upon completion of data analysis, I attempted the process of *member checking* (Patton, 2002). In September, 2013, I provided (to the email addresses specified by each of the participants) a written summary of the findings along with an invitation for feedback regarding the accuracy of the interpretations made by the researchers (See Appendixes O and P for the Email and Study Summary, respectively). This failed to yield any responses; therefore, I sent a repeat email in December, 2013 but have yet to receive any replies. In both cases only one of the email addresses generated a “Delivery Status Notification” of a non-existent email. Therefore, it appears the other nine should have reached the addressees. Therefore, we were unable to incorporate member checking of the team’s analysis and/or interpretations of the data.

I kept detailed *observational notes* during and following each of the interviews in order to document changes in behavioural responses (e.g., voice intonation and non-verbal responding) that participants exhibited while reading information in the decision aid. In general, participants engaged in fairly unremarkable, relaxed, attentive reading behaviour (i.e., sat oriented and slightly leaning in toward the computer screen while reading, and oriented toward me as I asked questions). The level of interpersonal engagement did vary across participants from a more socially engaged style (e.g., greater use of eye contact, a more conversational style, asking more

questions, more spontaneous verbalizations) to a more reserved social style. However, all participants seemed ready to share their thoughts and feelings about the information they were reading. It was clear that some participants had more well-formed opinions about the material than others.

Several participants exhibited more variation in both verbal and non-verbal behaviour. Most notably, there were 40 spontaneous verbalizations, of which 36 were made by men. Verbalizations ranged from very brief comments (e.g., one- or two-word comments such as “cool”, or “that’s good”) to more substantial comments consisting of two or more sentences containing a specific opinion about the information. Of the 36 verbalizations made by men, 24 were considered substantial; of the 4 by women, 2 were considered substantial. Some spontaneous verbalizations were delivered in an even tone/rate of speech; others were delivered at a higher tone/rate.

The verbalizations were diverse in content and contained several themes: (1) concern about implications of the information (e.g., negative side-effects of medication); (2) confusion about the material (e.g., outcome rates); (3) disagreement with the accuracy of the material (e.g., outcome rates); (4) agreement with statements in the material; (5) suggestions for improvement of the information; and (6) appreciation for the information. Topics receiving the most spontaneous verbalizations (i.e., from 3 participants or more) were: “What Happens when the Medications are Gradually Reduced and Eventually Stopped?” (men and women), “Tables: What are the Common Side Effects of Medications?” (men and women), “Long-Term Side Effects” (men only), “What are the Risks of Psychotherapy or Counselling?” (men only), and “Self-help Treatments” (men and women). These statements are reported in the Results section.

Coinciding with some of the above verbalizations were spontaneous non-verbal behaviours: quickly sitting back in the chair, looking intently at the computer screen, looking intently at me, head shaking/nodding, and eye rolling (very rare). Other than men's increased frequency of notable spontaneous non-verbal behaviour, there was no other obvious gender difference in the type or intensity of such behaviours.

### *Consideration of Quality*

Credibility depends upon the rigor and quality of a study. One way that it was addressed in the current study was via record keeping (e.g., writing journal notes while interviewing and documenting procedures of data analysis). Credibility was also established via several forms of *triangulation*. Triangulation refers to the use of multiple data sources, methods, theories, and analysts in order to help overcome the bias intrinsic in single-observer, single-method, and single-theory studies (Patton, 2002). In the current study, credibility is increased by the triangulation of data sources and research methods.

Data were collected from *multiple sources*: young adults reporting previous experience with depression (Study 1) as well as a non-clinical sample of university students (Study 2). In this way the current study can compare perceptions of the decision aid across those whose perspectives may vary based on whether or not there is a history of depression. The use of *multiple methods* was another form of triangulation. By using both qualitative and quantitative methods compared with either method alone, the current study gains a more comprehensive understanding of young adults' perceptions of the decision aid and is less susceptible to the error inherent in either method alone.

*Confirmability* relates to the degree of neutrality or objectivity brought to the process of research as a whole (Lincoln & Guba, 1985; Tutty et al., 1996). I documented the ongoing

analysis process via notes I made regarding issues such as coding procedures. I also documented in reflective notes my own personal reactions that occurred during the interview to help identify personal values, biases, and experiences that may have influenced the interpretation or final report of the data. An in-depth expert review of data analysis (e.g., Patton, 2002) by co-advisors (D. H-M and J.W.) confirmed the accuracy of data analysis and helped reduce the bias of my single perspective. I reviewed and analyzed 100% of the transcripts; J.W. and D. H-M. each reviewed 50% of the transcripts alongside my evolving coding schemes.

*Dependability* refers to the consistency or reliability of the study's results. One of the ways this can be established is through the use of a semi-structured interview protocol; another way is via the development of rules for coding; and yet another way is by documenting decisions made during data analysis (Tutty et al., 1996). Dependability is another aspect strengthened by expert review (above) which resulted in a positive judgment regarding the accuracy of data analysis.

*Transferability* pertains to the generalizability of findings recognizing that they are most often context specific (Lincoln & Guba, 1985). Participant and primary researcher demographic descriptions are included (below) so that readers can more clearly understand the context of the research and judge the applicability of the study's findings. Participant descriptions should aid conclusions about the transferability of findings to other populations of young adults. Information regarding the context of the interviews (see above) is also provided to help assess transferability.

### *Ethical Considerations*

This study took into consideration the challenges inherent in conducting in-depth interviews. Patton (2002) notes that "interviews are interventions" (p. 405). Given this, I took



care to pursue the purpose of research which is to gather data and minimize the impact on participants. To this end, I attempted to create a friendly environment and establish good rapport while making no attempts to influence participants' feelings or provide therapy. In cases where numerous participants have requested advice about getting help during interviews, some researchers (e.g., Patton) have opted to provide a list of helpful resources to every participant, whether or not they make such requests. In this way, some help can be provided without blurring lines between research and therapy roles. We employed this strategy in the current study.

During the consent procedure, I explained that the purpose of the study was to understand participants' past decision making process and also to inform revisions to a new decision aid for depression, and that the information would be reviewed by a team of researchers (J.W., D.H-M., B.Z) conducting research under the auspices of the University of Manitoba. I also informed them about the nature of the questions prior to the interview and that the information would be handled in a way that protects confidentiality as much as possible. In particular, I assigned each participant a participant number (code) which was written on each participant's digital recording and transcript. These codes were and are being stored separately from the audio files and transcripts so that materials have fewer identifying features.

The list of names and codes is stored in a locked cabinet at St. Boniface Hospital in a secure room. A professional transcriptionist, who had completed her Personal Health Information Act (PHIA) training and pledge was hired to transcribe audio files. The audio files were saved in Compact Disk (CD) format, password protected, and hand delivered. The researchers have not discussed individual responses with anyone outside the research team. The data will be destroyed (i.e., paper form will be shredded, electronic files will be deleted, digital recordings will be erased) five years after publication (approximately in the year 2019). I

informed participants of a slight risk that reading materials about depression may result in feeling upset, particularly given their personal history of depression. I also informed them of the benefits of participation that included a \$25.00 honorarium, learning about depression and treatment, and taking home a paper copy of the decision aid.

## Study 1 Results

### *Participants*

There were 5 women and 5 men within the target age range of 18-25 years, with a mean age of 20.7 years ( $SD = 2.31$ ). All participants were single-never married. Mean education was 12.6 years ( $SD = 1.75$ ) for participants, 15.8 ( $SD = 2.35$ ) for their mothers, and 14.6 ( $SD = 2.30$ ) for their fathers. Four out of 5 participants who had participated in post-secondary programs had completed some university; one had completed a year of college. Parents' post-secondary education included a mixture of apprenticeship, college, and university programs. Three out of 5 participants projected no debt from post-secondary education and two participants reported debt as \$8,000.00 and \$10,000.00 respectively. All participants reported a history of unipolar depression (no bipolar disorder) which corresponded with results of the administration of the relevant sections of the MINI. Three participants (all male) reported additional diagnoses: one had a diagnosis of borderline personality disorder (BPD); one had a diagnosis of attention deficit disorder (ADD); and one had diagnoses of both BPD and ADD.

Self-reported psychological distress ( $K6$ ) ranged from a total score of 5 to 23 with a mean of 11 ( $SD = 5.72$ ). Overall distress was relatively low, with only one participant scoring in the range of high distress (19 and above). This suggests an element of *transferability* of findings to other non-distressed groups of young adults with a history of depression.

### *Primary Researcher's Background and Experiences*

My sociodemographic background is provided as context to aid readers in understanding the design, questions, and results of this project. I am a 6' 3", 240 pound, 50-year-old male of European descent raised in rural Manitoba. I came to university after first pursuing a religious studies degree from a local Christian college. Since the year 2000, I have been transitioning from a primarily religious world view to a more universal and scientific perspective. As a result, I have come to accept and enjoy more diversity in for example, ideology, culture, ethnicity, and sexual orientation. I have also been transitioning from a more positivistic viewpoint to constructivism. Therefore, the study design, analyses, interpretation, and reporting are all susceptible to influence of these and other areas of my background. For example, a mixed-methods design reflects opposing epistemologies (above), both to which I have at least some philosophical affiliation. I agree with Creswell's (2003) argument that mixing methods predicated upon opposing epistemologies is justifiable based on pragmatic grounds.

My educational background includes a Bachelor of Arts from Providence College (2001), and a Bachelor of Arts (honours) majoring in Psychology (2003) as well as a Master's of Arts majoring in Clinical Psychology (2006), both from the University of Manitoba. One of my graduate courses focused on qualitative research methods and also provided didactic and practical training in interview skills. In my training, I have also conducted many semi-structured, structured, and unstructured clinical interviews across numerous settings and client populations.

### *Reactions to the Decision Aid*

#### *Familiarity*

Given that all participants had a history of depression, it was not surprising that much of the information in the decision aid was reported to be familiar. However, there were five areas of

*unfamiliarity*: (1) some of the outcome rates (as explained below), (2) treatment costs, (3) some treatment side effects, (4) therapy training across disciplines, and (5) the topic: “Tables: What Are the Common Side Effects of Medication Treatment?” (abbreviated as “Tables” from this point). Numerous participants were unfamiliar with outcome proportions regarding recovery from depression without treatment, rates of effectiveness of first trial medications, and chance that psychotherapy could lead to a worsening of depression. One of the men expressed his unfamiliarity and surprise regarding response rates to first trial medications:

*Yeah well other than the “six out of ten notice they feel a lot less depressed on the first medication they try”, um in fact I would have thought it was lower.... (25 years old).*

Several participants were unfamiliar with and alarmed by the statement that engaging in psychotherapy and counselling could cause harm. As one woman stated:

*Um I didn't know the statistic about “one out of ten people experience a worsening of their condition.” I think that's interesting, I didn't know that that happened (20 years old).*

Several participants were unfamiliar with financial costs of treatment, whether psychotherapy or medications. One woman said this of medication costs:

*...that was good...I didn't know about sample packages, my doctor's never done anything like that, and I didn't know about dispensing fees or asking them to do a larger period, that's really interesting as well (20 years old).*

The above woman was also unfamiliar with one of the less common potential side effects of some medications:

*I've never heard anything about allergic reactions to medications but that I mean makes perfect sense.*

Participants were generally familiar with the fact that multiple disciplines provide psychotherapy and counselling; however, they were less familiar with the variable amounts of training across disciplines. As one man put it:

*...I mean [I know] that these people exist...definitely familiar...the amount of training involved, not familiar and most people won't be (25 years old).*

The “Tables” of medication side effects was the least familiar for participants in this study. In this case, responses ranged from slightly unfamiliar to very unfamiliar. A 20-year-old man commented: “...cause I haven't seen information like this before” as did a 21-year-old woman: “...I guess just like all these numbers are kind of new” and a 20-year-old woman: “A lot of that's new...” A 25-year-old male felt others, like him, would find the information unfamiliar: “Uh gosh, not at all, I mean no not many people are going to know about the side effects for these different medications.”

#### *Amount*

For all but five topics, most participants evaluated that the amount of information was “about right.” One of the exceptions was on “Long-Term Side Effects”, where four respondents felt improvements could be made to the amount of information. A 25-year-old man thought this topic contained a bit too much information that may intimidate readers: “I would want there to be less just so you don't want to scare people...” Conversely, a 20-year-old woman thought a bit more could be added so as to balance this information with the amount of information in “Tables”:

*Um I think a little more could be added as to like...the previous tables as to which medications more commonly cause which side effects and how much they do.*

One of the men felt we should add information on a larger number of long-term physical side effects like “blood pressure and heart rate...and insert them into a table like the other one. It’s more consistent and fair.” (23 years of age). Two other participants (male and female) agreed with the notion that further development of this topic was warranted. A 20-year-old male participant: “...uh some numbers for weight gain would be nice...” He noted that probabilities were used for other elements on the topic, but not for weight gain.

Comments made about the topic of “What Are the Risks of Psychotherapy and Counselling?” indicated an interest for more information. While reading this page, a 23-year-old male participant spontaneously pointed to a section about the potential that depression can worsen during therapy and then stated: “More than that, way more than that. I would say for this one it’s more the, the factors in this one.” He explained that he would like to see the addition of information regarding individually based contributing factors. One of the women who had a strong tendency to suggest increased brevity and the use of bullets said “I like it ‘cause it was like really short” (19 years old). One of the male participants noted the difficult but necessary nature of this information:

*Yeah I mean this last one’s just a pill we all have to swallow, that’s the reality, that it doesn’t necessarily and it can be related to the actual therapist. It’s too bad but that’s the way it is and it needs to be presented that way...yeah this is a necessary but unfortunate section.*

Although most thought the amount of information contained in the “Tables” page was acceptable, there was acknowledgement from some participants that it was a lot of information. For example:

*I think it's good... obviously not everybody's going to like read the whole thing and know all those things, but it's a good reference to just look up you know about things you've heard of (20-year-old woman).*

Similarly, another participant noted that, although she initially felt overwhelmed by the amount of information on “Tables”, she felt the information was still helpful: “Once you find what you’re looking for, it’s pretty good” (18-year-old woman). She made a suggestion for improvement that might address a sense of information overload:

*...maybe like be able to search it or something, like have that option, where it's like have the list but then maybe be able to search it too...because it's just that would be a lot to go through.*

A 20-year-old man felt there was a disproportionately small amount of information on the topic of “Uncommon but Serious Side Effects” compared with the other side-effects pages:

*It seems alright, it's just... the amount of information per section seems a little unbalanced, I don't know if that's just sort of a, a visual thing...when you look at alcohol, people mixing medication with alcohol is probably as common as all the other sections, but it's so much smaller.*

Although most felt the amount of information on the topic of “Self-Help Treatments” was acceptable, one male participant (25years of age) felt quite strongly that it was too brief: “Um but yeah, so this definitely needs to be longer.” He expounded that self-help treatment is important because there are no other treatments that can provide 24-hour, day-to-day care because they rely on someone other than yourself: “Uh and it, and it really addresses the day-to-day stuff...And the only person that can be with you all the time is yourself...”

### Clarity

Overall, both men and women felt that the decision aid was very clear, with no areas of real concern or confusion. One participant commented:

*Yes it, it definitely is [clear]. It was easy to follow along and the words were good so it didn't confuse me at all... (19-year-old woman).*

*Oh yeah...again the whole short attention span thing like doubles as a compliment. If I can understand it then it's like probably five times...easier to read for everyone else (18-year-old man who had commented earlier on having challenges maintaining attention).*

Although he believed the decision aid was quite clearly written, one of the men suggested developing two versions of the decision aid: the current version as well as one written in more plain language. Another overall suggestion to improve clarity was to increase the use of bullet points, especially where there were longer paragraphs and pages.

There were two topics that were described as somewhat less clear (i.e., “What Happens to Depression without Treatment?” and “Tables”) especially regarding presentation of outcome rates. It seemed several participants had some difficulty comprehending outcome rates, at least earlier in their review of the decision aid. On “What Happens to Depression without Treatment?” one man articulated:

*It's not really clear...especially when it got down to “about two out of ten people will still be depressed two years later”, um I don't know if it was just the wording that threw me off because at the beginning it talked about “five out of ten people will recover...I don't know if it's just the wording in the whole thing or if it was uh, or if it's like the numbers (chuckle) I don't know.*



Further discussion seemed to indicate that the decision aid would have been clearer for this participant if it balanced information about the proportion of people who DO NOT recover spontaneously with information about those WHO DO recover (i.e., x/x will get better without treatment) versus ONLY presenting information stated positively.

Another topic deemed less clear by about half of the participants was “Tables”. These two tables were understandably complex because each provided information on the frequency of 10 different side effects for 11 different medications (same 11 medications on both tables). Three participants suggested small adjustments to improve clarity (e.g., adding lines between generic and brand names for drugs, carrying over table headings across pages). One man felt the use of symbols was a little confusing and thought it would be more helpful to use numbers for the proportion of persons taking the medicine who experienced these side-effects.

### *Balance*

All women and all but one man thought the decision aid was well balanced. A number of participants commented that they appreciated that the information described a range of different treatments and indicated that some but not all of those taking a particular treatment benefited from it. Some also commented that the material did not seem to be pushing a particular treatment but rather presented treatment options for the reader to consider. One woman commented:

*...Actually showing all the like different sides and how they can be combined and like how it works for some people, it doesn't work for other people... (20 years old).*

The man who did not think the material was as balanced said: “I would say 10% of the stuff on there is unfair” (21 years old). He felt the decision aid provided an unfair portrayal of treatments and available resources. However, the interview did not illuminate any specific concerns. This man presented himself as being quite skeptical about traditional treatments and described some

difficult treatment experiences he had encountered. One woman noted that there is more information on medications than other treatments, thereby creating a type of imbalance.

However, she also thought this was as an understandable and natural imbalance:

*No, I mean there's definitely way more information about medication but that's because there's way more that people want to and need to know about it...So I think it just makes sense. It's the amounts of information are appropriate to the subjects (20 years old).*

One woman thought the decision aid would come across as more balanced if we added information about how complicated and difficult it is to be depressed and to seek out, find, and engage with treatment:

*No, um (long pause) I, I think that there should be like ah, I don't know I, I said it in the beginning I guess just like a, a part saying that like people struggle with, with doing these things and that it's not the easiest thing in the world so not to like feel bad if it's, if you have a hard time with it...like that there's like sometimes like insane wait lists to see people and just like you get discouraged...like [the decision aid] ...kind of makes it seem like it's "oh just go do this and everything will happen fine." But sometimes it's a lot more complicated than that (21 years old).*

### *Trustworthiness*

As noted above, the first four participants (three men and one woman) were asked about the trustworthiness and helpfulness of the information on each topic. The only woman in this subgroup completed approximately half of the interview (entire Introductory section and all but one page of the Psychotherapy or Counselling section). Hence most of the topic-based responses for these items were collected from three men. The final six participants were asked about the

trustworthiness and helpfulness of each section (i.e., Psychotherapy or Counselling, Medication Treatments, and Combined/Self-help Treatments).

In terms of the topic based trustworthiness responses, all topics were either unanimously reported as trustworthy (i.e., 10 topics), or predominantly (i.e., 3 out of 4 responses for the balance of topics) reported as trustworthy. Topics where some participants felt trustworthiness was somewhat lacking included “What is Depression?”, “What Happens when Medications are Gradually Reduced and Eventually Stopped?”, and “What are the Risks of Counselling or Psychotherapy?”. Regarding “What is Depression?”, some participants explained that the lack of references on this topic detracted from trustworthiness. For example, one male participant described his perspective and approach to computer/web-based information:

*...usually I judge how trustworthy something on a computer is when it references other things...if someone wants to delve a little bit deeper, then they have some reference to the resources that they can pursue (20 years of age).*

The only female participant posed this item concurred:

*Well it doesn't really say where this information came from so...maybe if there was some kind of citing of where this information came from, 'cause I guess anybody can really find information on the internet and then kind of put it how they want... (23 years old).*

In terms of “What Happens when Medications are Gradually Reduced and Eventually Stopped?”, two of the three men felt that the subject matter (i.e., medications in general) was so important that the topic required more information in order to be trustworthy. For example, a 23-year-old man suggested adding a comment on medications being a “last resort” due to potential adverse side effects. A 20-year-old man suggested we add a recommendation for consumers to approach medication with skepticism (i.e., before starting the medication), and explained:

*It might be better to frame this as um the kind of mindset you should approach medication with, or maybe just add how should I approach considerations of taking medication, um I think it would be best to, from personal experience to remain skeptical because it's, it's sort of hard to um (short pause) assess everything when you're on the medications, 'cause they do affect how you think and how you feel.*

He went on to make another suggestion:

*Um it might be, it might have just missed a sentence or something, but I think it might be missing um something like um don't hesitate to talk to your doctor or psychiatrist if you experience any problems kind of thing.*

“What Are the Risks of Counselling or Psychotherapy?” was viewed as slightly less trustworthy due to concerns about the seriousness of the subject matter. For example, a 20-year-old man explained:

*Um I think just 'cause of the subject matter it seems a little less trustworthy...Uh just talking about the risks of, of therapy, just I guess it just sets off little alarm bells I think.*

This section indicated that one out of ten might have a worsening of their condition while participating in psychotherapy. He suggested that it might be helpful to have examples of what might happen if someone's condition was worse.

Responses to the section-based questions indicated strong participant consensus as to the trustworthy appearance of each section. For the Medication Treatments section, participants' assessment was based on congruence with their current knowledge, the amount of information provided, and the balanced nature of the material. For example, one man thought it was more trustworthy because it was congruent with what others had told him (he had never tried medications for depression):

*It, it seems like pretty legit just 'cause like I don't know anything, but you know what everybody else has told me is like what's on here so...you know if they're telling the truth and you know this is telling the truth then we're all good (chuckle).*

A 19-year-old woman highlighted how the balanced presentation of information affected trustworthiness:

*...[this section] gives you like a lot of highs and a lot of lows, like they're pretty equal, it doesn't seem like they're favoured in one way or another, so...there's a lot of like oh well it does this and this and this, but there are side-effects kind of thing, like they do give you a lot of side-effects and a really clear list of the side-effects too so...they're like oh yeah so it can help your depression but it can do this too...*

A 20-year-old woman emphasized how both the style of presentation and the range of information presented encouraged a sense of control that increased perceived trustworthiness:

*I think it seems very trustworthy because it doesn't even suggest really what anyone should do...it just says kind of you know this is info and here are some things you could try and here are some things other people have tried and...it gives you a lot of information to make your own decision...really helpful to feel like you're in control because with your emotions and yourself you don't feel in control a lot of the time.*

The 25-year-old male participant reiterated the importance of references because the “...accuracy of information on the Web is often questionable.”

All participants saw the trustworthiness of the Psychotherapy or Counselling section as similar to the Medications section and suggested that their assessment was based on personal resonance with the descriptions of experiences with treatment, the balanced presentation of information, the attention to detail, and with how realistic the expectations for treatment

outcomes seemed. For example, one woman emphasized how realistic expectations affect trustworthiness:

*It's good...um (long pause) I guess that you have like information about like both sides, like it will help for some people and for some people it won't help, so it's not making it seem like it's going to fix everyone. (21 years of age).*

All participants saw the Combined Treatment/Self-Help Treatment section as generally trustworthy. However, several participants noted a relative lack of “facts” and research findings that reduced the relative trustworthiness. For example, one woman said:

*...it seemed more like kind of opinionated...not like facts and information, but just kind of like this is another way... it didn't have like the, as many facts...like the other pages were just kind of like bombarding you with facts... (18 years of age).*

The 25-year-old male thought that adding citations would significantly increase trustworthiness, noting his belief that combined treatment is a helpful option and that, by adding concrete research findings, we would present this as a “very good one [option] and a very common one...” and would thereby increase someone’s chances for success.

### *Helpfulness*

In terms of the helpfulness, overall, many topics (i.e., 14 of 23) received unanimous responses as helpful information, including “Tables”, “Tips to Manage the Cost of Medication Treatment”, and “What is the Cost of Counselling or Psychotherapy?” Topics where at least one participant was unsure and/or did not report the topic as helpful were “What are the Risk Factors for Depression?”, and “What are the Results over Time?” All pages received helpfulness endorsements by a minimum of half of participants.

Regarding “What are the Risk Factors for Depression?”, two participants (one woman and one man) thought the information would be more helpful for others who did not have the personal experience and knowledge that they had gained: “...for me I know most of the stuff” (23-year-old male).

Regarding “What are the Results over Time?” one of the men felt that presenting aggregate data on recovery might be misleading, considering individual differences:

*So because um people have such varying experiences, condensing it down into a median might kind of feel misleading sort of...they might think “twenty treatments and I’m still here”... Yeah, I think it just ends up condensing what is really really personal experience into a timeframe when it’s not entirely realistic to look at in that, in that, in that way (20 years old).*

All respondents endorsed the Medication Treatments section as helpful. They discussed how informative, mind-opening, and how practical the section was and how it contributed to realistic expectations. For example, a 21-year-old woman said: “It’s helpful...giving ideas of what you can expect...” An 18-year-old male noted how reading the information opened his mind to trying something new:

*It’s pretty helpful. Like looking back if I would have like you know read all that and stuff and just had you know the knowledge kind of thing, I probably would have pursued like maybe taking medication or something.*

One of the male participants talked about both the informative and practical nature of the section:

*It covers a lot of ground, um and it gives you like usable bits of information not like passive information, you know what to actually do in terms of action... Uh not just how you should think of it but how you should approach it... (25-years of age).*

Similarly, all participants reported the Counselling or Psychotherapy section as helpful. Reasons for this opinion focused on how generally informative it was, how it informed considerations of costs/risks, and how it expanded knowledge of treatment options. For example, one of the women stated: “It was good ‘cause I didn’t realize, I didn’t know about most of it” (19 years of age). She explained that the information on cost of therapy would help her (currently) decide if she could afford to try therapy. One of the men felt his options at the time of past treatment decision making would have been significantly greater: “I wish I could have read all that stuff like five years ago... just like layout more options...” (18 years of age).

However, one man felt this section was less helpful than the Medications section due to reduced practicality:

*Pretty helpful. It didn’t seem to have the same resounding practical use that the other one [Medications section] did but maybe I’m just wavering a bit here. Um uh yeah this is a bit more information oriented it seemed...it doesn’t seem quite as practically useful (25 years old).*

He indicated one way to address this would be to add contact information for psychotherapy or counselling treatment. This was also suggested by another female participant.

All participants thought the Combined Treatment/Self-Help Treatments section was helpful. They commented on how informative it was in general and in its inclusion of references to self-help resources, and its way of expanding awareness of options. For example, one of the



men felt it was "...generally informative...super descriptive..." (18 years of age). Another woman emphasized how it expanded her sense of options:

*I think it's very helpful...just kind of the openness of it...it explores a bunch of different options and gives you lots of things that you can try kind of thing (20 years old).*

A 19-year-old female participant emphasized the helpful resources:

*...I didn't know about any of these like websites...that could be really helpful for a person like me, yeah.*

Two of the participants (one woman and one man) felt this section was less helpful due to its relative brevity compared with other sections. As the woman stated:

*I don't, I don't think the self-help was that much help, like there wasn't very much about it, like it was just kind of like there's books and there's like websites and stuff but that's about it, so it didn't seem like that helpful that one (18 years of age).*

Similarly, the male participant noted:

*You know in comparison to what you were offering or the tips and the information you were offering before it can't possibly be as helpful because there's not as much. (25 years old).*

### *Completeness*

*Areas of learning.* All participants reported that they learned something, the main themes being cost of treatment (especially medication treatment), rates of recovery, number of programs and resources in existence, and psychotherapy and counselling training levels across disciplines.

For example, one woman said:

*...Um the treatments definitely and the costs, that was a good one, like I didn't realize about the costs... (19 years old).*

Similarly, one of the men said: “Yeah a few things, yeah...probably about um costs of medications I think” (20 years old).

Another woman talked of learning about the rates of recovery from depression; she and others also mentioned healthcare practitioner expertise:

*Yeah I mean I learned that more people than I thought like get better after, which I guess is helpful for people to know, 'cause it gives them some kind of hope I guess...um most informative I guess was that page that talked about like all the different doctors and their training and different people that are available I guess (21 years of age).*

One of the men also noted professional training in therapy as well as more general information about resources:

*Oh definitely that bit about psychologists and psychiatrists, so that's good (chuckle). And then some of the other just the resources there are mentioned at the bottom, which I'm sure we have in the library but it's just good to kind of know about it like on hand type thing (20 years old).*

One of the men felt he had learned most about the topic of medications:

*Um just the whole like medication side of stuff, just because I've never you know put those shoes on and gone for a stroll (18 years of age).*

One of each of the men and women thought they came to the interview with a higher level of background and experiential knowledge about depression and that they did not learn much new information. As a man put it:

*Um I mean uh me I'm sort of a bad example uh so no not especially...but there was new stuff.... what is useful is just to have this in one little book... Uh but uh someone going in*

*cold, oh my goodness they're going to walk away with a lot of useful stuff, there's a lot of useful stuff* (25 years old).

The 18-year-old woman related that she saw the decision aid as much more beneficial for someone who's never had treatment and been educated about these matters.

*Topics missing?* Interestingly, only one participant (18-year-old male) reported missing topics. This man said he would have liked to have learned more about the impact of drug abuse on depression.

#### *Overall Usefulness/Helpfulness*

All participants with the exception of two women were sure the decision aid would have been useful during their personal treatment decision making. Themes of helpfulness emerged about how the decision aid would increase knowledge, broaden perspective, make for more realistic expectations, reduce confusion, and increase preparation for treatment seeking such as consultation with a physician.

One of the men emphasized the helpfulness of increased knowledge and empowerment, as well as broadened perspective. He said:

*...It would have been, I would have had more of a broad perspective on depression...because at the time it was limited to me, cause I didn't have, there was not much pamphlets...there was not much professional help, there, there was like oh here's some pills down your throat... (21 years old).*

A 20-year-old woman explained that the information could have been helpful if she could have referred to it after seeing her doctor. A 20-year-old man felt it would have helped him decide to find a new therapist sooner than he did, and another 20-year-old man thought it would have better prepared him for psychotherapy, particularly in terms of expectations. An 18-year-old man

said he thought it would have helped him while particularly confused in his depressed state, especially in terms of the decision to do something about the depression (as opposed to trying to ignore it).

One of the women stated she was currently (at time of interview) seeking treatment for depression. She noted how the decision aid increased her sense of urgency to follow through with seeking treatment:

*Yeah...It would have pushed me more, it did push me more, like I, I want to go now (chuckle)...like it, it definitely 'cause that's, we set up the appointment actually today for the counselor...to go meet with him and so I was kind of like hesitant...so like this makes me think that no I definitely should go and yeah it was very helpful (19 years of age).*

The oldest participant (male aged 25 years) in this sample thought it would have been helpful, however, less so for him, as he was 15- years-old at the time he was seeking help and may not have taken the time to read through this decision aid. He suggested a more youth-oriented version for younger teens. Two women said the decision aid would have been more helpful with the changes they suggested. One woman thought it would help to include contact information for healthcare practitioners (especially therapists):

*Um I guess so, like I don't really know because it doesn't, like I think the thing that like when people are ready to make that decision, the thing that people look for, I looked for most is like different places that you could go to get help...and...this doesn't really have...local resources, I don't know if it would have like helped a whole lot, I guess it would have helped knowing that there is a bunch of people that you can talk to, but just knowing where to find those people is the main struggle (21 years of age).*

The other woman believed that what she felt as the material's "dryness" would have been prohibitive to reading through the material:

*Um it would have been kind of, like I think it may have, I probably feel like the way I was would have read like maybe a couple of pages and then just been like, I don't want to read any more so, just 'cause it's so like dry, it's dry material so. If I read it, it probably would have been helpful but I couldn't say I'd probably read it. (18 years old).*

*Would they recommend the decision aid?*

Four out of five men said they would recommend this decision aid to someone they suspected was suffering from depression. The rationale for recommending the decision aid focused on how it was informative. For example, two men said:

*Yeah I think so... It goes over a lot of the information that I'd like to convey to someone who hasn't already sought out therapy (20 years old).*

*Actually yeah for sure... Um in many ways 'cause I've had um a couple of clients that they'll have like the cost thing...having you know troubles getting in contact with people and stuff like that, so like you know and questions with medications and all that kind of stuff. So I mean like yeah it would definitely be helpful (20 years old).*

One man felt he would wait till the suggested improvements had been made:

*I think I would trust it more if there was a lot more done to it...Um and I would refer it to a friend of mine and I have tons of friends that have depression...and they could really use something like this...it will help them realize there's a whole different world out there (23 years of age).*

For women, the responses ranged from “Definitely” to “Probably”, with accompanying rationale focused on increased knowledge, increased realistic expectations, and empowerment.

One woman explained:

*...It just gives a really good overall look at kind of this world...and the comfort you're going to get there is knowing what's going on and feeling like you're in control...and feeling like there are things you can do about it...and I mean it's perfect (20 years of age).*

Another woman stated:

*...I think it would be helpful to them to just know like about like different kinds of therapy or people that they can talk to and just like what to expect when you start medication and how long it should take and stuff 'cause people think it works the next day (21 years old).*

Another woman felt the decision aid would have an advantage over offering personal advice in terms of persuasiveness:

*...I think it would just kind of instead of just me saying you know this and this and this to them when I talk to them, there would be like another side, yeah you know what it's not just her blabbing, like oh and it's actually backed up... (18 years of age).*

#### *Format Suggestions*

Participants were asked how they thought it would be best to make this information available to people. Answers varied but included website; personal presentations at (e.g., schools and self-help organizations); a brief summary of information in a pamphlet with reference to the full decision aid on a website; and pamphlets placed in primary care offices, pharmacies, schools, and universities. The most common suggestion was on a website. For example, one woman said:

*I think like internet would be the best...because...I guess for my age group...and for like teenagers because no one really opens books and reads them, like maybe for older adults it would be good in like a book or something but for like the young adult or teen population everything we do is on the Internet... (21 years old).*

Similarly, a man said:

*In any way that you can, I mean on the Internet of course, having links to this on different associations... (25 years old).*

Another man mentioned a combination of a brief pamphlet and website:

*...As awesome as it would be to cram it all into a pamphlet, I think that would be difficult (chuckle)...Um I mean having like little information books kind of even...yeah that would still be good to like have, 'cause there's little handouts, websites are obviously great 'cause you know just say here go to the website. Even if you did have a little pamphlet of like the brief just summary of everything and then say here's a website you can get, get the full thing at the website or you know we have booklets (20 years of age).*

#### *Suggestions for Improvement*

Suggestions for improvement were reviewed by the primary investigator (PI) for the decision aid development project who made comments and/or incorporated suggestions into revisions to the decision aid materials. Two research associates then reviewed the comments and changes, and either agreed entirely with proposed revisions or non-revisions, or, disagreed and suggested an alternative course of action. There was a very high level of consensus across reviewers. This was then reviewed by the PI who made the final decision about what and how to make revisions (See Table 2 for categories and revisions).

Table 2

*Categories and Counts of Suggestions for Revision of the Decision Aid with Accompanying Revisions*

Category	Response counts	Revisions made for Study 2 decision aid
Slight wording changes	8	4
Format changes	6	8
Add content material	45	11
Handle or present the material differently	14	11
Add or update references	4	32

Table 2 shows that a variety of suggestions were made by interview participants. There were several suggestions to slightly revise wording to increase understanding and/or correct typos. The format change suggestions primarily focused on presenting information more concisely and/or using bullets to present information and to make material more appealing to young adults. Suggestions for added content were most numerous and included suggestions to include contact information for therapists, to add more to the “Self-Help Treatment” topic, to add the suggestion that readers obtain medication information sheets from pharmacists, and to describe a variety of available psychotherapy groups. Suggestions to present material differently included using warmer language, representing probabilities differently, and making slight organizational changes (e.g., move a paragraph to another page).

*Overarching Themes*

As data were coded and categorized, several overarching themes emerged: (1) information is essential in decision making; (2) depression treatment is a serious matter—inform yourself; and (3) trustworthiness is strengthened with citations to external source materials.



### *Information is Essential*

All participants mentioned the positive impact of information at various points throughout the interview. They said that where there is substantial information, they gained a sense of increased knowledge (including knowledge of treatment options, risk/benefits/expectations of treatments, and broadened perspective), increased sense of preparedness for decision making (including a sense of empowerment, reduced confusion), and increased trustworthiness of the material. One of the women summed up how the breadth of information contained in the decision aid increased knowledge and perceived control:

*...It just gives a really good overall look at kind of this world...and feeling like there are things you can do about it... (20 years of age).*

Conversely, less information equates to less of a perceived positive impact. Recall that in a section where participants thought there was relatively less information and fewer “facts” (i.e., Combined Treatment/Self-Help Treatment section), some also felt the decision aid was less helpful and less trustworthy.

### *Depression Treatment is a Serious Matter—Inform Yourself*

Numerous participants raised the issue of the seriousness of depression treatment, both for medications and counseling or psychotherapy. For example, a 20-year-old male participant expressed that representations of probability for improvement in depression using both counselling or psychotherapy and medications was “...overly optimistic...” Another woman was surprised at the higher-than-expected rates of improvement in medications, and one of the men expressed his belief that readers in general would have some anxiety about engaging in counselling of psychotherapy:

*...a lot of people are going to be a bit afraid, a bit nervous, anxious about doing this, giving them a heads up as to what they can expect to happen, this is great (25 years of age).*

Although responses pointed out the serious nature of both medications and counseling or psychotherapy, the majority of related comments were made about medications. For example, after reading the Medications section, a 20-year-old man suggested we add information regarding “reasons NOT to take medications...” and a comment for readers “...to approach meds with skepticism”. A 20-year-old woman expressed less optimism regarding the effectiveness of medications and noted that “...meds are not magic” and a 23-year-old man felt that “...meds are a last resort...” One of the women suggested the decision aid better emphasize how intense and persistent medication side-effects can be:

*...I think you should be like aware of the side-effects...it just sounds like kind of like you're saying that you shouldn't worry about them at all...just that like I guess you should be like cautious or like not let it completely stop you but that you should still be aware of what the side-effects are 'cause they can be, like some of the medications I've been on has like unbelievable side-effects that it's not even, like you can't even take it (21 years old).*

Three participants noted the difficulty of weaning off of medications. For example, one of the men referred to information regarding discontinuation symptoms on “What Happens When Medications Are Gradually Reduced and Eventually Stopped?”:

*... 'cause that's a huge thing and I know a lot of people just, oh should I stop my meds...no you shouldn't do that... (20 years old).*

Two participants commented on the importance of protecting oneself when looking for and/or engaging with medication treatment. A 20-year-old male participant felt it important to add a comment that readers interested in medication treatment read information handouts that pharmacies provide with medications:

*I just want to make sure there's a part about carefully reading the information packages they always give out... 'cause I know I, I always read them...I don't know if other people do.*

A 20-year-old woman responding to “Tables” emphasized the importance of informing/empowering consumers in terms of medications:

*Um just I mean having all those different kinds of medication, I mean I haven't heard of all of them for sure and I think it's really cool to have you know just kind of a brief basic of what could you experience, what's more common, I think that's really good because people get this recommendation from their doctor and it's like okay take this thing with a long name, and you're like what okay and he's like you know it could do this and this and this, it's like okay what usually happens, like what, you know you have no idea what to expect and so I think it's really good to just have a reference and be like okay let's find it on here, okay this is what generally happens and now we kind of have a ballpark of what you're getting yourself into (chuckle).*

#### *Trustworthiness is Strengthened by Citations to External Source Materials*

Four of the participants mentioned (repeatedly in two cases) the impact of the presence or lack, of citations on their sense of trustworthiness of the materials. For example, a 25-year-old male participant raised this issue three times. After viewing the Psychotherapy or Counselling section, he stated:

*...other than you know maybe put the same suggestion I had before, sort of consistently reminding people of where we got this information from or, or whatever it is, um you know that might be good...*

After viewing the “Self-Help Treatment” page (which contained references to self-help resources), a 19-year-old female participant felt that the listing of books increased trustworthiness:

*...Yeah ‘cause then it gives, like it shows you that it’s actually out there, so then you want to like oh maybe go get it and so it makes you believe it more...*

In developing the decision aid the research team had always planned to include references in subsequent versions. In planning the web-based version we had made provisions for the references for each section to be included in a pop-up link – so as not to make the sections appear even longer. There was some concern that the inclusion of references would elicit a negative reaction – as being too technical in addition to being longer. It is clear from the responses of these participants that there was a strong interest in seeing references and that these were seen as adding to the trustworthiness of the materials.

### Study 1 Discussion

Results of Study 1 indicate that, overall, participants had positive opinions about the decision aid and that most would have found it quite helpful during their own depression treatment decision making. This finding was reassuring and encouraging. However, there were ways participants thought the decision aid could be improved in terms of amount and clarity of information in some topics/sections; they also noted ways the decision aid or sections thereof could be more helpful and/or trustworthy. These suggestions resulted in numerous revisions to the decision aid. Consequently, we expect that this round of consumer evaluation has increased

the helpfulness and future potential for use of the decision aid for others with depression. This endeavor also satisfies calls to include consumer input early in the process of decision aid development and evaluation in order to increase consumer and service provider acceptability and usage (Coulter et al, 2006).

Study 1 results serve as a reminder of the important impact (positive or negative) that the presentation of information can have on a reader's interest and ability to absorb information. Current results suggest that readers require enough information to feel informed and ready to make decisions. There were numerous comments about the importance of sufficient information on one's fuller understanding of concepts related to depression and its treatment, including expectations and the sense that one was prepared for decision making. Participants also noted how more limited information had a negative effect on their sense of the helpfulness and trustworthiness of the information in some instances. This is in line with research finding that healthcare consumers (patients and nonpatients) have consistently expressed a need for information regarding health problems(e.g., Hill & Laugharne, 2006). It also fits with research focused on depressed patients who expressed the common unmet need for information regarding, for example, treatment duration, adverse drug reactions, and medication dependence and dosage (Garfield et al., 2004).

However, there were times when participants thought there was too much information and/or that presentation in paragraph form was somewhat overwhelming. In such cases, suggestions were made to further condense information and/or present it in bullet format. One participant noted how it encouraged her to read on if she could see the end of the page in one screen shot and that there didn't appear any more-condensed text on the page. Hence, there

appears a tension between being thorough enough to sufficiently inform readers and not so thorough so as to overwhelm readers.

An additional layer to perception of amount of information is that evaluations were not only absolute but also relative. That is, participants noticed variability in the amount of information across pages and sections and made interpretations based on this variability. One interpretation is that information is seen as less important or less credible on topics/sections with *relatively* less information than other topics/sections. Hence, providing information such as this requires consideration of balance of amount of information across topics to avoid unintentionally creating a sense of variable importance and/or credibility across topics/issues.

Another issue coming out of Study 1 data is the importance of the use of plain language. Although overall opinion was that the decision aid was relatively clear, there was some confusion over presentation of probabilities. This was evident on “What Happens to Depression without Treatment?” where three participants reported lower clarity on the presentation of probabilities (e.g., “six out of ten”). This is consistent with general research finding the public’s lower average comprehension of probabilities (e.g., Lipkus, 2007). Given best practices for conveying probabilities or risks entails presentation in more than one format (Lipkus), future versions of the decision aid should consider the employment of numeric, verbal, and graphic formats.

Similarly, given that half of the participants found “Tables” less clear, future iterations of the decision aid may explore alternative methods and/or the addition of methods to more clearly represent probabilities of side-effects of medications. For example, use of a different visual scheme (other than boxes and dashes) could be tested; the addition of numeric (in fact one participant suggested use of a numeric scheme) and verbal representation could also be explored

to see how comprehension may or may not be affected. This would more closely align with best practices (Lipkus, 2007).

Related to the use of plain language is participants' preference for the use of "warm" language. Two participants noted the cool (or "textbooky" as one woman put it) nature of the information and that they preferred the use of warmer language. However, the current study did not go into depth as to what might constitute warmer language. This may be an important area for future research so as to create a decision aid that provides sufficient "facts" for informed decision making, but that does so in a fashion that increases the likelihood of reader engagement. One method of providing warmth and personal interest planned for the web-based decision aid is to include personal stories that the visitor may read and video material providing expert opinions.

Another issue arising from Study 1 is that of balancing the breadth and depth of the materials. For optimal efficiency, a decision aid should be general enough to apply to various contexts (rural, urban, provincial, national, etc.); however, participants mentioned a need for more context-specific information (e.g., therapist contact information for certain regions). In the web-based decision aid where space is less limited, the research team plans to have contact information available for resources at the regional level (e.g., web links to Canadian Mental Health Association offices in provinces and regions).

### *Reflexive Considerations*

The process and outcomes of the interviews are undoubtedly affected by several factors related to the research setting, the decision aid and research questions, participant characteristics, and characteristics of me as the interviewer. For example, the research setting is located in an urban center which decreases the likelihood of input from rural residents. The focus on the decision aid material and repeated questions limited feedback to more specific aspects of the

decision aid rather than more open-ended dialogue regarding, for example, more general issues around mental health treatment seeking. Participants had a history of depression and brought unique personality traits that also influenced their interpersonal style and content of their answers; therefore, other research utilizing participants divergent in these ways might collect different feedback on the decision aid. A clear gender effect emerged in terms of men being much more apt than women to spontaneously react to the information and verbalize opinions. Factoring in my male gender, physical size, and age raises the potential issue that women, who were less spontaneously verbal, also felt less comfortable/willing to share the full content of their opinions in general. Although this may be true, feedback from numerous individuals (supervisors, friends, family members) suggests I have an interactional style that is warm and that I help others feel at ease. Future studies might counterbalance interviewer gender to help control for this potential effect.

Another concern is why my attempts to conduct a member check failed. It is possible that the length of the interviews created an inordinate response burden so that participants were reluctant to engage in the added burden of the member checking. It could also be that I did not interact sufficiently with participants that they felt a connection to me and to the project. If so, I would consider making adjustments to the interview format so as to increase personal interaction. For example, I might suggest we replace some of the repeated evaluative content questions with some of the early open-ended questions about mental health decision making that were discarded due to time pressure. These items may have increased rapport with some of the participants. However, this type of interview was utilized with the first 4 participants and they were also unresponsive to my invitations. Interviews were conducted while participants and I faced the computer screen, then while I posed questions, I oriented myself toward the



interviewee and used eye contact. It was most common that participants partially oriented toward me while they answered; however, setting up the interview so that there was more face-to-face interviewing may have also increased a sense of interpersonal engagement. Participants received a \$25.00 honorarium for attending the interview; the lack of financial incentive for engaging in the member checking activity may have also been a factor. It may be wiser to offer honoraria for both the interview as well as the member check in future studies.

## Study 2 Method

### *Sample and Recruitment*

Participants were recruited from the University of Manitoba Introductory Psychology Classes' Participant Pool in winter of 2012-2013. The decision aid website was linked to an electronically posted experiment on the Department's Research Participation website. Students were informed of the voluntary nature of the study and, if they chose, proceeded to a consent webpage to read and click "yes" that they agreed to participate (See Appendix Q). Students received four participation credits awarded by the University. The intended sample size was 200 and was based on other evaluation studies of decision aids utilizing quantitative methods where consumers were recruited (e.g., Frosch et al., 2008; Hochlenert et al., 2006; Sheridan et al., 2004). Another current goal was that of approximate gender balance.

### *Measures*

*Demographic questions.* These were nearly identical to those used in Study 1 other than the addition of two items which allowed students to report their (1) university faculty, and (2) major. See Appendix R for the questionnaire.

*Kessler Psychological Distress Scale--6 (K6; Kessler et al., 2002).* As in Study 1, participants completed this brief screening measure of general psychological distress. This measure is described in Study 1.

*Evaluative questions.* Two sets of questions asked for opinions about the decision aid content: one set was situated at the end of each webpage, and the other set occurred at the end of the decision aid. There were five questions at the end of each webpage. The first asked: “Was the amount of information on this topic ‘much too little’; ‘too little’; ‘just right’; ‘too much’; or ‘way too much’?” The next two items were based on a 5-point Likert scale from ‘strongly disagree’ to ‘strongly agree’: “Is the information on this topic clear and understandable?” (i.e., clarity) and “How trustworthy does the information on this page appear?” (i.e., trustworthiness). A fourth item asked “How familiar are you with this topic information?” with response options of ‘very familiar’; ‘somewhat familiar’; ‘unsure’; ‘somewhat unfamiliar’; and ‘very unfamiliar’. Finally, one open-ended question asked: “Do you have any suggestions for improving the information on this page or for other things that should be included?” (See Appendix S.)

At the end of the decision aid, a series of questions asked for opinions regarding the overall decision aid. Some of these items derive from a measure originally developed to assess acceptability of treatment and screening decision aids for medical conditions such as atrial fibrillation (e.g., Man-Son-Hing et al., 1996) and hormone replacement therapy for menopause (O’Connor et al., 1998). Other items were created for this study. Ratings addressed the comprehensibility of components of the decision aid, its length, amount of information, balance of presentation, and overall fit for decision making (O’Connor). For example, the item addressing perceptions of balance had five possible responses: “slanted towards trying psychotherapy or counselling treatments”; “slanted toward trying medication treatments”;

“slanted toward trying combined treatment”; “slanted toward trying self-help strategies”; or “balanced descriptions of treatments” (See Appendix T).

One of the final items was developed in two forms: for those with and those without a history of depression and treatment seeking. For the former, the item included instructions in bold print stating: “For those who have had difficulties with depression and looked for treatment in the past (all others click ‘Not Applicable’)” and stated: “This decision aid would have been helpful for me when I was looking for treatment for depression.” For the latter, the item’s bold-print instructions stated: “For those who have NOT had problems with depression (all others click ‘Not Applicable’)” and then stated: “This decision aid would be helpful to me IF I was having problems with depression and looking for treatment.” In both cases, responses were based on a 5-point Likert scale ranging from ‘strongly disagree’ to ‘strongly agree’.

*Web-behaviour.* SurveyGizmo software was used as the Internet platform for this study. It tracked web-times across individual webpages and for the total survey. In this way, this study was able to indirectly observe participants’ usage of the decision aid. In order to increase confidence in the validity of findings, outliers were removed based on preliminary testing of reading time for the content (further discussed below). In addition, participants were instructed to try to focus their time and attention on the decision aid.

#### *Procedure*

University of Manitoba (UM) Introductory Psychology students who logged onto the Participant Pool website encountered a brief description of the study’s purpose (See Appendix U) as focused on gathering young adults’ opinions in a survey concerning a new decision aid about depression and its treatment. They were informed that the data would be used to improve future versions of the decision aid. They were provided with contact information should they have questions about the decision aid or process of participation in the study. Interested students

progressed to a consent page and clicked “yes” to indicate their informed consent. They then progressed to a webpage (See Appendix V) that contained a link to a pdf of Helping Resources (See Appendix W). Following this page, participants encountered an Instructions page (See Appendix X) after which they began progressing linearly through the topic webpages.

Each of the topic webpages included the five evaluative questions and the decision aid culminated in the final evaluative questions regarding the overall decision aid. These were followed by the final page which contained a link that allowed interested participants to print a copy of the decision aid and receive a Feedback form (See Appendix Y). They were also invited to go to a link that allowed them to provide their contact information to send them a future Study Summary (See Appendix Z) following completion of the project. Participants were not required to complete any of the questions in the survey due to instructions from the Human Research Ethics Board (discussed below).

Each participant continued through the decision aid in the identical order until they clicked “next” to transition to the first page concerning treatment. At this point, a SurveyGizmo-generated alternating strategy was employed to counterbalance the order of presentation of the medication and psychotherapy/counselling treatment sections. Following pages concerning the above treatments, all participants once again viewed pages in identical order (beginning with combined treatment) to the end of the decision aid. Self-help strategies comprised the final topic for the decision aid.

The order of presentation of the topics was based on other decision aids as well as logic. It is very common for decision aids in pamphlet form (e.g., Sheridan et al., 2004) and on the Internet (e.g., <http://decisionaid.ohri.ca/Azsumm.php?ID=1058>; <http://decisionaid.ohri.ca/Azsumm.php?ID=1311>, both accessed February 23, 2011) to begin by

describing the problem and establishing that there is a decision to be made, and then to present the various treatment options including risks and benefits of each along with probabilities of the same. This is also how the current decision aid is ordered.

The combined treatment section followed the medications and psychotherapy/counseling sections so the reader would be familiar with the treatments being combined. The treatment webpages finished with self-help options. Hence, priority in sequence was given to both pharmacological and psychological interventions because it was deemed that they have generated a more substantive evidence base. Inclusion of self-help strategies was based on research showing young people are highly interested in these kinds of options (e.g., Cunningham et al. in press; Oh et al., 2009). Importantly, decision aids (including the examples above) also include a values clarification exercise (O'Connor et al., 2011), a feature not yet included in the current aid. This feature may be incorporated in a future iteration of the decision aid.

## Study 2 Results

### *Participants*

The total participant sample consisted of 592 Introductory Psychology students (374 men; 216 women), all of whom completed the survey (i.e., progressed through to the “Thank-you” webpage). There were 42 whose ages fell outside the target range of 18-25 years. The total sample falling within the target age range consisted of 550 participants (355 men; 194 women). However, data from 355 participants were eliminated based on outlier (minimum and maximum time) criteria calculated for this study. Pilot testing for reading times indicated that it would take a minimum of 35 minutes to allow the respondent to read the material as opposed to skipping the reading and likely random responding. The University of Manitoba Human Research Ethics Board required that we make no questions (other than providing a student number which was

used to allocate credit) “required” (“Your participation in this study is completely voluntary. Should you choose to withdraw from the study at any point or feel that you would rather leave some question(s) unanswered, you may do so without any penalty [e.g., you will still receive 4 research participation credits]” verbatim from consent form). As a result, many ( $n = 355$ ) progressed through the survey very quickly (i.e., 7-34 minutes). Due to the risk that these responses would not be valid, the responses from these participants were not included in the analysis of the survey results. Others ( $n = 21$ ) took an excessively long time (i.e., up to two weeks) to complete the survey after signing on. A maximum time criterion of 120 minutes was chosen to control for the potential that participants were engaged in highly distracting activities (e.g., web surfing, leaving the survey for long periods of time), thereby also potentially providing unreliable responses. These participants were also removed from the data analysis as outliers whose data might not reflect on-task, focused, responding based on reading the information. The final sample meeting the time criteria was 175 (115 men; 60 women). Although fewer than the 200 we had targeted, the sample was of sufficient size to conduct all planned data analyses.

Tables 3 and 4 display demographic characteristics across the total ( $n = 592$ ) sample, the total sample within the target age range ( $n = 550$ ), the sample within the target age range but whose times were below the minimum ( $n = 355$ ), and the final sample within the target age range and acceptable time ( $n = 175$ ). Tables 2 and 3 indicate demographic similarities across samples.

Table 3

*Comparison of Sample Characteristics (Categorical Data)*

Variables	Full sample <i>n</i> = 592		Target age range <i>n</i> = 550		Target age: brief time <i>n</i> = 355		Target age: acceptable time <i>n</i> = 175	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
<b>Gender:</b>								
Males	374	63%	355	65%	223	63%	115	66%
Females	216	37%	194	35%	131	37%	60	34%
<b>First language:</b>								
English	457	77%	426	78%	277	78%	136	78%
French	7	1%	6	1%	5	1%	1	1%
Other	127	22%	117	21%	73	21%	38	22%
<b>Faculty:</b>								
University 1	427	72%	409	75%	275	78%	120	69%
Science	89	15%	84	15%	39	11%	41	23%
Business school	21	4%	21	4%	16	5%	4	2%
Arts	19	3%	13	2%	8	2%	5	3%
Other	34	6%	21	4%	15	4%	5	3%
<b>Major:</b>								
Psychology	38	6%	35	6%	20	6%	14	8%
Sociology	5	1%	4	1%	3	1%	1	1%
Other	322	54%	300	55%	199	56%	91	52%
Not declared	227	38%	211	38%	133	38%	69	39%

Variables	Full sample <i>n</i> = 592		Target age range <i>n</i> = 550		Target age: brief time <i>n</i> = 355		Target age: acceptable time <i>n</i> = 175	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Marital status:								
Single/never married	557	94%	528	96%	340	96%	170	97%
Married/ common-law	23	4%	11	2%	6	2%	3	2%
Divorced	4	1%	4	1%	3	1%	1	1%
Separated	2	<1%	1	<1%	1	<1%	0	0%
Depression history:								
Yes	256	43%	235	43%	151	43%	75	43%
No	243	41%	229	42%	155	44%	66	38%
Not sure	88	15%	81	15%	44	12%	34	19%
Depression counselling:								
Yes	72	12%	62	11%	40	11%	21	12%
No	502	85%	472	86%	302	85%	152	87%
Not sure	12	2%	10	2%	7	2%	2	1%
Depression medications:								
Yes	30	5%	23	4%	19	5%	4	2%
No	551	93%	517	94%	327	92%	170	97%
Not sure	7	1%	6	1%	5	1%	1	1%



Variables	Full sample <i>n</i> = 592		Target age range <i>n</i> = 550		Target age: brief time <i>n</i> = 355		Target age: acceptable time <i>n</i> = 175	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Depression combined:								
Yes	23	4%	17	3%	13	4%	4	2%
No	554	94%	519	94%	330	93%	169	97%
Not sure	8	1%	7	1%	6	2%	1	1%

*Note.* University 1 = University of Manitoba's first year undergraduate program.

Table 4

*Comparison of Sample Characteristics (Continuous Data)*

Variable	Full sample ( <i>n</i> = 592)	Target age range ( <i>n</i> = 550)	Target age range: brief time ( <i>n</i> = 355)	Target age range: acceptable time ( <i>n</i> = 175)
	<i>M</i> (95%CI)	<i>M</i> (95%CI)	<i>M</i> (95%CI)	<i>M</i> (95%CI)
Age	19.4 (19.1-19.6)	18.9 (18.8-19.0)	18.9 (18.7-19.0)	19.0 (18.8-19.2)
Education(years):				
Participant	13.1 (12.9-13.3)	13.0 (12.8-13.3)	13.1 (12.7-13.5)	12.8 (12.7-13.0)
Mother	15.7 (15.2-16.1)	15.6 (15.1-16.1)	16.0 (15.3-16.8)	14.7 (14.2-15.2)
Father	15.9 (15.5-16.3)	15.9 (15.4-16.4)	16.0 (15.3-16.8)	15.5 (15.0-16.0)
Expected debt	17809 (15403-20310)	17995 (15574-20416)	17957 (16251-21161)	16207 (13941-18472)
K6 distress scale	12.5 (12.2-12.9)	12.5 (12.1-12.9)	12.6 (12.0-13.1)	12.4 (11.8-13.0)

*Note.* K6 distress scale scores range from 0 – 24.

The mean age of respondents was approximately 19 years with mean years of total education of almost 13 years. Mothers' and fathers' education were very similar, with mothers reported to have a mean of 14.7 years and fathers 15.5 years. The majority reported English as their first language and that they were currently enrolled in University 1 (University of Manitoba's first year undergraduate program).

Parents' postal code data were collected in order to provide an indicator of SES; however, they were not used in this study. I had contact with a faculty member at the Manitoba Centre for Health Policy who provided information about the steps required to apply for permission to access data that linked postal codes with income quintiles. The expected wait time was lengthy (several months at a minimum) and the services were provided on a cost recovery basis which was prohibitive. Because a good proportion of our final sample (approximately 80%) provided information regarding parental education, and because maternal education has been found to be a good indicator of SES in Canada (e.g., Luo, Wilkins, Kramer, et al., 2006), we decided to use maternal education as a stand-in for our SES indicator.

Participants were asked to indicate "Yes", "No", or "Not sure" to the following questions: "Was there a period in the past when you were having problems with depression that was causing a lot of distress or interfering with your everyday life?"; "Have you ever tried counseling for problems with depression?"; "Have you ever had medication treatment for problems with depression?"; and "Have you ever taken medication and counseling at the same time for problems with depression?" Table 5 presents reports of history of depression and various treatments across women and men. Men and women did not differ significantly in their reports.

Table 5

*Reports of Depression, Counselling, Medication, and Combined Treatment for Men and Women  
Included in the Final Sample*

Variable	Men <i>n</i> = 115		Women <i>n</i> = 60	
	<i>n</i>	% (95% CI)	<i>n</i>	% (95%CI)
History of depression:				
Yes	53	46% (37-55%)	22	37% (25-50%)
No	43	37% (28-46%)	23	38% (26-50%)
Not sure	19	16% (9-22%)	15	25% (14-36%)
Counselling for depression:				
Yes	13	11% (5-17%)	8	13% (5-22%)
No	101	88% (82-94%)	51	85% (76-94%)
Not sure	1	1% (-1-3%)	1	2% (-2-6%)
Medication for depression:				
Yes	3	3% (0-6%)	1	2% (-2-6%)
No	111	97% (93-100%)	59	98% (95-101%)
Not sure	1	1% (-1-3%)	0	0% (0-0%)

Variable	Men <i>n</i> = 115		Women <i>n</i> = 60	
	<i>n</i>	% (95% CI)	<i>n</i>	% (95%CI)
Combined medication and counselling for depression:				
Yes	3	3% (0-6%)	1	2% (-2-6%)
No	111	97% (93-100%)	58	97% (93-101%)
Not sure	1	1% (-1-3%)	0	0 (0-0%)

#### *Data Analysis and Display Strategy*

Our strategy for data analysis was based on the exploratory nature of the study. The data gathered were primarily opinion ratings concerning the characteristics of the information provided in the decision aid. We did not have any hypotheses that we planned to evaluate with the ratings data but rather we wished to use the ratings to understand the participants' opinions about the information. Experts in the analysis of psychological and educational data (e.g., Cumming & Finch, 2005; Curran-Everett, 2009) recommend the use of *confidence intervals* (*CI*s) as a preferred method for illustrating the inter-individual variability in this type of data. *CI*s allow the reader to review patterns in the data and note any differences that are large enough in magnitude to be important. To aid the reader's review, we also noted with an asterisk any differences we observed when 95% *CI*s did not overlap. The reader should note that there are many potential comparisons that can be made with this type of data and should consider the size (the larger intervals indicating where there is less precision) and symmetry (or in some cases, the

lack thereof) of the *CI*s as well as the size of the differences between any non-overlapping *CI*s in deciding whether differences in ratings are important (Finch & Cumming, 2009).

*Participant Ratings of Decision Aid Content*

Participants rated the clarity and trustworthiness of the information for each topic as well as the overall decision aid. Section scores were also computed for the Introduction, Medication Treatments, Psychotherapy or Counseling Treatment, and Combined/Self-Help Treatment sections. Table 6 presents proportions, means, and 95% *CI*s for these ratings.

Table 6  
*Ratings of Clarity and Trustworthiness of Information for Individual Topics, Sections, and Overall Decision Aid*

Information Topics	Information is clear			Information is trustworthy		
	Agree	Disagree	Mean rating (95% CI)	Agree	Disagree	Mean rating (95% CI)
<b>Introductory section</b>						
What is depression	91%	1%	4.1 (4.1–4.2)	82%	3%*	3.9 (3.7-4.0)
Risk factors for depression	91%	2%*	4.2 (4.1–4.3)	87%	1%*	4.1 (4.0-4.2)
What happens without treatment	77%	3%	4.0 (3.8–4.1)	80%	3%	4.0 (3.9-4.1)
Treatments for depression	73%	6%	3.8 (3.7-3.9)	66%	9%	3.7 (3.6-4.1)
Introductory section mean ratings			4.0 (4.0-4.1)			3.9 (3.9-4.0)
<b>Medication treatment section</b>						
Medication treatments (introduction)	84%	3%*	4.0 (3.9-4.1)	82%	3%	4.0 (3.9-4.1)
How long till medications start to work	84%	4%*	4.0 (3.9-4.1)	77%	5%	3.9 (3.8-4.1)

Information Topics	Information is clear			Information is trustworthy		
	Agree	Disagree	Mean rating (95% CI)	Agree	Disagree	Mean rating (95% CI)
How much does medication treatment cost	71%	6%*	3.8 (3.7-4.0)	69%	6%	3.8 (3.7-3.9)
Tips to manage medication costs	88%	1%*	4.1 (4.0-4.2)	68%	3%	3.8 (3.7-3.9)
What are common side effects of medications	83%	2%*	4.0 (3.9-4.1)	70%	5%	3.8 (3.7-3.9)
Tables: common side effects of medications	56%	12%	3.5 (3.3-3.7)	67%	4%	3.8 (3.7-3.9)
Long-term side effects	78%	1%*	4.0 (3.9-4.1)	82%	2%*	4.0 (3.9-4.1)
Uncommon but serious side effects	84%	2%*	4.1 (4.0-4.2)	88%	1%*	4.2 (4.0-4.3)
Medication section mean ratings			3.9 (3.9-4.0)			3.9 (3.9-4.0)
<b>Psychotherapy or counselling section</b>						
Psychotherapy (introduction)	82%	1%*	4.0 (3.9-4.1)	83%	3%*	4.0 (3.9-4.1)

Information Topics	Information is clear			Information is trustworthy		
	Agree	Disagree	Mean rating (95% CI)	Agree	Disagree	Mean rating (95% CI)
Who provides psychotherapy	85%	3%*	4.1 (4.0-4.3)	79%	2%	4.0 (3.9-4.1)
Working effectively in psychotherapy	88%	2%*	4.2 (4.0-4.3)	75%	3%	3.9 (3.8-4.0)
What are the results over time	82%	3%*	4.0 (3.9-4.1)	85%	2%*	4.1 (4.0-4.2)
How much does psychotherapy cost	77%	3%*	3.9 (3.8-4.0)	74%	5%	3.8 (3.7-4.0)
Tips to manage cost of psychotherapy	81%	5%*	4.00 (3.9-4.1)	69%	6%	3.8 (3.7-3.9)
What are the risks of psychotherapy	79%	3%*	4.0 (3.9-4.1)	78%	4%	3.9 (3.8-4.0)
Counselling or psychotherapy section mean ratings			4.0 (4.0-4.1)			3.9 (3.9-4.0)



Information Topics	Information is clear			Information is trustworthy		
	Agree	Disagree	Mean rating (95% CI)	Agree	Disagree	Mean rating (95% CI)
<b>Combined and self-help treatment section</b>						
What about combining meds/psychotherapy	80%	3%*	4.0 (3.9-4.1)	86%	2%*	4.0 (4.0-4.2)
Self-help treatments	86%	1%*	4.1 (4.0-4.2)	82%	3%*	4.1 (4.0-4.2)
Combined and self-help treatment section mean ratings			4.1 (4.0-4.1)			4.1 (4.0-4.2)
<b>Overall decision aid</b>	91%	2%*	4.2 (4.1-4.3)	93%	1%*	4.3 (4.2-4.4)

*Note.*  $N = 175$  for above items. Ratings ranged on a 5-point rating scale from 1 (Strongly Disagree) to 5 (Strongly Agree). Strongly Agree was combined with Agree; Strongly Disagree was combined with Disagree. Responses falling in the Unsure category were excluded from table. \*= No ratings within the Strongly Disagree category. Section ratings = grand means and 95% CIs.

Table 6 illustrates that a large proportion of respondents agree that the material throughout the decision aid is clear. In terms of ratings of the overall materials, 91% agreed that the decision aid was clear, and topic-specific clarity ratings were consistently high, but with some variation across topics. That is, the mean ratings (provided together with 95% *CI*s) of clarity were highest for “What are the Risk Factors for Depression?” (4.2; 4.1 – 4.3), “Who Provides Counselling or Psychotherapy?” (4.1; 4.0 – 4.3), and “Working Effectively in Counselling or Psychotherapy” (4.2; 4.0 – 4.3). Topics with slightly lower mean ratings were “Tables” (3.5; 3.3 – 3.7), “How much does Medication Treatment Cost?” (3.8; 3.7 – 4.0), and “Treatments for Depression” (3.8; 3.7 – 3.9). Mean ratings of clarity were very similar across the section scores.

Trustworthiness ratings were also consistently high. That is, 93% of respondents agreed that the overall information was trustworthy. Though reliably high, ratings of trustworthiness varied slightly across topics. The highest mean ratings of trustworthiness were for “Uncommon but Serious Side Effects of Medications” (4.2; 4.0 – 4.3), “What Happens when Medications are Gradually Reduced and Eventually Stopped?” (4.1; 4.0 – 4.2), and “What are the Risk Factors for Depression?” (4.1; 4.0 – 4.2). Trustworthiness ratings were slightly lower for “How much does Medication Treatment Cost?” (3.8; 3.7 – 3.9), “Tips to Manage the Cost of Medications” (3.8; 3.7 – 3.9), and “Tips to Manage the Cost of Psychotherapy or Counselling” (3.8; 3.7 – 3.9). Section scores of trustworthiness were also very similar.

Participants also rated the information in terms of the familiarity and amount. Table 6 displays these ratings in terms of proportions, means, and 95% *CI*s. This table also provides reading grade levels and participant viewing times.

Table 7

*Ratings of Familiarity and Amount of Information, Grade Level, and Web-times for Individual Topics, Sections, and Overall Decision Aid*

Information topics/sections	Familiarity with information			Amount of information			Mean rating (95% CI)	Read grade level	Mean time seconds/100 words (95% CI)
	Familiar	Unfamiliar	Mean Rating (95% CI)	Just right	Too little	Too much			
<b>Introductory section</b>									
What is depression	72%	17%	3.6 (3.5-3.8)	79%	15%	6%	2.9 (2.8-3.0)	7.9	57 (49-65)
Risk factors for depression	65%	21%	3.6 (3.4-3.7)	85%	8%*	7%	3.0 (2.9-3.0)	9.8	40 (31-49)
What happens without treatment	45%	34%	3.1 (3.0-3.3)	68%	25%	7%	2.8 (2.7-2.9)	10.6	30 (26-34)
Treatments for depression	38%	34%	3.0 (2.9-3.2)	59%	35%*	6%	2.7 (2.6-2.8)	12.2	55 (47-63)
Introductory section values			3.3 (3.2-3.4)				2.9 (2.8-2.9)	10.0	43 (38-48)

Information topics/sections	Familiarity with information			Amount of information			Mean rating (95% CI)	Read grade level	Mean time seconds/100 words (95% CI)
	Familiar	Unfamiliar	Mean Rating (95% CI)	Just right	Too little	Too much			
<b>Medication treatment section</b>									
Medication treatments (introduction)	39%	39%	2.9 (2.8-3.1)	77%	14%	9%	3.0 (2.9-3.0)	10.6	33 (29-37)
How long till medications start to work	29%	49%	2.7 (2.5-2.9)	68%	24%	9%	2.9 (2.8-3.0)	10.2	26 (22-30)
What happens when medications reduced/stopped	24%	56%	2.6 (2.5-2.8)	74%	8%	18%#	3.1 (3.0-3.2)	11.1	22 (19-25)
How much does medication cost	21%	65%	2.3 (2.1-2.4)	54%	1%*	18%#	3.5 (3.4-3.6)	11.1	23 (19-27)
Tips to manage medication costs	25%	58%	2.5 (2.3-2.7)	82%	11%*	7%	3.0 (2.9-3.0)	11.9	27 (24-30)
What are common side effects of medications	50%	33%	3.2 (3.0-3.4)	59%	37%	4%	2.7 (2.6-2.8)	10.4	43 (36-50)

Information topics/sections	Familiarity with information			Amount of information			Mean rating (95% CI)	Read grade level	Mean time seconds/100 words (95% CI)
	Familiar	Unfamiliar	Mean Rating (95% CI)	Just right	Too little	Too much			
Tables: common side effects of medications	9%	81%	1.7 (1.6-1.9)	48%	7%	45%	3.5 (3.4-3.6)	12.3	30 (23-37)
Long-term side effects	26%	58%	2.4 (2.3-2.6)	60%	37%	4%	2.7 (2.6-2.8)	12.6	36 (30-42)
Uncommon but serious side effects	43%	43%	2.9 (2.7-3.0)	79%	7%	14%	3.1 (3.0-3.1)	11.8	22 (19-25)
Medication section values			2.6 (2.5-2.7)				3.0 (3.0-3.1)	11.1	27 (25-29)
<b>Psychotherapy or Counselling section</b>									
Psychotherapy (introduction)	41%	38%	3.1 (2.9-3.2)	65%	34%	2%	2.7 (2.6-2.7)	10.9	35 (28-42)
Who provides psychotherapy	52%	33%	3.2 (3.0-3.4)	66%	3%*	31%	3.3 (3.2-3.4)	11.6	25 (22-28)

Information topics/sections	Familiarity with information			Amount of information			Mean rating (95% CI)	Read grade level	Mean time seconds/100 words (95% CI)
	Familiar	Unfamiliar	Mean Rating (95% CI)	Just right	Too little	Too much			
Working effectively in psychotherapy	34%	44%	2.8 (2.6-3.0)	85%	3%*	13%	3.1 (3.0-3.1)	10.5	27 (24-30)
What are the results over time	27%	51%	2.6 (2.4-2.8)	77%	17%	7%	2.9 (2.8-3.0)	10.1	31 (20-42)
How much does psychotherapy cost	26%	53%	2.5 (2.4-2.7)	73%	7%*	20%	3.1 (3.0-3.2)	11.4	35 (21-47)
Tips to manage cost of psychotherapy	25%	49%	2.6 (2.5-2.8)	76%	14%	10%	3.0 (2.9-3.0)	7.4	36 (30-43)
What are the risks of psychotherapy	29%	43%	2.7 (2.6-2.9)	52%	47%	1%#	2.5 (2.5-2.6)	9.5	47 (39-55)
Psychotherapy or counselling section values			2.8 (2.7-2.9)				2.9 (2.9-3.0)	10.4	32 (29-35)

Information topics/sections	Familiarity with information			Amount of information			Mean rating (95% CI)	Read grade level	Mean time seconds/100 words (95% CI)
	Familiar	Unfamiliar	Mean Rating (95% CI)	Just right	Too little	Too much			
<b>Combined and self-help treatment section</b>									
What about combining meds/psychotherapy	25%	52%	2.6 (2.4-2.8)	72%	22%	6%#	2.8 (2.7-2.9)	10.9	33 (17-47)
Self-help treatments	47%	27%	3.3 (3.1-3.4)	80%	6%	14%	3.1 (3.0-3.2)	10.0	21 (17-25)
Combined and self-help treatment section value			2.9 (2.9-3.0)				3.00 (2.9-3.0)	10.4	26 (20-32)
<b>Overall decision aid</b>	50%	37%	3.1 (3.0-3.3)	75%	3%*	22%	3.2 (3.1-3.3)	10.6	37 (35-39)

*Note.*  $N = 175$  for above items. Familiarity ratings varied over 5 categories: Very Unfamiliar, Somewhat Unfamiliar, Unsure,

Somewhat Familiar, and Very Familiar. The Unfamiliar categories were combined as were the Familiar categories. Responses in the

Unsure category were excluded from table. Amount ratings varied on categories of Much Too Little, Too Little, Just Right, Too

Much, and Way Too Much. The Too Little categories were combined as were the Too Much categories. \* = no responses within the Much Too Little category. # = no responses within the Way Too Much category. Flesch Kincaid reading level score calculated using MS WORD. Time = seconds calculated by SurveyGizmo software (per 100 words). Section values = grand means and 95% CIs. N/A = Not Applicable.



Table 7 illustrates high ratings of approval of the total amount of information. That is, 75% of participants endorsed “Just Right” for the overall amount of information. In terms of amount ratings for individual topics, “Risk Factors for Depression”, “Working Effectively in Psychotherapy or Counselling”, and “Tips to Manage the Costs of Medications” had the largest proportions endorsing “Just Right” (85%, 85%, and 82%, respectively). “What are the Risks of Psychotherapy or Counselling?” received the greatest proportionate ratings of “Too Little” information (47%), and “Tables” received the highest proportionate ratings of “Too Much” information (45%).

Fifty percent of the sample reported familiarity and 37% reported unfamiliarity with the overall decision aid (13% endorsed “unsure”). In terms of topic-based ratings, highest mean familiarity was reported for “What is Depression?” (3.6; 3.5 – 3.8) “Risk Factors for Depression” (3.6; 3.4 – 3.7), and “Self-Help Treatments” (3.3; 3.1 – 3.4). Lowest familiarity was reported for “Tables” (1.7; 1.6 – 1.9), “How Much does Medication Treatment Cost?” (2.3; 2.1 – 2.4), and “Long-Term Side Effects of Medication Treatment” (2.4; 2.3 – 2.6). Section scores reflect some variation in familiarity. That is, the Introductory section was rated as more familiar than any other section. Approximately equally unfamiliar were the Medication Treatments section (which was less familiar than either the Introductory or the Combined and Self-Help Treatments sections) and the Psychotherapy or Counseling section (which was less familiar than the Introductory section only).

Reading grade levels (i.e., Flesch Kincaid) were variable across topics and sections. The lowest reading levels are attributed to “Tips to Manage the Cost of Counselling or Psychotherapy” and “What is Depression?” (7.4 and 7.9, respectively). Highest reading levels are shown for “Long-Term Side Effects” and “Tables” (12.6 and 12.3, respectively).

SurveyGizmo software recorded each participant's time on each webpage as well as on the overall website survey. The mean time (standardized to seconds per 100 words) spent on the overall decision aid was 37 seconds, and topic-based times ranged from 21-57 seconds. The times and 95% *CI*s are fairly comparative across individual topics; however, "What is Depression?" (57; 49 – 65) and "Treatments for Depression" (55; 47 – 63) had the greatest time values and "Self-Help Treatments" (21; 17 – 25) and "Uncommon but Serious Side Effects" (22; 19 – 25) had the lowest time values. The Introductory section had the highest time value (43; 38 – 48); whereas the Combined/Self-Help section had the lowest (26; 20 - 32).

Altogether two associations were found between time on a topic and ratings data. That is, on a topic with lowest familiarity ratings ("Tables"), participants also spent less time than the average time (30 seconds/100 words versus the average of 37 seconds/100 words). They also provided slightly lower than average clarity ratings (3.5 versus mean overall rating of 4.2) and a slightly higher than mean amount rating compared to amount rating for the overall decision aid (i.e., 3.5 versus 3.2). The second observed relation was between time on "What Are the Risks of Counseling or Psychotherapy?" and ratings of amount of information. Specifically, participants spent an above average amount of time (third highest topic amount) on this topic and also rated the amount of information on this topic as less than the mean rating for amount of information across all content areas (i.e., 2.5 versus 3.2).

Respondents rated their perceptions of the balance of presentation of information in the decision aid. Table 8 presents proportions and 95% *CI*s for these ratings across grouping variables.

Table 8

*Ratings of Balance across Total Sample, Order of Presentation, and Participant Characteristics*

Grouping variables	Balanced % (95% CI)	Slanted to psychotherapy % (95% CI)	Slanted to medications % (95% CI)	Slanted to Combined % (95% CI)	Slanted to self-help % (95% CI)
Total sample	40% (33-47%)	26% (19-32%)	21% (15-27%)	11% (7-16%)	2% (1-5%)
Order of presentation:					
Medications first	35% (2-42%)	27% (20-34%)	22% (16-28%)	14% (9-19%)	3% (0-5%)
Psychotherapy or counselling first	44% (37-52%)	25% (19-31%)	20% (14-26%)	9% (5-14%)	2% (0-4%)
Age:					
Younger (18-20)	40% (3-47%)	27% (21-34%)	19% (13-25%)	12% (7-17%)	2% (1-4%)
Older (21-25)	43% (36-50%)	18% (12-24%)	29% (20-36%)	7% (3-11%)	4% (1%-6%)
Gender:					
Females	52%* (44-59%)	22% (16-28%)	17% (11-22%)	8% (4-12%)	2% (1-4%)
Males	34%* (27-40%)	28% (21-34%)	23% (16-28%)	13% (8-18%)	3% (0-5%)

Grouping variables	Balanced % (95% CI)	Slanted to psychotherapy % (95% CI)	Slanted to medications % (95% CI)	Slanted to Combined % (95% CI)	Slanted to self-help % (95% CI)
History of depression:					
Yes	32% (25-39%)	33% (26-40%)	23% (17-29%)	9% (5-14%)	3% (0-3%)
No	42% (35-50%)	20% (14-27%)	23% (17-29%)	14% (9-19%)	2% (0-3%)
Not sure	53% (46-60%)	21% (15-27%)	12% (7-17%)	12% (7-17%)	3% (0-5%)
Mothers' education:					
Higher (15 years or more)	21% (15-28%)	13% (7-19%)	6% (2-10%)	6% (2-10%)	.7% (0-2%)
Lower (less than 15 years)	19% (12-26%)	15% (9-21%)	12% (7-18%)	5% (1-9%)	2% (0-4%)
Fathers' education:					
Higher (15 years or more)	22% (15-29%)	15% (9-21%)	10% (5-14%)	7% (3-11%)	0% (0-0%)
Lower (less than 15 years)	18% (12-24%)	14% (8-20%)	8% (4-13%)	4% (1-7%)	2% (0-4%)

Grouping variables	Balanced % (95% CI)	Slanted to psychotherapy % (95% CI)	Slanted to medications % (95% CI)	Slanted to Combined % (95% CI)	Slanted to self-help % (95% CI)
<i>K6:</i>					
Low (mean of less than 13)	45% (38-53%)	28% (21-35%)	16% (11-22%)	10% (5-14%)	1% (0-3%)
High (mean of 13 or more)	33% (26-40%)	24% (18-30%)	26% (19-32%)	14% (9-19%)	4% (1-7%)

*Note.* Order of presentation was alternated. *K6* distress scale scores range from 0 – 24; *K6* High and Low groups created via median

split. Mothers' and Fathers' education groups created via median split.\* = no overlap between 95% CIs.

Table 8 illustrates that about 40% (33 – 47%) of participants reported that the decision aid was “balanced”, 26% (19 – 32%) reported it was “slanted toward trying counselling or psychotherapy”, 21% (15 – 27%) reported it was “slanted toward trying medication treatments”, 11% (7 – 16%) reported it was “slanted toward trying combined treatment”, and 2 % (1 – 5) reported the decision aid was “slanted toward trying self-help treatment”. Gender-based ratings of balance differed in that a larger proportion of women (52%; 44 – 59%) versus men (34%; 27 – 40%) reported that the overall decision aid provided a balanced description of treatments.

Ratings of overall decision aid content were compared across total sample, order of presentation (i.e., Medications first or Psychotherapy first), and participant characteristics. Participants who reported past depression and depression treatment seeking rated how helpful they thought the information would have been *when* they were deciding on depression treatment. Participants reporting no history of depression were asked how helpful it might be *if* they would be involved in such a decision process in the future. Table 9 displays these results.

Table 9

*Ratings of Overall Content across Total Sample, Order of Presentation, and Participant Characteristics*

Grouping variables	Clarity	Amount of information	Trustworthy	Familiar	Helpful: past depression <i>n</i> = 44	Helpful: no past depression <i>n</i> = 126	Recommend
	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)
Total sample	4.2 (4.1-4.3)	3.2 (3.1-3.3)	4.1 (4.0-4.3)	3.1 (3.0-3.3)	3.8 (3.5-4.0)	4.2 (3.9-4.4)	4.0 (3.9-4.1)
Order of presentation:							
Medication first	4.1 (4.0-4.3)	3.2 (3.1-3.4)	4.2 (4.0-4.4)	3.1 (2.9-3.4)	3.7 (3.2-4.1)	4.1 (3.9-4.3)	4.0 (3.9-4.2)
Psychotherapy or counselling first	4.3 (4.2-4.5)	3.2 (3.1-3.3)	4.3 (4.2-4.4)	3.1 (2.9-3.3)	4.0 (3.8-4.2)	4.1 (3.9-4.4)	4.0 (3.8-4.2)
Age:							
Younger (18-20)	4.2 (4.1-4.3)	3.2 (3.1-3.3)	4.2 (4.2-4.3)	3.1 (2.9-3.3)	3.9 (3.6-4.1)	4.2 (4.0-4.3)	4.1 (3.9-4.2)
Older (21-25)	4.2 (4.2-4.5)	3.3 (3.1-3.6)	4.3 (4.1-4.6)	3.2 (2.8-3.6)	4.0 (3.3-4.5)	3.8 (3.1-4.5)	3.8 (3.3-4.2)

	Clarity	Amount of informa- tion	Trust- worthy	Familiar	Helpful: past depression <i>n</i> = 44	Helpful: no past depression <i>n</i> = 126	Recom- mend
Grouping variables	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )	Mean rating (95% <i>CI</i> )
Gender:							
Female	4.3 (4.2-4.5)	3.1 (2.9-3.2)	4.3 (4.1-4.4)	3.2 (2.9-3.4)	4.0 (3.6-4.4)	4.1 (3.8-4.4)	4.0 (3.8-4.2)
Male	4.2 (4.1-4.3)	3.3 (3.2-3.4)	4.3 (4.2-4.3)	3.1 (2.9-3.3)	3.8 (3.5-4.1)	4.1 (3.9-4.3)	4.0 (3.9-4.2)
History of depression:							
Yes	4.3 (4.2-4.4)	3.3 (3.1-3.4)	4.3 (4.2-4.4)	3.4 (3.1-3.6)	3.8 (3.5-4.0)	N/A	4.0 (3.8-4.2)
No	4.2 (4.1-4.4)	3.2 (3.0-3.3)	4.2 (4.0-4.4)	2.8 (2.6-3.1)	N/A	4.2 (3.9-4.4)	4.0 (3.7-4.2)
Not Sure	4.1 (3.9-4.3)	3.1 (3.0-3.3)	4.3 (4.0-4.5)	3.2 (2.9-3.3)	N/A	N/A	4.2 (3.9-4.4)



Grouping variables	Clarity	Amount of information	Trustworthy	Familiar	Helpful: past depression <i>n</i> = 44	Helpful: no past depression <i>n</i> = 126	Recommend
	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)
Mothers' education:							
Higher (15 years or more)	4.3 (4.1-4.4)	3.2 (3.1-3.4)	4.3 (4.1-4.4)	3.0 (2.7-3.3)	4.0 (3.7-4.3)	4.0* (3.9-4.1)	4.0 (3.9-4.1)
Lower (less than 15 years)	4.3 (4.1-4.4)	3.2 (3.1-3.3)	4.3 (4.1-4.4)	3.2 (3.0-3.5)	3.6* (3.4-3.8)	4.3* (4.2-4.5)	4.1 (3.9-4.1)
Fathers' education:							
Higher (15 years of more)	4.2 (4.1-4.4)	3.1 (3.0-3.3)	4.3 (4.1-4.4)	3.1 (2.8-3.3)	3.8 (3.5-4.1)	4.1 (3.9-4.3)	4.0 (3.9-4.2)
Lower (less than 15 years)	4.3 (4.1-4.5)	3.3 (3.2-3.4)	4.3 (4.1-4.4)	3.2 (2.9-3.4)	3.8 (3.5-4.1)	4.3 (4.1-4.4)	4.1 (4.0-4.2)
<i>K6</i> :							
Low (mean of less than 13)	4.3 (4.2-4.4)	3.2 (3.1-3.3)	4.3 (4.1-4.4)	3.0 (2.8-3.2)	3.8 (3.3-4.2)	4.3 (4.1-4.4)	4.0 (3.9-4.2)
High (mean of 13 or more)	4.2 (4.0-4.3)	3.2 (3.1-3.4)	4.3 (4.1-4.4)	3.2 (3.0-3.5)	3.9 (3.6-4.2)	3.8 (3.5-4.1)	4.0 (3.8-4.2)

*Note.*  $N = 175$  for above items. Clarity, Trustworthy, Helpfulness (both), and Recommendation ratings varied across 5 categories from Strongly Disagree to Strongly Agree. Familiarity ratings varied over 5 categories: Very Unfamiliar, Somewhat Unfamiliar, Unsure, Somewhat Familiar, and Very Familiar. Amount ratings varied on categories of Much Too Little, Too Little, Just Right, Too Much, and Way Too Much. Mothers' and fathers' Higher and Lower education groups created via a median split. *K6* High and Low groups based on a median split. \* = no overlap between 95% *CI*s.

Table 9 illustrates high mean ratings of clarity (4.2; 4.1 – 4.3) and trustworthiness (4.1; 4.0 – 4.3) of the overall information in the decision aid. Participants also reported an overall mean rating suggestive of very close to the perceived Just Right (3.2; 3.1 – 3.3) amount of information. Additionally, they reported a fair level of overall familiarity with the information (3.1; 3.0 – 3.30). Helpfulness ratings were 3.8 (3.5 – 4.0) for those reporting perceived helpfulness *when* making a past decision about depression treatment, and 4.2 (3.9 – 4.4) for those reporting perceived helpfulness *if* they were to find themselves in a future decision about depression treatment. Respondents agreed that they were quite willing to recommend the decision aid to someone else whom they thought might be struggling with depression.

Table 9 also demonstrates associations between evaluative ratings and demographic variables of participants' depression history and maternal education. Those who reported a history of depression (versus no history of depression) also reported higher mean ratings of familiarity with the overall decision aid. Additionally, among those reporting no history of depression, the participants reporting higher maternal education compared with lower maternal education also provided lower ratings of perceived helpfulness of the decision aid for use in a hypothetical future decision. Among participants reporting a history of depression, those reporting lower maternal education compared with higher maternal education provided lower mean ratings of helpfulness of the decision aid for use in a past decision. It should be noted that the magnitude of differences related to maternal education was modest and ratings of helpfulness were reasonably high for all of these subgroups.

Helpfulness ratings data were converted to proportions agreeing and disagreeing with the helpfulness of the decision aid. Participants also provided ratings of their willingness to recommend the decision aid to someone else. Results are displayed in Table 10.

Table 10

*Proportions of Total Sample Ratings of Helpfulness (Those with Past Depression and Those without Past Depression) and Willingness to Recommend the Decision Aid*

Helpful: past depression <i>n</i> = 44		Helpful: no past depression <i>n</i> = 126		Recommend	
Agree	Disagree	Agree	Disagree	Agree	Disagree
77%	7%*	80%	5%	81%	5%
(64.6-89.3)	(-0.54-14.5)	(73.0-87.0)	(1.1-8.8)	(75.2-86.8)	(2.0-8.2)

*Note.* Helpfulness (both) and Recommendation ratings varied across 5 categories from Strongly Disagree to Strongly Agree. Agree and Disagree categories were combined. Responses in the Neutral category are excluded from table. \* = no responses within the Strongly Disagree category.

As Table 10 demonstrates, the majority of participants (77% with past depression; 80 % no past depression) endorsed the helpfulness of the decision aid. Eighty percent of the total sample reported they would also recommend it to someone whom they thought might be struggling with depression.

To control for order effects between the major sections of Medication Treatments and Psychotherapy or Counselling, the survey software alternated the section presentation across participants. One order effect was found: those who viewed the Medication Treatments section before the Psychotherapy or Counselling section took less time to progress through the Medication Treatments section (See Table 11).

Table 11

*Comparison of Web-Times across Order of Presentation*

	Introductory section	Medication treatment section	Psychotherapy or counselling section	Combined and self-help section	Overall
Medication treatments first	41 (36-45)	22* (20-25)	35 (30-39)	23 (16-30)	35 (33-38)
Psychotherapy or counselling first	45 (36-53)	31* (27-35)	29 (24-34)	31 (19-43)	39 (36-42)

*Note.* Web-time = mean seconds/100 words. Section values = grand means and 95% CIs. N/A =

Not Applicable.\* = no overlap between 95% CIs.

To investigate this order effect, comparisons of opinions of the four sections (and the overall decision aid) across the two order groups were conducted. See Table 12 for these comparisons.

Table 12

*Comparison of Section Based Ratings across Presentation Order Groups*

	Familiar	Clarity	Amount	Trust-worthy
<b>Information topic sections</b>	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)
<b>Introductory section:</b>				
Medications first	3.4 (3.2-3.5)	4.0 (3.9-4.1)	2.8 (2.8-2.9)	3.9 (3.8-4.0)
Counselling or psychotherapy first	3.3 (3.1-3.5)	4.0 (4.0-4.2)	2.9 (2.8-3.0)	4.0 (3.9-4.1)

	Familiar	Clarity	Amount	Trust- worthy
<b>Information topic sections</b>	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)	Mean rating (95% CI)
<b>Medication section:</b>				
Medications first	2.6 (2.5-2.8)	3.9 (3.8-4.0)	3.0 (2.9-3.1)	3.9 (3.8-4.0)
Counselling or psychotherapy first	2.5 (2.4-2.7)	4.0 (3.9-4.0)	3.1 (3.0-3.1)	4.0 (3.9-4.1)
<b>Counselling or psychotherapy section:</b>				
Medication first	2.9 (2.7-3.0)	4.0 (3.9-4.1)	2.9 (2.8-3.0)	3.9 (3.8-4.0)
Counselling or psychotherapy first	2.7 (2.5-2.9)	4.1 (4.0-4.2)	3.0 (2.9-3.0)	4.0 (3.9-4.1)
<b>Combined and self-help treatment section:</b>				
Medications first	3.0 (2.9-3.1)	4.0 (3.9-4.1)	2.9 (2.8-3.0)	4.1 (3.9-4.2)
Counselling or psychotherapy first	2.9 (2.7-3.0)	4.1 (4.0-4.2)	3.0 (2.9-3.1)	4.1 (4.0-4.2)
<b>Overall decision aid:</b>				
Medications first	3.1 (2.9-3.4)	4.1 (4.0-4.3)	3.2 (3.1-3.4)	4.2 (4.0-4.4)
Counselling or psychotherapy first	3.1 (2.9-3.3)	4.3 (4.2-4.5)	3.2 (3.1-3.3)	4.3 (4.2-4.4)

*Note.*  $N = 175$  for above items. Familiarity, Clarity, and Trustworthy ratings varied across 5 categories from Strongly Disagree to Strongly Agree. Familiarity ratings varied over 5 categories: Very Unfamiliar, Somewhat Unfamiliar, Unsure, Somewhat Familiar, and Very

Familiar. Amount ratings varied on categories of Much Too Little, Too Little, Just Right, Too Much, and Way Too Much. Section values are grand mean ratings for each section.

Table 12 demonstrates a great deal of similarity in participant ratings across both orders of presentation. That is, all of the 95% CIs overlapped.

For each topic, respondents were given an open text box as an option to provide suggestions for improvement (i.e., “Do you have any suggestions for improving the information on this page or for other things that should be included?”). At the end of the decision aid, they were similarly given an opportunity for open-text responses (i.e., “Do you have any overall suggestions that you did not describe previously for improving the information in the decision aid?”). Open-ended comments were reviewed and copied into a table organized by topic and overall decision aid. There were a total of 255 comments and suggestions that fell into 8 response categories (See Table 13).

Table 13

*Categories and Counts of Suggestions for Revision of the Decision Aid*

Category	Response counts
Positive comments without suggestions for change	43
Negative comments without suggestions for change	18
Suggestions for wording changes	9
Suggestions to add content material	73
Suggestions to handle or present the material differently	69
Suggestions to remove certain content material	2



Category	Response counts
Suggestions for format changes	17
Suggestions to add or update references	24

The most common themes in the comments were suggestions to add information (73 responses) and suggestions that we handle or present the information in a different way (69 responses). Prominent examples of the former include the suggestion that we “use more examples” (10 responses) and the suggestion that we add information that helps normalize depression and its treatment so as to decrease stigma (7 responses). Major examples of the latter include suggestions to “be more specific” (16 responses) and that we combine topic pages (12 responses). Another common theme was the suggestion to add or update references (24). However, there were also many positive comments made about the decision aid (43). There were only 2 comments made suggesting that this format of informing a potentially depressed person about depression and treatment would be inappropriate for such a person (i.e., too lengthy to expect him/her to read through it). The summarized comments were reviewed by members of the development team to consider which would be useful in strengthening the content of the decision aid.

### Study 2 Discussion

Below is a discussion of only those Study 2 results that do not overlap with Study 1 results. Overlapping results across Studies 1 and 2 are addressed in the General Discussion (these include the more general results of Study 2). The key goal unique to Study 2 was to examine participants’ quantitative evaluation of the information (ratings on a variety of dimensions) and how participants’ ratings varied based on demographic background. Additionally, the purpose was to ask participants for open-ended suggestions for ways to improve the decision aid content

for individual topics and overall decision aid. A secondary goal was to explore if and how web-times varied across topics and across sections of the decision aid survey and if there were any associations between web-times and ratings data. Finally, a goal was to explore if and how participant factors (i.e., gender, age, education, parents' education, current psychological distress, history of depression, and history of depression treatment) might be related to web-times.

Of interest is the proportion of Study 2 participants reporting past depression (43%) which is greater than the lifetime prevalence rates of major depression found in epidemiological research (9-17%; Kessler, 2003), including a U.S. survey finding that 18% of university students met criteria for a mood disorder during the prior year (Blanco, Okuda, Wright, Hasin, Grant, Liu, et al., 2008). This implies that a good portion of this sample may have chosen to participate due to personal interest in the topic of depression treatment based on their personal experience with depression. Equally of interest is that a greater proportion of men versus women who completed the survey reported a history of depression (46% and 37%, respectively) which is contrasted in epidemiological research showing that women report major depression at rates between one-and-a-half and three times that of men (Kessler). These sample characteristics suggest that participants with more keen personal interest engaged with the decision aid (in established reading times) and potentially provided more thoughtful and educated feedback than a more demographically representative sample.

The fact that participants reporting past depression also rated the decision aid as more familiar than those without a history of depression is not surprising and likely reflects lessons learned from personal experience and research. It was interesting that those reporting past depression were slightly more likely to report that the decision aid seemed slanted toward trying

psychotherapy or counselling. Those with past depression who had participated in treatment were about four times more likely to have participated in counselling versus medication treatments. Perhaps personal experience with counselling affected participants' perception of slant towards trying counselling or psychotherapy. Given the current study did not collect explanatory data for this finding, future decision aid studies might consider exploration of interrelations between experience of depression, various forms of its treatment, and perceptions of balance or slant.

Among participants reporting no history of depression, those reporting higher maternal education provided lower helpfulness ratings compared with the ratings provided by those reporting lower maternal education. However, the size of the difference is modest and the majority of respondents in all groups described the information as helpful.

The difference in helpfulness ratings based on maternal education was not evident among the subgroup of participants reporting a history of depression. Those reporting past depression and lower maternal education endorsed lower helpfulness ratings than those endorsed by participants reporting no past depression, no matter what level of maternal education was reported. It is difficult to interpret this finding without more information about the experiences of depression of this sample. Assuming our SES indicator is fairly accurate, one could speculate that those having experienced past depression and who come from less affluent homes may have experienced more intense, persistent symptoms due to reduced access to the best treatment. Based on theories such as learned helplessness (Seligman, 1975), these individuals might have learned not to expect their efforts to be rewarded with relief of depression. This may translate to a reduced feeling of hope about the helpfulness of any intervention such as a decision aid compared with those from more affluent homes with better access to effective treatment where

efforts lead more consistently to rewarding outcomes. Future studies might ask participants more fine grained questions about their experience of depression such as whether or not they were formally diagnosed, the duration and intensity of symptoms, the availability of and engagement with more preferred treatments, and the effectiveness of treatment(s).

There was also a gender-based finding that showed that a larger proportion of women (52%) versus men (34%) rated the overall decision aid as portraying a balanced description of treatments. Related evaluation studies have either not measured and/or not reported such a gender-based difference in balance ratings. Although speculative, perhaps there is a link between men's perceptions of balance or slant and aspects of their typical experience of mental health problems. For example, research shows men to report depression at lower rates than women, even when symptoms are similarly prominent and that this contributes to lower treatment seeking in men; once men do identify their depressive symptoms, they appear to be as likely as women to seek help (WHO, 2002). Perhaps men viewing any literature that endorses treatment for mental health diagnoses perceive that the material is written so as to encourage readers to seek that help when necessary. Study 2 men may have felt there was a *slant* toward the two treatments for which that they perceived the strongest positive case was made (psychotherapy/counselling and medications). Future studies examining gender differences in perceptions of balance within decision aids materials may replicate this finding, warranting further focus on important gender differences that would inform approaches to decision aid development and other shared decision-making strategies in general.

The mean time per 100 words spent on the overall decision aid was 37 seconds, and topic-based times ranged from 21-57 seconds. These time ranges are in line with established reading times (usually calculated in words/minute; Carver, 1992). For example, the overall time

of 37 seconds works out to approximately 160 words per minute. Converted topic-based values ranged from 100-300 words per minute. These viewing speeds fall into established reading speed categories of “reading for comprehension” (200-300 words per minute) and “reading for learning” (100-200 words per minute) across numerous samples (Carver).

Topics logging highest mean times were “What Is Depression?”, “Treatments for Depression”, “What Are the Risks of Psychotherapy or Counselling?” and “What Are the Common Side Effects of Medication Treatments?” and pages with lowest mean times were “Self-Help Treatments” and “Uncommon but Serious Side Effects”. Greater mean times on some topics may or may not indicate some intrinsic interest. Alternatively, higher times, especially for the first topics/sections may more so indicate greater freshness and motivation at the start of the survey and a process of orienting to the task. Lower times, especially for later topics may then indicate the effects of fatigue and loss of motivation or that readers are familiar with the task and moving through it more quickly. This may best explain the fact that the Introductory section (located at beginning of the decision aid) grand mean had the highest time value (i.e., 43); whereas the Combined/Self-Help section (at the end) had the lowest (i.e., 26; although the Self-Help page also included numerous book and website references that were likely skimmed and likely accounted for some of this time discrepancy).

Although there was a general lack of relationship between the times participants spent on individual topics and their ratings data (i.e., amount, clarity, familiarity, and trustworthiness), there appear to be two topics where an association between time and at least some of these ratings exist. That is, participants spent less time on “Tables” than most any other topics; they also endorsed the lowest familiarity rating of all topics, a slightly lower clarity rating, and a slightly higher amount rating than many other topics. Additionally, participants spent the third

highest mean time on “What Are the Risks of Counseling or Psychotherapy?”; however, other than a slightly lower rating of amount, ratings did not vary with their time.

Taking into consideration the nature of the information in the decision aid as well as the data being reviewed, it may be helpful to posit some explanations for the above findings. In the first case (“Tables”), the nature and intention of the use of tables may explain why times were shorter. It is generally understood that a table is intended to display a large amount of information through which readers will skim for information of interest. Based on this general understanding, participants were *cued* to skim by the presentation of tables. Their process may have resembled the following: readers, likely only familiar (confirmed by the data) and/or interested in a few drugs and side-effects, would quickly find them in the tables, review them, and move on. The complexity (including probabilities, which are known to present difficulties for consumers; Reyna, Nelson, Han, & Dieckmann, 2009) and larger amount (confirmed by the data) of information would also contribute to skimming, for example, as a way of conserving time and energy in their participation. Corresponding to slightly lower clarity ratings was a higher than average Flesch Kincaid reading level (i.e., 12.3 versus 10.6, likely due to inclusion of long, technical medication names). Hence, inclusion of a large amount of unfamiliar, technical medication names with probabilities likely contributed to notably difference evaluative ratings and contributed to readers choosing to skim through the topic.

Above appears an example of the inherent difficulty in providing healthcare consumers and other members of the public important, desired, but more technical information about medication side-effects. Future iterations should consider incorporation of numerical and other forms of graphic representation of probabilities for side-effects, as research demonstrates

increased understanding of probabilities when these multiple formats are used (e.g., Lipkus, 2007; Wills & Holmes-Rovner, 2003).

In the second case (i.e., “What Are the Risks of Counseling or Psychotherapy?”), participants indicated higher clarity than the former (“Tables”) page which also coincides with a lower Flesh Kincaid reading level of grade 9.5. Indeed, the material on this topic contains less technical information (e.g., no medication names). They also rated the information as more familiar and reported that there was slightly less information than desired. This may indicate information of intrinsic interest presented in a more easily understood format (i.e., text) than condensed tables of probability information, symbols, and medication names.

Participants who viewed the Medications section first spent considerably less time on the Medications section than those who viewed the Psychotherapy or Counselling section first, indicating an order effect. There were no other significant differences in time across any sections and/or on the overall decision aid. Participant ratings data also failed to reveal any differences in perceptions of clarity, amount, or familiarity based on order that may have been used to help explain this interesting finding. One potential explanation for the order effect is that participants who encountered the Medication section were eager to advance to the Psychotherapy or Counselling section, but those who encountered the Psychotherapy or Counselling section were less motivated to rush through the Medication section. This is logical, given participants were Introductory Psychology students and they may have been most interested in psychological treatment. A review of the literature on order effects failed to uncover analogous studies that might help explain this interesting finding. Future web-based studies should consider the inclusion of measures specific to this phenomenon. For example, in order to ascertain the meaning of differences in section times, research could ask participants in the different order

groups about their treatment interests and preferences prior to exposure to the different treatment sections. Also, use of free navigation among the different topics could help uncover areas and levels of intrinsic interest (based on time *voluntarily* spent on a topic/section) across the different order groups.

The trend toward quicker times as the survey progressed may reflect fatigue and/or familiarity with the decision aid (including the 4 repeated ratings questions) more so than lack of interest. During the interview, one of the Study 1 participants began spontaneously answering the questions immediately after reading pages as he had memorized the questions. This decreased time in his interview and this kind of phenomenon may have decreased time for survey takers progressing through the decision aid in Study 2 as well. Future studies are planned with the current decision aid to track usage based on free navigation. The strength of the current method was that we were able to gather opinions from each sample of the whole decision aid.

#### *Time Outliers*

One of the main challenges inherent in Study 2 was how to deal with time outliers. Given many logged total times so low that they were unrealistic reading times, the majority of data were eliminated. We see this as an interaction between the Human Research Ethics Board's (HREB) restriction on making any items mandatory and a tendency for Introductory Psychology university students to rush through studies for experimental credit if they are able. In fact, the HREB suggested it would take up to 120 minutes to read the materials (even though we reported preliminary testing that showed an average of under 60 minutes); hence we were instructed to offer students double the experimental credits (4 versus 2) for participation in Study 2. This may have made participation in this project very attractive, especially if students were highly motivated by credits. The fact that they could race through the survey (many in less than 15



minutes; some in less than 6 minutes), skip questions at will, and still get their 4 credits (usually earned with 120 minutes of participation), may have made the current study very attractive.

Although no way to verify, word of mouth may have spread across students about the easy 4 credits, making recruitment easier, but collection of usable data more difficult.

This problem has been communicated with a member of the HREB who will place the issue under their review. An alternative that may reduce the above problem, while maintaining the ethical standard of ongoing consent (which allows participants to “opt out” at any point or for any item), might be to make items mandatory but add a “prefer not to answer” option. Then, students would be required to respond *in some way* to all items for their experimental credits without being forced to provide responses that might contribute to stress. Another potential solution would be to have participants access the decision aid on a computer in a lab with a researcher present. This might reduce the likelihood of someone rushing through the decision aid. Incidentally, this could be setup so no other web browsers could be opened and might also reduce the likelihood of distraction. In the end, removing outliers still resulted in an adequate sample of women and men who spent time on the survey sufficient to suggest adequate time for reading the material.

### General Discussion

There are as yet no published studies that have examined and incorporated the opinions and suggestions of young adults (with and without a history of depression treatment) regarding a depression treatment decision aid. Furthermore, this is the first to utilize a mixed-methods model of inquiry so as to more fully explore associations across topic and demographic background. Hence, the current findings provide an increased breadth and depth of important information about how young adults perceive depression treatment information, whether or not they have a

history of depression or depression treatment. Their feedback informed two rounds of revisions to the decision aid material. For example, the three versions of “Tables” are shown across Appendices AA (reviewed by Study 1 participants), BB (reviewed by Study 2 participants), and CC (the current version) that represent how the decision aid has evolved based on feedback from the current study participants as well as other evaluation project participants. The ultimate goal was to answer the call to use a systematic process to provide high quality, evidence-based, mental health information that incorporates the input of healthcare consumers and other members of the public early in the development process (Coulter et al., 2006).

### *Evaluative Findings*

In terms of evaluative data, there were areas of both concordance and discordance across qualitative and quantitative findings of Study 1 and Study 2. These are discussed below. Findings between the current study and our team’s other study examining opinions regarding the current decision aid material (i.e., Walker, Zacharias, Sexton, & the Mobilizing Minds Research Group, 2012) will also be used to compare and contrast across samples of young adult members of the public and older adult professionals. Specifically, Walker and colleagues (2012) collected evaluative data from a sample of 25 practicing psychologists and 8 psychology graduate students who participated in an online evaluation survey almost identical to the current study. The content and central questions were identical; there were a few extra questions specific to professionals. Responses by psychologists and graduate students did not differ significantly and were combined in reporting the data (Walker et al.).

### *Familiarity*

The qualitative findings of Study 1 suggest greater overall familiarity than the quantitative findings of Study 2. In Study 1, there was often a fair degree of consensus as to a

level of familiarity with each topic in the decision aid. However, Study 2 ratings of the overall decision aid suggest a fairly broad range of responses with 50% of ratings falling into the *somewhat familiar* and *very familiar* categories and 37% falling into the *somewhat unfamiliar* and *very unfamiliar* categories (the balance were *neutral* ratings). This is not surprising, given that a greater proportion of Study 1 participants (100%) compared with Study 2 participants (43%) had experience with depression and its treatment. It is interesting to note the level of unfamiliarity among a sample of fairly well educated young adults. However, the overall decision aid contains substantial information which may not be familiar, even to otherwise highly educated individuals.

In both studies, familiarity varied across topic areas. One of the most striking levels of concordance was for the very first page: “What is Depression?” where 9 out of 10 interviewees described the information as *very familiar*. Similarly, 72% of participants in Study 2 rated this page as *somewhat* or *very familiar*. Mental health literacy, given its correspondence with *familiarity*, can provide data with which to compare our current findings. Similar to the current study, Marcus, Westra, and the Mobilizing Minds Research Group (2013) found that approximately 80% of 18-24 year-old Canadians in their sample were familiar enough with depression to be able to correctly recognize that people in vignettes were suffering from it (Marcus et al., 2013). This is a similar finding as Reavely and colleagues’ (2012) study of Australian university students and staff, 70% of whom could also recognize depression (Reavley, McCann, & Jorm, 2012).

Some of the areas of *unfamiliarity* in Study 1 were similar to those of Study 2 including treatment costs, tips to manage costs (especially of medications), and the possibility that psychotherapy could worsen depression. Participants across studies found the “Tables” quite

unfamiliar. Study 1 verbal descriptions such as “unfamiliar” and “totally new” and comments such as “...cause I haven’t seen information like this before” and “...I guess just like all these numbers are kind of new” corresponded with the greatest proportion of those rating a page as either *somewhat* or *very unfamiliar* (i.e., 81%) in Study 2.

Walker et al. (2012) found similarly high ratings of familiarity among professionals in that 97% rated the overall decision aid as familiar or very familiar. Topics slightly less familiar were also similar to the current findings and included “What Is the Cost of Medication Treatments?”, “Tips to Manage the Costs of Medication Treatments”, and “Tables”. In keeping with their education and professional experience, costs for psychological treatment were rated as more familiar than for medications (Walker et al.). These findings indicate gaps in consumer and non-medical professional knowledge that can be targeted by future knowledge translation efforts.

Only one other decision aid evaluation study (i.e., Smith et al., 2009) examined perceptions of familiarity as they evaluated a screening decision aid with a sample of 75 older adults. Participants were grouped according to higher education (having a university degree or college diploma) or lower education (no formal post-secondary education). Interestingly, those in the lower education group were more likely than those in the higher education group to report that “none of the information was new” (i.e., 33% versus 16%; Smith et al.). Current results did not yield lower ratings of familiarity based on education; however, this may be due to the overall higher education level of the current sample.

#### *Amount*

Reports of amount were similar across Studies 1 and 2. That is, for almost all topics, Study 1 interviewees thought that the amount was “about right”, which corresponded with amount ratings from Study 2 where 75% of participants endorsed “just right” for the overall

amount of information. Amount ratings converged for “What are the Risks of Counselling or Psychotherapy?”, which was seen as slightly low by Study 1 participants and also received the greatest proportionate ratings of “too little” information (i.e., 47%) in Study 2. Another similarity across studies was that the “Tables” page received the highest proportionate ratings of “too much” information (i.e., 45%) in Study 2 and was also described as one of the longer pages in Study 1.

Walker and colleagues (2012) also found a large proportion (i.e., 76%) rating the amount of information in the overall decision aid as “just right” with the lowest proportionate ratings of “just right” on topics of “What Is the Cost of Psychotherapy or Counselling?”, “What Is the Cost of Medication Treatments?”, and “Tables”. The authors note that these topics contained more complex, detailed information than other topics of the decision aid. Similar to the current study, a larger proportion rated the amount of information in “What Are the Risks of Psychotherapy or Counselling?” as “too little” in Walker et al.’s sample. Recall that several Study 1 participants described this information as surprising, unfamiliar, and interesting. It may be that the quantitative findings of the current Study 2 (i.e., a larger than average proportion [i.e., 43%] reported that this topic was unfamiliar) and Walker et al. imply an area of interest and that some participants wanted to read more about this topic. Future studies could add questions about whether information is interesting and qualitative research could ask why it is interesting.

Ratings of amount across the eight relevant published decision aid evaluation studies (focused on diverse health problems and types of raters) were very similar to the current study in that proportions of ratings of “just right” for the overall decision aid ranged from 65% (i.e., Chiew et al., 2007) to 93% (i.e., Hess et al., 2013). Given these studies pertained to the perceptions of older adults viewing different material, we are unable to confidently compare

amount ratings across age groups. What is observed is that the current sample of young adults generally provide similar amount ratings as older adults when viewing *a* decision aid.

Unfortunately, none of the above decision aid evaluation studies reported findings based on individual topics and comparisons cannot be made as to opinions of amount specific to topics.

As discussed above, “Tables” was the one topic where concern was more consistently expressed about there being “too much” (either too much or way too much) information across both legs of the current study and Walker et al. (2012). In general, reports of higher amount may be related to education level. Recall that Smith et al. (2009) assessed perceptions of amount of information in a bowel cancer screening decision aid with a sample of older adults with higher and lower education. They found that greater proportions of participants with lower education rated the decision aid as “a little too much” information (i.e., 16%) versus those with university or college education (i.e., 9%; Smith et al., 2009). Even though education levels of participants from Studies 1 and 2 were relatively high for their age, most participants were too young (i.e., 18-20 years of age) to have had time to match education levels of the higher education group of Smith et al. and may therefore have been more likely to rate the information as too much.

In Walker et al.’s (2012) study, participants had either already achieved a doctoral degree and had been working for several years as registered psychologists, or they were enrolled in graduate studies in psychology. This sample was therefore more highly educated in general, and much more experienced in issues related to mental health than the current participants. Their mean ratings of amount for “Tables”, though higher than their average ratings, were not as elevated as ratings from the current study (3.3 versus 3.5, respectively). The proportion in the Walker et al. study rating the information as “too much” was elevated for their sample (second highest: 30%); however, this was also lower than the proportion of the current Study 2 (i.e.,

47%). These findings may correspond to Smith's (2009) findings of an education effect among older adults contemplating bowel cancer screening. Although differences in amount ratings across the current study and the Walker et al. study may be mainly due to the effects of professional training, it is also possible that age may have affected ratings, as seen in other areas of research on treatment decision making (e.g., Jorm et al., 2006; Sareen, Cox, Afifi, Clara, & Yu, 2005).

The similar amount ratings between the young adults of the current study and across the eight related studies with older adults suggests that young adults may hold similar views of amount as older adults when viewing a decision aid. This notion is somewhat speculative, as the materials that were evaluated varied across the studies and it is very likely that perceptions and ratings varied as a function of the content and type of decision aid, not to mention participant characteristics aside from age (e.g., being a current patient). Having said that, it is interesting to see the degree of similarity in amount ratings across Walker et al.'s (2012) study and the current study; this finding supports the notion of similarity across younger and older adults in this domain. Also, the current study was limited to young adults who were more highly educated than average. To examine potential differences across education levels within young adults, future studies could include young adults with a wider range of educational backgrounds from a variety of settings.

Although one might be inclined to interpret current reports of too much information for the "Tables" page as suggestive of a desire for less information, information such as this has been reported as important to members of the public in the past (Anderson et al., 2011), though samples are of older adults than those in the current study. The above ratings may not actually be indicative of a desire for less information; alternatively, they may reflect mere acknowledgement

and acceptance of this higher amount as necessary. As explained by some Study 1 participants, it was understood that tables such as these were not cumbersome because they are not intended for detailed reading and rather are for skimming for information of interest. Considering the reduced time spent on “Tables” in Study 2, it is likely that participants were skimming and moving on and may not be suggestive of a desire to reduce information. In terms of facilitating the process, one Study 1 participant suggested we incorporate a search engine. Indeed, this has been incorporated in the current web-based version of the decision aid. This will also allow for the ability to revisit the material for future reference, as also suggested by one of the above participants.

### *Clarity*

Overall, both studies revealed positive perceptions of clarity of the information. As one Study 1 interviewee put it:

*Yes it, it definitely is [clear]. It was easy to follow along and the words were good so it didn't confuse me at all... (19-year-old woman).*

Study 2 results were similar in that 91% of participants rated the overall decision aid as clear. Ratings of lower clarity were consistent across studies for “Tables”. Walker et al. (2012) found similarly high ratings of clarity where 97% of participants rated the overall aid as clear and understandable. Only two pages were rated as slightly less clear: “Tables” and “What Are the Costs of Medication Treatments?” (Walker et al.). In order to provide important rates of side-effects across several common medications for depression, this table was necessarily more complex and participants in both studies reported that this was the case.

The current decision aid has a relatively high reading grade level of 10.6 and is even higher on the “Tables” page (i.e., Grade 12.3). However, participants did not rate the decision aid



as unclear or difficult to read in general. These results highlight the challenge in providing members of the public with complex information that has been reported as important in treatment decision making (e.g., Stewart et al., 2013). However, it is encouraging that clarity ratings were only slightly lower for the more technical information such as contained in “Tables”.

The current overall clarity ratings are similar to many other decision aid evaluation studies (e.g., Anderson et al., 2011; Chiew et al., 2007; Dowding et al., 2004; O’Connor et al., 1998). For example, Anderson and colleagues (2011) piloted a decision aid booklet for asymptomatic women with ovarian cancer about whether or not to engage in second line cancer treatment. Quantitative results indicated that 79% of participants agreed or strongly agreed that the decision aid was easy to understand; similarly, qualitative results showed clarity in that 16 of 20 interviewees described the decision aid as “self-explanatory” and “easy to understand” (Anderson et al.). Anderson and colleagues’ decision aid also contained a table, in their case to summarize treatment options, and unlike the current study, participants provided equally high clarity ratings of the table. Closer examination of this table showed that it differed from the current study in its size (one page), content (only text), and purpose (summarized more detailed information from previous pages). Therefore, differences in reports of clarity regarding a table across the current study and Anderson et al. (2011) may have more to do with the type of table than participant characteristics.

### *Balance*

The concept of balance within the decision aids literature is multi-faceted, with a focus on any one or more of the following: (1) the degree to which both risks and benefits of a given screening/treatment option are presented (e.g., Anderson et al., 2011); and (2) the degree to which balanced descriptions are provided across options (e.g., O’Connor et al., 1998).

In general, results of Study 1 reflect somewhat greater perceptions of balance than Study 2. That is, interviewees were almost unanimous that the decision aid was balanced. In contrast, only 40% of Study 2 participants provided a rating of “balanced” (Walker et al., 2012 did not pose this question in their study). However, this discrepancy is qualified by the fact that the item was posed differently across studies. Whereas Study 2 respondents were faced with a multiple choice task that included other alternatives (e.g., “slanted toward trying combined treatment”), Study 1 participants were only asked if they thought the information was balanced overall, and only in a few cases was an additional prompt required that asked if the “information and the way it was presented was unfair to any particular perspective.” Future interview protocols may consider inclusion of options similar to those in the current Study 2. For example, interviewers could ask if interviewees thought the decision aid was “slanted” toward each of the treatments, in addition to asking if they thought it was balanced.

Given that the bulk of information focused on either psychotherapy/counselling or medication, it seems fitting that, where Study 2 participants endorsed imbalance, they had a strong tendency to endorse the decision aid as slanted toward trying either of those interventions. It was clear from at least two Study 1 interviewees (one male/one female) that they would have liked more information on self-help and/or combined treatments. Although future iterations may work to provide more information on these interventions, the challenge is that the current evidence base for these types of interventions is more limited and we therefore have less information to summarize. Given Study 2 participants’ tendency to endorse imbalance was approximately equal across psychotherapy/counselling and medications, it would appear their perception was of approximate balance at least across the two main treatments.

Across other relevant studies, ratings of the extent to which decision aids present a balanced picture of treatment options range from 47% to 95% (Ameling et al., 2012; Anderson et al., 2011; Smith et al., 2009; Sundaresen et al., 2011; Wakefield et al., 2011). For example, Wakefield and colleagues (2011) found that 47% of men with a family history of prostate cancer who viewed an online prostate cancer screening decision aid rated the aid as balanced; whereas, 36% and 18% thought it either encouraged or discouraged PSA screening, respectively. At the higher balance range, Anderson et al. (2011) found that 90% of women rated their decision aid as balanced (i.e., “equally emphasizing downsides and benefits”). Related research has generated mixed findings between balance ratings and education. Smith et al. (2009) found that ratings of balance varied with education. That is, those with less education were more likely to rate the decision aid as imbalanced. However, Ameling (2011) described lower education in their sample (i.e., most with General Education Diploma or less) and reported high balance ratings. Comparatively, current balance ratings fall in the lower range.

Future studies might consider a more fine-grained approach to assessing participants’ perceptions of balance, as Study 1 illustrates another way that reviewers/consumers may perceive balance or lack thereof: *amount* of information. Recall that where participants reported less information, they also tended to describe this as an imbalance favouring the topic/section with more information. Therefore, the concept of balance is likely more multi-faceted than are current conceptualizations (described above) and may indicate the need to identify and incorporate other facets (such as amount of information) into a more comprehensive understanding of balance in decision aids evaluation.

### *Trustworthiness*

Across both studies, participants reported the information as trustworthy; however, stronger ratings of trustworthiness were reported for the quantitative study. Qualitative results, although reflecting overall trustworthiness, also included remarks about lower trustworthiness due to missing citations, caution about treatment risk information such as side-effects and risk of worsening of depression when engaged in psychotherapy/counselling, and a limited amount of information provided (specific to the Combined/Self-Help section). Quantitative results indicated consistently high ratings of trustworthiness, as 93% of respondents agreed that the overall information was trustworthy. Part of the revision process following Study 1 was to add references to most topics of the decision aid; this may explain what appears to be higher overall trustworthiness in Study 2. Even so, a few Study 2 participants made comments that they would prefer more citations added to the material. Interestingly, although there were a few other topics without references in Study 2, the three topics with lowest trustworthiness ratings were among those having no references, indicating the influence of references on trust.

Topic-based variation in participants' reports of trustworthiness differed across Studies 1 and 2 which likely reflects differences between a sample of young adults all of whom have personal experience with depression and its treatment and a sample with a lower proportion with this experience. For example, there was more of an emphasis on caution in Study 1, especially about treatment risks for both medications and psychotherapy. The interview did not delve into specifics in this area; however, the skepticism reported by 2 of the 5 men about treatment may have been related to difficult personal experience in treatment and the persistence of depression despite treatment. These very cautious attitudes toward treatment may reflect somewhat idiosyncratic attitudes with these 2 Study 1 participants. Indeed, this skepticism about treatment

was not reported by others, either in Studies 1 or 2. Future studies should consider collecting more data on the nature of participants' previous experiences with depression treatment so as to better interpret reports of evaluative domains such as trustworthiness.

Section reports of trustworthiness were similarly high across Studies 1 and 2. There were some qualitative data suggesting that the relative lack of information, especially definitive information backed up by statistics within the Combined Treatment/Self-Help Treatment section, reduced trustworthiness for those sections. However, this concern did not manifest in Study 2. This discordant finding may be based on idiosyncratic attitudes or experiences that are less generalizable; alternatively, it may represent an influential component on readers' feelings of trust regarding health information that may generalize to broader populations. Other than the fact that participants' reduced sense of trustworthiness was due to issues with the information itself (and how it was presented), the Study 1 interview did not delve deeply enough to rule out whether other factors such as if and how the *treatments themselves* may have also influenced readers' feeling of trustworthiness. If the issue is primarily/exclusively the information itself, the decision aid is perceived as less credible in this section and we would want to develop strategies to shore up credibility. To the degree that participants are also judging the trustworthiness of the treatments described, what they may be referring to is more akin to wariness about these particular treatments.

If participants are referring also to their wariness regarding certain treatments due to a lack of research evidence as provided in the decision aid, and that lack of evidence is representative of the scientific literature for these treatments, then we may have succeeded in clearly communicating the state of affairs and in instilling a reasonable sense of consumer caution. Future studies might consider further exploration of the factors influencing readers'

perceptions of trust. For example, evaluation of the current decision aid while incorporating a survey instrument such as used by Corritore and colleagues' (2012) study of trust of online health information might also find that participants' perceptions of several factors of credibility (i.e., honesty, expertise, reputation, and predictability) influence reported trust (Corritore, Wiedenbeck, Kracher, & Marble, 2012). The addition of a question(s) regarding relative amount of information may confirm its influence on readers' varying sense of trustworthiness.

From a methodological perspective, the somewhat discrepant findings across Studies 1 and 2 may be due to the different methods used. Study 1 allowed participants much more freedom to express their perceptions about the decision aid via the open-ended interview questions compared with the quantitative rating scales in Study 2. Study 1 participants were observed as they interacted with the decision aid and were encouraged to read the material and respond in an informed manner. Study 2 participants were not observed and the degree with which they engaged with the decision aid is not known. The combination of Study 1's qualitative design and in-person interviews facilitated greater engagement and freedom to respond resulting in participants sharing their fuller experience while interacting with the decision aid than those in Study 2. This likely contributed to a finding unique from Study 2.

Walker et al. (2012) also found high ratings of trustworthiness in the current decision aid, with 94% agreeing or strongly agreeing that the overall information was trustworthy. Topic-based ratings were also consistently high. Slightly lower evaluations of trustworthiness were found in the only decision aid evaluation study we reviewed that assessed trustworthiness. Bailey and colleagues (2013) found that 70% of women (59% pregnant women; 41% new mothers) "trusted the information" in the decision aid regarding participation in a Fragile X newborn screening pilot study. Factors such as the sensitive nature of the decision may have led to lower

reports of trustworthiness. The current review has highlighted a number of factors seen to influence trust in health information. Inclusion of these variables in future studies with this decision aid should hone our understanding of their influence on this tool and help us make further improvements.

### *Helpfulness*

Both Studies 1 and 2 generated evidence of the perceived helpfulness of the decision aid. Qualitative results showed that most topics were seen as helpful, particularly the Psychotherapy or Counselling and the Medication Treatments sections. All but 2 Study 1 participants thought the decision aid would have been helpful when making decisions about treatment for depression. Rationale explaining helpfulness fell into themes of the decision aid's informative and mind-opening nature, how it contributes to realistic expectations, how it prepares one to engage with health professionals, and how it can offer practical advice for action (especially the Medication Treatments section). Qualitative results indicated reduced helpfulness where information was comparatively briefer as in the Combined/Self-Help section or where there was less practical content (e.g., lack of service provider contact information).

In general, quantitative results were similar to qualitative results and showed that most participants saw the decision aid as either potentially helpful in an actual past decision (77%), or potentially helpful in a hypothetical future decision (80%). Contrary to findings in the qualitative results, quantitative results did not find lowered helpfulness ratings based on a perception of reduced information and/or less practically helpful information. This discordance may again highlight the importance of incorporating qualitative methods. Perceptions of helpfulness and the factors that influence these perceptions could be further explored to identify, for example, strategies to develop decision aid information that strengthens a reader's hope and belief that the

materials can help; this should increase the likelihood a reader will use the decision aid when needed.

Walker and colleagues' (2012) sample of current and future psychologists also provided high ratings of the decision aid's helpfulness as a consumer decision tool. That is, the majority of their participants (94%) said they would provide the decision aid to their clients within either their current (registered psychologists) or future (clinical psychology graduate students) psychological practice.

### *Completeness*

Completeness was measured in Study 1 only, where all participants described learning something, the main areas of learning being cost of treatment (especially medication treatment), rates of recovery, number of programs and resources in existence, and psychotherapy and counselling training levels across disciplines. Only one (male) participant suggested a missing topic which was on the impact of drug abuse on depression. No related published studies report data on completeness. Even so, it would appear that this construct is important in the evaluation of decision aids. By evaluating completeness (i.e., what was learned; what was missing), we not only obtained data on participants' overall sense of the ways the decision aid made them feel informed, we were also able to obtain any outstanding suggestions for as yet excluded topics.

### *Recommendation of the Decision Aid*

Qualitative and quantitative results were consistently positive regarding recommending the decision aid to someone whom participants thought might be suffering from depression. Qualitative results showed that almost all participants (8 out of 9 who were posed this question) reported they would recommend this decision aid, with accompanying rationale falling into themes of the decision aid as informative, able to increase realistic expectations, and able to



increase a sense of empowerment. The one participant who was not ready to recommend the decision aid was holding off until revisions were made (numerous of which had to do with adding references); it is quite possible that he would now be willing to recommend it in its revised state. Quantitative results also indicated high levels of recommendation in that 81% said they would recommend the decision aid. Related research has generated similar levels of recommendation of decision aids by patients and other members of the public, ranging from 75% willing to recommend a chest pain choice decision aid (Hess et al., 2013) to 95% reporting they would recommend an ovarian cancer treatment decision aid (Anderson et al., 2011).

#### *Study 1 and the Importance of Information Presentation*

Results specific to Study 1 offered several important lessons about providing information to mental healthcare consumers. These included the importance of providing enough, but not too much information for decision making. It is a tenuous balance and likely somewhat idiosyncratic; however, consideration of amount of information should inform further revisions to the decision aid. Based on Study 1 and Walker et al. (2012), the current decision aid (especially certain topics) may be slightly too long and require paring down. The current Flesch-Kincaid reading levels are also high indicating a need to simplify language, which sometimes means an increase in the number of words which will likely increase the length of the decision aid. Hence, there is a tension between these needs. Given future iterations will include free navigation and that readers will not be asked to read the entire aid, the need to make the decision aid briefer may not be as important as the need to reduce the complexity of the language.

In terms of complexity, decision aid developers tasked with delivering inherently complex and/or less familiar information (e.g., medication names) do not always have the luxury

of complexity reduction. Future versions of the current decision aid may incorporate optional glossaries to reduce complexity.

Another lesson is that of the impact of *relative* amount of information. Participants' perceived imbalance of amount of information in the various sections impacted their sense of the relative importance and credibility of the information. Where there was noticeably less information, the common interpretation was that the information was less important and/or less credible. Hence, providing information such as this requires consideration of balance of amount of information across topics to avoid unintentionally creating a sense of variable importance and/or credibility across topics. Given there is sometimes much less research on some topics, an amount imbalance is not always avoidable.

Another issue coming out of Study 1 data is the importance of the use of plain language. Although overall opinion was that the decision aid was relatively clear, there was some confusion over presentation of probabilities. This was evident on the "What Happens to Depression without Treatment?" topic where three participants reported lower clarity over probability representation (e.g., "six out of ten"). This is consistent with research finding the public's lower average comprehension of probabilities (e.g., Lipkus, 2007). Given best practices for conveying probabilities or risks entails presentation in more than one format, future versions of the decision aid should consider employing verbal and visual formats as well the current numeric representation.

Similarly, given that half of the participants found "Tables" less clear, future iterations of the decision aid may explore other ways and/or the addition of ways to more clearly represent probabilities of side-effects of medications. For example, use of a different visual scheme (other than boxes and dashes) could be tested; the addition of numeric (in fact one participant suggested

use of a numeric scheme) and verbal representation could also be explored to see how comprehension may or may not be affected. This would more closely align with best practices (Lipkus, 2007).

Related to the use of plain language is participants' preference for the use of "warm" language. Two participants noted the cool (or "textbooky" as one woman put it) nature of the information and that they preferred a warmer use of language. However, the current study did not go into depth as to what might constitute warmer language. This may be an important area for future research so as to create a decision aid that provides sufficient "facts" for informed decision making, but that does so in a style of language that increases the likelihood of reader engagement. Developers of the current decision aid are also considering use of personal stories to increase warmth.

Another issue arising from Study 1 is that of balancing the breadth and depth of the material. For optimal efficiency, a decision aid should be general enough to apply to various contexts (rural, urban, provincial, national, etc.); however, participants mentioned a need for more context-specific information (e.g., therapist contact information for certain regions). Developers are giving this issue serious consideration.

#### Results in Light of Decision Theory

Even though we did not set out to test the decision aid based on decision theories, it is possible to consider the results in light of theory. For example, recall the discussion regarding participants' behaviours with, and ratings of, the "Tables" topic. In this case, participants spent less time on the topic, but also rated it as less familiar, less clear, and more in terms of amount of information. And also recall that expected utility theory is used to predict a person's choices under uncertainty (e.g., Hellinger, 1989). Often, people's attitudes toward a risk involve some

comparison of desirability across two or more alternatives. Given that most situations involve uncertainty, each alternative can be viewed as a *gamble*, entailing its inherent outcomes and associated probabilities. Our participants were faced with a situation called *risk neutrality* (i.e., “the utility of a gamble equals the utility of the expected value of a gamble” Hellinger, p. 274). In probability theory, the *expected value* refers to the value of a variable we can *expect* to find if we could repeat the process of measuring that variable an infinite number of times and then take the average of all values (Ross, 2007, p. 38). In this case the readers were faced with a gamble: strategy A = skim the tables for information of interest; strategy B = read more or even all of the tables to get the information of interest. Given the understanding of the nature of tables (above), the expected value of A would have greatly exceeded B for many if not all of the readers; A also imposed very little risk of missing important information. Therefore, the decision rule to select A was optimal, provided the readers were rational and were neutral toward gambles. If not neutral, decision rules would have varied depending on the individual’s level of risk aversion.

Recall that the conflict theory model of decision-making (Janis & Mann, 1977) proposes that engaging in a decision making process creates stress, conflict, and uncertainty, the reduction of which is based on efforts to search out and evaluate information and/or alternatives. Study 1 participants provided responses in keeping with conflict theory in that they frequently and consistently reported the value of the acquisition of good, trustworthy information regarding management of depression. They reported that obtaining this information reduced their stress and uncertainty and, in fact, was quite empowering. However, we did not recruit participants in the process of deciding about treatment and therefore cannot speak to their real-time stress related to treatment decision making. Future studies could consider such a study design to measure the

effect of the current decision aid on people's stress and conflict in the actual decision regarding depression treatment.

Prospect theory proposes that the way in which a prospect is described or *framed* affects the choices made by individuals. Research in this area has demonstrated a tendency for individuals to place greater value on losses than gains (Tversky & Kahneman, 1981). Some of the findings from Study 1 relate to prospect theory in that people expressed an interest in how the material was framed in a number of ways. First, there appeared an influential frame related to *scientific credibility* in that participants commented on the importance of external citations. Second, there appeared a frame related to *relative amount of information* in that individuals commented when there was less information on some topics than others and the implication that the topic with less relative information was not as important (e.g., the section on self-help and combined treatment that are shorter, due to there being relatively less evidence available to report). Third, a frame mapping more directly on *losses versus gains* was observed when participants showed increased interest in the medication side-effects section and the possible negative effects of therapy section versus the sections related to potential gains of the treatments.

We did not pose choice options to participants while systematically varying framing of losses versus gains and therefore did not observe whether responses would vary as prospect theory would predict (i.e., that participants would exhibit a tendency to become risk seeking when faced with a potential loss and risk averse when faced with a potential gain). Hence, we cannot provide evidence that either confirms, extends, or disconfirms prospect theory. Future studies could replicate Tversky and Kahneman (1981) utilizing variables relevant to depression treatment choices to see if individuals in these spheres exhibit similar tendencies as in other, more hypothetical decision making tasks.

### Implications for Clinical Practice

Little is known about the attitudes and opinions of 18-25 year-old adults regarding mental health treatment decision making and decision aids (Sareen et al., 2005), even though prevalence rates of depressive disorders peak during these years (Kessler, 2007). Hence, increasing our understanding of the opinions of young adults regarding decision aids can only strengthen our ability to develop the most effective materials for this vulnerable group. In the current studies, young adults expressed appreciation for a decision aid in their verbal and ratings data similar to that expressed by older adults for other decision tools. There was a high proportion that reported this decision aid would be helpful. Similar to older adults (e.g., Dowding et al., 2004; O'Connor et al., 1998), Study 1 interviewees expounded that it would have helped in past decisions in numerous ways. Where there was less information or where information was less practical, qualitative results also indicated a reduced sense of helpfulness. Similar to older adults (e.g., Bernstein et al., 2011), these younger adults therefore seem to be asking for a substantial amount of information.

Importantly, the current sample expressed similarly high ratings for web-based mental health treatment information as have other young adults (e.g., Leach, Christensen, Griffiths, Jorm, & Mackinnon, 2007; Oh, Jorm, & Wright, 2009; Stewart et al., 2013). Study 1 respondents elucidated some of the reasons for this preference. Some of the respondents emphasized the advantage of having an Internet decision aid for future reference. As one woman put it:

*I think like internet would be the best...because...I guess for my age group...and for like teenagers because no one really opens books and reads them, like maybe for older adults it would be good in like a book or something but for like the young adult or teen population everything we do is on the internet... (21 years old).*

Also, factors contributing to lower mental health literacy found among young adults include lower knowledge of treatment options and social stigma of mental health problems (Jorm, Wright, & Morgan, 2007). Given the current high level of acceptability of the decision aid, providing this information in the preferred web-based format may increase the likelihood of utilization by this young group of consumers and members of the public.

### Strengths and Limitations

Utilization of a mixed-methods design was based on concerns that examining the perceptions of young adults regarding a new decision aid constituted early exploration of a new area of research. Use of qualitative methods for Study 1, then, imposed fewer assumptions regarding participants' experiences and views and succeeded in providing the open-ended, in-depth data regarding the opinions of young adults concerning the content of the decision aid. The addition of a quantitative study increased comprehensiveness of findings and triangulation of findings increased confidence in results. Where qualitative results generated rich, in-depth but potentially more idiosyncratic data about participants' views of the decision aid, quantitative results have succeeded to establish generalizability of certain findings to a broader group of young adults. There were numerous areas where qualitative and quantitative results converged; however, as would be expected, there were areas of divergence as well. These findings were also helpful and lead to increased confidence that we have looked across a broader spectrum of the opinions held by these young adults about our decision aid. In either case, we have increased confidence in findings and appreciate that both methodologies generated new questions to pose in future studies.

The decision aids evaluation literature is methodologically heterogeneous and ranges from an exclusive focus either on quantitative methods or qualitative methods. However, recent

trends have begun to focus more on multiple or mixed-methods designs similar to the current study. One of the strengths of the current study is its utilization of mixed-methods in an unusually comprehensive fashion. For example, studies such as White et al. (2013) used both interview and questionnaire data; however, both the interviews and questionnaires were relatively brief and data generated were limited. Additionally, studies that collect in-depth data based on discrete subsections of a decision aid are rare (e.g., Anderson et al., 2011) and none were found that posed questions on a topic-by-topic basis. Most often, participants are asked overarching questions at the end of a decision aid (e.g., Hochlenert et al., 2006; Sivell et al., 2012; Wakefield et al., 2011). Asking questions more frequently can allow for more fine-grained analysis of participants' perspectives on the information and for more focused and accurate suggestions which can guide consequent revisions. The comprehensiveness of the current findings combined with the positive impact they had on the content of the decision aid may encourage other decision aid developers to use a similar framework.

Participants from Study 1 represent another strength of this project, as they are young adults, all of whom report having experienced depression treatment. The in-depth, experientially informed opinions of these young people were essential to revisions of the decision aid. However, as all were members of a mood disorders consumer self-help organization, their opinions may not represent those of the wider group of young adults suffering from depression outside of these kinds of organizations. Some representativeness is inferred, as the opinions of University students in Study 2 were somewhat similar to those of Study 1, although still limited to people with university education (recall that half of Study 1 participants were/had been enrolled in university/college).



A convenience sample of Introductory Psychology students were recruited for Study 2 due to the proportion likely to meet the age interval of interest combined with a concern regarding feasibility of an already ambitious doctoral thesis. Use of the University's online participant pool further facilitated timely recruitment and data collection. This strategy obviously limited the generalizability in terms of opinions and especially reading level. Future research is needed to ascertain opinions of young adults without higher education (and/or with non-university post-secondary education) to gain an understanding of broader public and consumer perceptions and to incorporate suggestions into the decision aid from these segments. Given the higher than average rates of past depression in Study 2 participants, their data also represent a relative strength in that they may have been more interested/engaged and more able and apt to offer educated feedback.

Given how little is known about the opinions of young adults regarding depression treatment information, the types and amount of data analyzed in the current study are also considered study strengths. Overall, young adults provided very similar evaluative data to older adult psychologists and clinical psychology graduate students viewing the same material. Their opinions were also similar to other published decision aid evaluations in terms of amount, clarity, familiarity, trustworthiness, and helpfulness of the decision aid. They were similarly willing to recommend the decision aid to others struggling with depression. There may be other areas of convergence and perhaps divergence (e.g., Oh, Jorm, & Wright, 2009) revealed as mental health related studies with this population continue.

It is important to note that, although the current study focused on participants some of whom reported a history of depression, their opinions may not reflect those of young people surveyed during the process of depression treatment decision making in the midst of a depressive

episode. Studies such as the latter with young adults were not found in the current literature review, but future studies may find opinions varying based on depressive symptoms such as reduced concentration, irritability, and feelings of hopelessness.

The current decision aid evaluation entailed procedures and tasks that are both similar and dissimilar to the expected usage in the field. Similar to the current study, users will likely read topics of a decision aid that they find relevant and/or interesting; however, users may only read selected parts that are of particular personal interest (e.g., a particular treatment). The advantage of the current study was that it provided evaluative comments from the same individuals across all of the different treatment options. Future studies are planned that will examine opinions of decision aid content using free navigation. These studies may also examine pre-to-post knowledge change. Like Joseph-Williams et al. (2010), results can shed light on whether or not users are learning from the decision aid.

Future iterations of the decision aid may also include a values clarification exercise. Like many other decision aids, this will allow users to indicate the personal importance of certain probabilities (e.g., success rates; rates of side effects) related to each treatment and obtain feedback as to their leaning. As values have been seen to change over time and experience, the benefit of a web-based tool is that users can re-visit the site, update their personal importance for each probability, and obtain an updated report of their choice leaning. In fact, one of the Study 1 participants spoke of this benefit in terms of having the information online for future reference.

Another strength of this project is that it helps move the decision aid one step further in the IPDAS development process. Study 1 assesses perceptions and gains feedback from the intended users with a history of depression; Study 2 field tests the content for acceptability and input from the general public. Future studies are planned to address the remaining criteria. Given

the high Flesch-Kincaid Grade Reading level of 10.6 (with pages ranging up to grade 12.6), one of the most important upcoming revisions is to simplify language. Although current evaluators did not complain about the complexity of the text, other non-university readers will likely find it challenging. Another next step is to develop a values clarification exercise and an upcoming iteration would likely be based on an RCT to determine effects of the decision aid on components of informed and shared decision making such as decisional conflict and satisfaction with decision (e.g., Banegas et al., 2013; Hess et al., 2013; O'Connor et al., 2011).

The fact that numerous revisions were carried out as a result of the suggestions made by Study 1 and 2 participants constitutes another strength of the study. These revisions have ultimately resulted in what is a more helpful, understandable decision aid. One important change that came about from suggestions was to increase the use of bullets for enhanced readability. While it is very important to hear and understand all of the comments made by participants, it was not possible to incorporate all the suggestions that were made. This was especially true where idiosyncratic values led to contradictory suggestions across participants. For example, some suggested more information on a topic while others suggested less information on the same topic. Other comments reflected strong personal biases such as “medications are a last resort” that would likely not generalize to other readers.

As previously discussed, concerns have been raised about the quality of health and treatment information provided to consumers on the Internet and otherwise (e.g., Cline & Haynes, 2001; Coulter, Entwistle, & Gilbert, 1998, 1999; Raynor et al., 2007), including criticisms about information that is inaccurate, incomplete, misleading, ignoring of uncertainties, and based on insufficient evidence (Cline & Haynes; Coulter et al., 1999). Similar concerns have arisen from information quality studies on mental healthcare websites (Reavley & Jorm, 2010;

Walsh et al., 2010). Other authors have suggested that there be more input from healthcare consumers and other members of the public on health information (e.g., Coulter et al., 2006). The current study is an attempt to provide high quality information about depression and its treatment that also incorporates the input from consumers and other members of the public. It is also an attempt to further integrate shared decision making into mental healthcare (Wills & Holmes-Rovner, 2006).

### Summary of Key Findings and Recommendations

It was interesting that these samples of young adults evaluated the decision aid very similarly to older (and sometimes more educated) adults viewing the identical information as well as older adults evaluating other decision aids. This was true for evaluative ratings; it was also true in terms of the emphasis placed on the importance of obtaining information, which mirrors the reports found in studies within general healthcare (e.g., Grime et al., 2007) as well as mental healthcare (e.g., Hill & Laugharne, 2006) where consumers report a desire for ample information about their health issues as well as pros and cons regarding screening and treatment options.

The young people participating in this research, particularly in Study 2, endorsed lower balance ratings than any other surveyed study. Besides the potential that this was mainly a function of their younger age, factors such as question construction and number of options across which to judge may also have been influential. Given that imbalance was reported as slanted towards medications or psychotherapy/counselling, which were the longest sections, it is possible that *relative amount* may be another component of perceived balance.

The fact that Study 2 female participants evaluated the decision aid as more balanced than did men is also of interest and something yet to be reported in related decision aids research.

Perhaps there are as yet unidentified gender-based links between women's and men's attitudes and experiences of mental health problems and their perceptions of slant toward related treatments.

Using a mixed-methods design helped maximize the inherent strengths of both qualitative and quantitative methodologies while minimizing their inherent weaknesses. As a result, we were able to gain an increased depth and breadth of findings from which to generate new questions and recommendations for decision aids research. What is evident in the decision aids literature is that few studies incorporate mixed-methods research in as comprehensive a manner as the current study. It is our intent that the comprehensiveness of the current findings will encourage other researchers to use a similar approach.

The current study indicated that reports of lower maternal education were associated with lower ratings of expected helpfulness of the decision aid, but only when the participant also reported a history of depression. It is possible that those less affluent in our sample who experienced past depression also had poor access to the most effective treatments and now have less hope for future help from a tool such as a decision aid versus those without depression and with better access to the best healthcare. A process such as this would fit within a learned helplessness model (Seligman, 1975).

Some qualitative data suggested that the relative lack of information, particularly decisively-written information providing supportive statistics within the Combined Treatment/Self-Help Treatment section, reduced trustworthiness. However, our questions did not tap further into any relationships between trustworthiness and relative amount of information, and we are left pondering if the reaction is primarily about the presentation of the *information* on

treatments (i.e., credibility of that part of the decision aid) and/or if the issue is also regarding the trustworthiness of the *treatments* described (i.e., credibility of the treatments).

Men were significantly more expressive during interviews than were women. If there was some effect of my gender and/or physical size that made it more difficult for women to express themselves, then there may be important data gone uncollected about how women think and feel about the decision aid.

The current samples consisted of fairly homogeneously well-educated individuals likely with above average reading ability. Hence, even though our reading level is higher than recommended by IPDAS (i.e., grade 8), we did not receive reports of lack of clarity. We did receive requests to use more “warm” language.

Participants’ reduced time on “Tables” may indicate a common understanding of how to maximize the utility of a table by skimming for relevant, important information versus taking extended time reading through a large amount of mainly irrelevant material. Although speculative, drawing from expected utility (EU) theory (e.g., Hellinger, 1989) would predict that our participants would have held a positive attitude toward the gamble that skimming would pay off over fully reading the tables. However, unlike EU studies, we do not know the level of risk aversion of our participants and how this may have influenced their choice. Lower ratings of clarity, familiarity, and higher ratings of amount, taken together with the reduced time on this topic, may indicate readers were less engaged with what they saw as a large amount of complex and mainly irrelevant material through which they skimmed.

Below are key recommendations for future decision aids research:

- Utilize comprehensive mixed-methods models for in-depth examination of the opinions of evaluators.

- Using both qualitative and quantitative approaches, incorporate a detailed review of content areas one at a time versus relying exclusively on global responses to the decision aid.
- Similar to Joseph-Williams and colleagues (2010), incorporate free navigation and measure free usage and its correlates with components of informed and shared decision making.
- Explore potentially important differences in perceptions of helpfulness of decision aids by asking more fine-grained questions about participants' experience of depression such as whether or not they were formally diagnosed, the duration and intensity of symptoms, the availability of and engagement with more preferred treatments, and the effectiveness of treatment(s). Incorporate aspects of SES.
- Summarize participants' suggestions for revision as well as indicate changes made to the decision aid in response to suggestions.
- Consider matching interviewers to the gender of interviewees to optimize data collection.
- Consider making efforts to include young adults along with older adults to continue to uncover age-related areas of concordance and discordance and thereby increase our understanding of any unique decision-making needs to incorporate into future decision aids development and evaluation.
- Hone in on perceptions of *balance*. For example, in addition to asking if material is seen as balanced and/or if it provides pros and cons of different options, asking more open-ended questions as to *what it is about the information* that influences their perception of balance or slant may uncover more components of perceived balance such as relative amount of information, as found in the current study.

- Examine gender differences, for example, in perceptions of balance within decision aids materials to potentially replicate the finding that female participants differ from males in their sense of balance. If so, further focus on important gender differences could inform approaches to decision aid development and other shared decision-making strategies in healthcare.
- Further explore the factors influencing readers' perceptions of trustworthiness such as honesty, expertise, reputation, and predictability. This may further illuminate specific ways to improve the decision aid. The addition of a question(s) regarding relative amount of information may confirm its influence on readers' variable sense of trustworthiness.
- Simplify language in the decision aid and/or include a pop-up glossary for words and phrases higher than grade 9 reading level so that readers across more reading levels can better understand and benefit from the decision aid.
- Increase the research focus on readers with more average or below average reading ability to assess their perceptions of the decision aid and to consider and incorporate suggestions for improvement from these less-educated groups.
- Consider incorporation of numerical and other forms of graphic representation of probabilities for side-effects, as research demonstrates increased understanding of probabilities when these multiple formats are used (e.g., Lipkus, 2007; Wills & Holmes-Rovner, 2003).
- Incorporate decision theories such as expected utility or prospect theory (e.g., Hellinger, 1999) into testable predictions of participants' opinions and behaviours in interacting with the decision aid.
- Consider incorporation of a values clarification component.



- Consider evaluating effects of the decision aid on real-time decisions of consumers via, for example, an RCT.
- A rapidly expanding evidence base now exists for risk communication within the realm of decision aids development. Developers of decision aids as tools intended to facilitate evidence based decision making are encouraged to apply these principles to improve the quality of risk communication (Trevena et al., 2013).

### Conclusion

The systematic evaluation of a high quality, evidence-based decision aid (Coulter et al., 2006; O'Connor, Llewellyn-Thomas, & Stacey, 2005) for depression treatment (Wills & Holmes-Rovner, 2006) was intended to fill a gap in decision support and knowledge translation for young adults. Given the growing diversity of treatment options for depression, each with its own unique risk/benefit profile, consumers, friends or relatives of consumers, or other members of the public, require assistance in the process of making well-informed, values-congruent treatment choices. It was satisfying to observe the high levels of acceptability of the current decision aid across young adults with and without a history of depression. It is likely that acceptability and utility will increase since many suggestions made by current participants led to revisions that have been incorporated since the current evaluations (Coulter et al., 2006).

Our intent was that making the decision aid available on the Web will increase its accessibility and utility for many others in the public, including older adults. Incorporating the helpful evaluative feedback from individuals from the target age range including those with personal experience with depression and its treatment should also make for a more acceptable and usable decision aid.

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## Appendixes

**Appendix A: Ottawa Decision Support Framework (ODSF): Cut due to copyright laws.**

## Appendix B: Study 1 Demographics Questionnaire:



### Department of Psychology

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### *A Few Questions about You:*

***For each question, please place a check mark in the circle to the left of the response that best describes you:***

1. Your gender:     Male     Female

2. Your age:     18    19    20    21    22    23    24    25

3. *Your education:*

How many years of education have **you** completed in the following areas?

Grade School 1 – 12 (or 13):  seven or less    8    9    10    11    12    13

Apprenticeship:     1    2    3    4    5

College, technical, business, vocational, nursing (non-university)

1    2    3    4    5    6

University program

1    2    3    4    5    6    7    8    9    10    11    12 or more

4. *Mother's education:*

How many years of education has **your mother** completed in the following areas?

Grade School 1 – 12 (or 13):  seven or less    8    9    10    11    12    13

Apprenticeship:     1    2    3    4    5

College, technical, business, vocational, nursing (non-university)

1    2    3    4    5    6

University program

1    2    3    4    5    6    7    8    9    10    11    12 or more

5. *Father's education:*

How many years of education has **your father** completed in the following areas?

Grade School 1 – 12 (or 13):  seven or less  8  9  10  11  12  13

Apprenticeship:  1  2  3  4  5

College, technical, business, vocational, nursing (non-university)

1  2  3  4  5  6

University program

1  2  3  4  5  6  7  8  9  10  11  12 or more

## 6. Please fill in the postal code(s) of parents in the blanks below:

\_\_\_\_\_ (parents residing together)

\_\_\_\_\_ (father)

\_\_\_\_\_ (mother)

## 7. If you are in a post-secondary program of education, approximately how much do you expect your total debt to be for education when you have completed your program?

\$\_\_\_\_\_

## 8. Marital status:

Single/Never married

Married/common-law

Divorced/separated

**[INSERT K6]**



## Appendix C: Study 1 Initial Interview Protocol:

### [START FORMAL INTERVIEW BY SAYING]:

*“Do you have any questions before we begin?”*

*“First, I’d like to get to know you a bit better. Can you tell me something about your main activities right now such as whether you are working or going to school or involved in some other activities?”*

### History of Depression and Treatment Information:

*“Many people have some problems with depression over their lifetime...”*

1. Could you tell me about your experiences with depression?”

Follow-up probes (if necessary):

a. How did depression affect your day-to-day life?

b. What helped you cope with depression?

2. Often when people are first having problems they do not realize that it is depression. How did you decide that the problem was depression?

3. When was that?

4. [IF NECESSARY]: Where did you get information to help you identify that you were depressed? (Any other ways?)

Follow-up probes (if necessary):

a. Medical doctor?

b. Friends/family?

c. Books?

d. The Internet?

e. A pamphlet?

*“People find information about getting help for depression in many ways, for example, through pamphlets, talking with family members or friends, asking the doctor, or searching on the Internet.”*

5. What were the ways that you found information about getting help for depression? Any other ways?

(FOR EACH METHOD IDENTIFIED ASK HOW THEY FOUND AND USED THAT INFORMATION.)

Follow-up probes (if necessary):

- a. Medical doctor?
  - b. Friends/family?
  - c. Books?
  - d. The Internet?
  - e. A pamphlet?
6. If you had treatment for depression, how did you decide what treatment to take?  
(DEVELOP A DESCRIPTION OF THE PROCESS FOR THAT PERSON.)

Were there other factors involved in the process of your decision?

7. Did you use the information from \_\_\_\_\_ (DESCRIBE INFORMATION SOURCES ABOVE) to help you decide what kind of help you wanted to try for depression?

[IF YES]: How?

8. Were there any sources of information that were most helpful for you or that you relied on most?

**Opinions about Information in Decision Aid:**

*“Now I am going to show you information that has to do with depression and some ways in which it is treated. We will review the information a section at a time. After you’ve had a chance to read the information in each section, I’m going to ask you a couple of questions about what you’ve read. There are no right or wrong answers. What I’m most interested in are your opinions about the information.”*

**Presentation of Information:**

**(PRESENT EACH SECTION FOLLOWED BY THESE QUESTIONS):**

1. How familiar to you or new to you is the information on this topic?
2. What is your opinion about the amount of information provided on this topic?

Follow-up probes (if necessary):

- a. Was it too little or too much?
- b. Was it about right?

3. How clear and understandable was the information?

Follow-up probes (if necessary):

a. Are there any words and/or sentences that are difficult to understand?

4. Is there other information that should be included?

Follow-up probes (if necessary):

a. What kind of information?

5. How trustworthy do you feel the information is?

6. How helpful was this information?

7. Do you have any (other) suggestions for improving the information provided on this topic?

**(AFTER THE FINAL SECTION):**

*“Now I would like to get your opinions about the overall information in the decision aid and your experience reading it.”*

1. Overall, is the information clear and understandable?

2. Are there any areas where the information could be clearer?

3. Were there any areas that seemed confusing?

4. Was the information balanced overall?

Follow-up probes (if necessary):

a. Were the information and the way it was presented unfair to any particular perspective, for example, medications or psychological treatment?

5. Do you feel you learned anything new as a result of reading the information in the decision aid?

Follow-up probe (if necessary):

a. What are the areas you found most informative?

6. Were there any topics you were hoping to learn about regarding depression and treatment but were missing in the decision aid?

Follow-up probe (if necessary):

a. What topics?

*“Now, I’d like you to think back to when you were at the point of making a decision about treatment for depression. With that in mind:”*

7. Would a decision aid like this one have been useful for you?

Follow-up probes (if necessary):

- a. If so, how?
- b. If not, why not?

8. Would you recommend this decision aid to someone you know who was having problems with depression? How do you think it might be helpful to them?

9. Thinking of your experiences in dealing with depression, how do you think it would be best to make this information available to people?

*“That covers the things I wanted to ask; is there anything you would like to add?”*

## **Appendix D: Study 1 Revised Interview Protocol:**

### **[START FORMAL INTERVIEW BY SAYING]:**

*“Do you have any questions before we begin?”*

*“First, I’d like to get to know you a bit better. Can you tell me something about your main activities right now such as whether you are working or going to school or involved in some other activities?”*

### **History of Depression and Treatment Information:**

*“Many people have some problems with depression over their lifetime...”*

1. Could you tell me about your experiences with depression?”

Follow-up probes (if necessary):

- a. How did depression affect your day-to-day life?
- b. What helped you cope with depression?

### **Opinions about Information in Decision Aid:**

*“Now I am going to show you information that has to do with depression and some ways in which it is treated. We will review the information a section at a time. After you’ve had a chance to read the information in each section, I’m going to ask you a couple of questions about what you’ve read. There are no right or wrong answers. What I’m most interested in are your opinions about the information.*

*Here is the outline of the information you’ll be reviewing today. There are 25 topics starting with ‘What is Depression’...and ending with ‘Self-help Treatments’. We appreciate your feedback and value all your suggestions for improving the information. However, you do not need to feel pressured to comment on every page you read.”*

### **Presentation of Information:**

**(PRESENT EACH SECTION FOLLOWED BY THESE QUESTIONS):**

1. How familiar to you or new to you is the information on this topic?
2. What is your opinion about the amount of information provided on this topic?

Follow-up probes (if necessary):

- a. Was it too little or too much?

- b. Was it about right?
3. How clear and understandable was the information?

Follow-up probes (if necessary):

- a. Are there any words and/or sentences that are difficult to understand?
4. Is there other information that should be included?

Follow-up probes (if necessary):

- a. What kind of information?
5. Do you have any (other) suggestions for improving the information provided on this topic?

**ASK #6 ONLY AFTER:**

- O “UNCOMMON BUT SERIOUS SIDE EFFECTS”**
- O “WHAT ARE THE RISKS OF THERAPY?”**
- O “SELF-HELP TREATMENTS”**

*Thinking of the whole section on (name section just reviewed)...*

**6. How trustworthy does the information seem to you?**

Follow-up probes (if necessary):

- a. What is it about the information in this section (name section) that made it seem more (or less) trustworthy to you?

**ASK #7 ONLY AFTER:**

- O “UNCOMMON BUT SERIOUS SIDE EFFECTS”**
- O “WHAT ARE THE RISKS OF THERAPY?”**
- O “SELF-HELP TREATMENTS”**

*Thinking of the whole section on (name section just reviewed)...*

**7. How helpful does the information seem to you?**

Follow-up probes (if necessary):

- a. What is it about the information in this section that made it seem more (or less) helpful to you?

**(AFTER THE FINAL SECTION):**

*“Now I would like to get your opinions about the overall information in the decision aid and your experience reading it.”*

1. Overall, is the information clear and understandable?
2. Are there any areas where the information could be clearer?
3. Were there any areas that seemed confusing?
4. Was the information balanced overall?

Follow-up probes (if necessary):

a. Were the information and the way it was presented unfair to any particular perspective, for example, medications or psychological treatment?

5. Do you feel you learned anything new as a result of reading the information in the decision aid?

Follow-up probe (if necessary):

a. What are the areas you found most informative?

6. Were there any topics you were hoping to learn about regarding depression and treatment but were missing in the decision aid?

Follow-up probe (if necessary):

a. What topics?

*“Now, I’d like you to think back to when you were at the point of making a decision about treatment for depression. With that in mind:”*

7. Would a decision aid like this one have been useful for you?

Follow-up probes (if necessary):

c. If so, how?

d. If not, why not?

8. Would you recommend this decision aid to someone you know who was having problems with depression? How do you think it might be helpful to them?

9. Thinking of your experiences in dealing with depression, how do you think it would be best to make this information available to people?

*“That covers the things I wanted to ask; is there anything you would like to add?”*

Appendix E: Outline for Study 1 Interviewees: Psychotherapy or Counseling first:

## **Evaluating an Information Aid--Treatment Choices for Depression**

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- 1. What is depression?**
- 2. What are the risk factors for depression?**
- 3. What happens to depression without treatment?**
- 4. Treatments for depression**
- 5. Psychotherapy or counseling for depression (outline)**
- 6. Treatment with psychotherapy or counseling**
- 7. Who provides counseling or psychotherapy?**
- 8. Working effectively in counseling or psychotherapy**
- 9. What are the results over time?**
- 10. How much does counseling or therapy cost?**
- 11. Tips to manage the cost of counseling or therapy (if there is a cost):**
- 12. What are the risks of therapy?**
- 13. Medication treatments section (outline)**
- 14. Medication treatments for depression**



- 15. How long till the medication starts to work?**
- 16. How long do you keep taking the medication?**
- 17. What happens when the medication is gradually reduced and eventually stopped?**
- 18. How much does medication treatment cost?**
- 19. Tips to manage the costs of medication treatment**
- 20. What are the common side effects of medication treatment?**
- 21. Tables: What are the common side effects of medication treatment?**
- 22. Long-term side effects**
- 23. Uncommon but serious side effects**
- 24. What about combining medication treatment and psychotherapy or counseling?**
- 25. Self-help treatments**

Appendix F: Outline for Study 1 Interviewees: Medications first:

## **Evaluating an Information Aid--Treatment Choices for Depression**

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- 1. What is depression?**
- 2. What are the risk factors for depression?**
- 3. What happens to depression without treatment?**
- 4. Treatments for depression**
- 5. Medication treatments section (outline)**
- 6. Medication treatments for depression**
- 7. How long till the medication starts to work?**
- 8. How long do you keep taking the medication?**
- 9. What happens when the medication is gradually reduced and eventually stopped?**
- 10. How much does medication treatment cost?**
- 11. Tips to manage the costs of medication treatment:**
- 12. What are the common side effects of medication treatment?**
- 13. Tables: What are the common side effects of medication treatment?**

- 14. Long-term side effects**
- 15. Uncommon but serious side effects**
- 16. Psychotherapy or counseling for depression (outline)**
- 17. Treatment with psychotherapy or counseling**
- 18. Who provides counseling or psychotherapy?**
- 19. Working effectively in counseling or psychotherapy**
- 20. What are the results over time?**
- 21. How much does counseling or therapy cost?**
- 22. Tips to manage the cost of counseling or therapy (if there is a cost):**
- 23. What are the risks of therapy?**
- 24. What about combining medication treatment and psychotherapy or counseling?**
- 25. Self-help treatments**

## Appendix G: Study 1 Decision Aid Content:

### Evaluating an Information Aid--Treatment Choices for Depression

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#### What is depression?

Feelings of sadness are a normal part of life. Our emotions are important because they help us understand and respond to important experiences and events in our life.

For many, however, there are times in life when feelings of sadness are so intense and last so long (two weeks or more) that they start to interfere with life. We refer to this problem as 'clinical depression', or, more simply put, 'depression'.

These are key characteristics of clinical depression that are present most of the day, nearly every day, for at least two weeks:

- Depressed mood and/or
- Greatly reduced interest or pleasure in most activities.

Additionally, several of these characteristics are present nearly every day:

- Decrease or increase in appetite compared to usual
- Sleeping much less or more than usual
- Having problems concentrating or making decisions
- Feeling extremely tired and weak, or feeling very low on energy
- Feeling worthless or guilty (not just guilt about feeling depressed)
- Feeling restless or slowed down – so much that other people notice it
- Thinking a lot about suicide and/or death (not just fear of death).

Other common experiences during periods of depression are:

- Increased irritability
- Decreased motivation
- Withdrawal from usual activities
- Feeling less interested in sex.

More than 1 in 20 people will have serious problems with depression in any year and 1 in 6 will cope with depression at some point in their lifetime.

Depression becomes more common during the teenage years and is especially common in young adult years when people are going through many life changes. Twice as many women as men experience problems with depression. It is a common problem throughout the adult years.

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## **What are the risk factors for depression?**

When a person has problems in one of the following areas, his/her risk of having depression increases. The more risk factors, the greater the risk of depression. It is important to know also that many people experience these risk factors and do not have problems with depression.

1. Family history: Many traits that make up who we are run in families, including positive traits such as good health and negative ones such as health problems. This is also true with depression. Men and women with many close relatives who have experienced depression are more likely to experience depression themselves. This does not mean that someone with a strong family history of depression is certain to have problems with depression. But it does tell us that there is an increased risk, especially when the person has other risk factors.

2. Stressful experiences during childhood can increase the risk for depression later in life, including:

- conflict in the home
- parents who are separated or divorced and the stress that may go along with this
- family stress such as a serious illness or death of a loved one
- a parent who struggles with depression or other emotional problem
- not being emotionally close to parent(s) or caregivers
- emotional, physical or sexual abuse.

3. Life stress during the adult years can lead to an increased risk for depression. Depression can be more likely if a person experiences a major loss such as:

- a break up in a relationship

- disruption in relationships with family and friends (for example, marital or family conflict)
- death or serious illness of someone close
- serious disappointment at work or school (for example, a lost job or a failed exam).

4. Chronic stresses such as financial pressure, long-term illness, excessive work, and conflict in relationships also increase the risk of depression.

5. Misuse of alcohol or other drugs: Frequent use of alcohol or recreational or illegal drugs is a risk factor for the development of depression.

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## **What happens to depression without treatment?**

Brief bouts of depression happen to many people, often when they are faced with stresses such as ending a relationship, losing a job, or having troubles solving a problem. Often, people can get over depression with their own coping approaches, especially if the depression does not go on for too many weeks. Some people prefer to handle their own problems without seeing a professional.

Research suggests that if people do not seek treatment for depression (which has lasted for at least two weeks), about 5 out of 10 will have recovered within three months of the start of the depression. 6 out of 10 people will have recovered within six months. However, for those who continue to experience depression beyond 6 months without treatment, recovery after this point is more limited. About 2 out of 10 people will still be depressed two years later.

It can be more difficult to overcome depression on your own if the depression goes on for many weeks, or if it seems severe and interferes with your everyday life. Depression is also more of a problem if you have had more than one period of depression over the years. In these situations, it can be very helpful to speak with someone about treatments for depression.

If you have repeated periods of depression over the years, treatment may reduce problems with depression in the future.

It is especially important to seek help if you start to feel hopeless, that life is not worth living, or if you have serious thoughts of ending your life.

There are many people you can speak to about depression, including your family doctor, another health care provider, a school counsellor, or a telephone help line.

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## **Treatments for depression**

People who receive treatments that are known to be effective usually see a great reduction in feelings of depression. They also see improvement in their quality of life, relationships, ability to work and be productive, and sense of health and well-being. While treatment involves time, cost and effort, most people who receive effective treatment find it very helpful.

The two approaches to treatment that have been most carefully studied and evaluated are:

- **Medication treatments**
- **Counseling or psychotherapy**

There are many medications available for the effective treatment of depression. The main groups are the anti-depressant medications and another group of medicines called mood stabilizers.

Counseling or psychotherapy is also effective in treating depression. In this approach, you work with a trained professional to develop strategies to overcome depression. Therapists often use aspects of more than one form of therapy to help their clients overcome depression. Some therapies shown to be effective with depression include:

- Cognitive behavior therapy (commonly referred to as CBT) focuses on understanding how thoughts and actions affect emotions
- Emotion-focused therapy identifies a person's emotional and self-critical patterns linked to depression
- Interpersonal therapy deals with problems in relationships that may be related to the development of depression
- Problem-solving therapy develops helpful approaches to understand and manage life problems
- Short-term psychodynamic therapy focuses on troubling feelings that stem from unresolved painful events.

More information is provided about medication and counseling/psychotherapy in the following pages.

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## **Psychotherapy or counseling for depression**

The following pages contain information about:

- Counseling or psychotherapy
- Who provides treatment for depression?
- Working effectively in counseling or therapy
- How long does treatment continue?
- What happens when therapy is completed?
- How much does counseling or therapy cost?
- What are the common risks of counseling or therapy?

## **Treatment with psychotherapy or counseling**

Counseling has been used for years and is a safe and effective form of treatment. Different professionals provide different forms of therapy, depending on their training and where they work. Treatment may be offered on an individual basis (you alone with a therapist) or group basis (you participate with a therapist along with others, who are all working to overcome problems with depression).

About 6 out of 10 people who will feel much less depressed after eight to 20 sessions of psychotherapy or counseling. If you do not feel better, talk to your therapist about making changes to the therapy approach. You may consider a different therapist or type of treatment (including medication).

**Confidentiality:** What you say to your therapist is kept between the two of you, and will not be shared with anyone else without your permission. Your therapist or counselor should explain the nature of confidentiality and its limits at the beginning of therapy.

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## **Who provides counseling or psychotherapy?**

Counseling or psychotherapy is provided by a range of professionals (described below) who provide different forms of treatment. Some counselors or therapists specialize in certain problems or work with specific groups of people (such as younger or older people). When you consider seeing someone, ask any questions that are important to you, such as:



- What is the training and experience of the person whom you will be seeing?
- What types of problems are treated?
- What is the cost of the service, if any?
- What approaches to treatment are used?
- How long does treatment usually last?
- What times are appointments scheduled?
- Is there a waiting list to be seen?

**Professionals who provide counseling or therapy (presented in alphabetical order):**

**Family doctors** typically have a bachelor's degree, plus four years training in medicine and two years of training in family medicine (Qualification: MD and Fellowship in Family Medicine, CCFP). Some family doctors have training in counseling and a few of them practice psychotherapy as a major part of their work. The amount of training they have in these areas varies. This work is usually covered by provincial health plans, so there is no cost.

**Nurses** have two to four years of training in nursing through a college or university (Qualification: R.N. or B.N. or R.P.N. for registered psychiatric nurse). Some have additional training in counseling or therapy or more advanced university training. Services by nurses are provided with no charge by some hospitals or community health services.

**Psychiatrists** usually have a bachelor's degree, plus four years of training as a medical doctor. After this, they take five years of specialized training in psychiatry, covering treatment of a range of different health and mental health problems with medication and/or psychotherapy (Qualification: MD and Fellowship in Psychiatry, FRCPC). Their work is covered by provincial health plans so there is no cost for these services. Many psychiatrists focus on assessment and consultation, where they see a patient for one or two sessions, then make recommendations for treatment to the family doctor.

**Psychologists** have a bachelor's degree plus six or seven years of graduate university training in psychology (Qualification: Ph.D. (doctorate) in Psychology [masters degree in a few provinces]; and registration as a psychologist [C.Psych.]). Specialized training in clinical, counseling, applied or educational psychology covers treatment of a range of different health and mental health problems with counseling or therapy. Services by psychologists are provided with no charge by some hospitals or community health services. Many psychologists

work in a private practice setting where there is a charge for the service. Psychology services are often partially covered by some extended health insurance plans.

**Social workers** have four (for bachelor's level) or six years (master's level) of training in social work and related fields (Qualification: B.S.W. or M.S.W.) Training often covers counseling or therapy with individuals, families, and groups with a range of health and mental health problems. Social work services are provided by some hospitals and many community agencies with no or minimal charge. Private social work services are partially covered by some extended health insurance plans.

**Therapists or counsellors.** This term is not regulated in most Canadian provinces so people with different kinds of background may use this term. Many have training in education, psychology, social work, marriage and family therapy, occupational therapy, or the clergy. Services by counsellors are provided with no charge by some hospitals or community health services. A small number of people practicing in this area have very limited training. Ask about the person's training and experience when arranging to see a counsellor or therapist. The province of Ontario is developing a College of Registered Psychotherapists and Mental Health Therapists that will register and regulate these groups in Ontario.

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## **Working effectively in counseling or psychotherapy**

### **What to expect in the first meeting:**

The first visit is a consultation meeting, when you and the therapist will get to know each other and plan for your work together. Your therapist may ask what brings you to therapy, your concerns, and any symptoms you experience and may ask you to complete some questionnaires.

Your therapist may want to learn about your background, including your childhood, education, work history, current relationships, and long term goals. Don't feel pressured to talk about topics that are uncomfortable for you. Opening up can be hard, and it may take time for you to trust your therapist. Your thoughts, feelings and experiences will help your therapist's understanding of your difficulties and how to best help you, so it is important that you feel comfortable enough to be open with your therapist and say what is on your mind.

A good "fit" with your therapist is key to successful therapy. Your first therapy

sessions are an opportunity for you to decide if his or her approach and personality will work for you. If, after two or three sessions, you do not feel comfortable or you don't feel you have a good working relationship with your therapist, it may be best to try someone else.

### **What to expect during the following meetings:**

The rest of therapy is devoted to helping you understand and resolve current difficulties, and help you achieve the changes you want. Therapy can be quite different, depending on the approach used by the therapist. Some will take a directive role, providing feedback on your progress, homework exercises to practice some of the techniques learned in therapy or suggestions of what he/she thinks might be helpful. Others will give you more space to draw your own conclusions and direct the course of therapy. Therapists may be willing to adapt their style to your needs, so it is important to discuss your preferences.

Improvement is faster if your therapist can understand and relate positively to you, and you can work together on goals you both agree on. A good therapist will guide and support you, and challenge you when you are ready to be challenged. It is normal to disagree with your therapist from time to time. When this happens, it is important to honestly share any feelings or concerns you have about how therapy is going. This will give your therapist a chance to address your needs and maximize the benefits you can receive from therapy.

Keep in mind that therapy is designed to equip you with long-term solutions rather than a quick fix. Any change in life involves time and effort. Your commitment to attend appointments regularly, courage to look at yourself honestly, and willingness to make some difficult changes in your life will be important assets.

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## **What are the results over time?**

### **How long does it take before therapy starts to work?**

Often people start to feel less depressed within the first few weeks of treatment. Many feel better once they know they are doing something to deal with their problem.

### **How long does therapy continue?**

The length of treatment depends on your situation, including the seriousness of your depression. Most people require eight to 20 treatment sessions in order to see great improvement. Sessions are usually started on a weekly basis, then spread over longer periods of time (for example, once every other week) to allow time between the sessions to work on the problem.

### **What happens when therapy is completed?**

Research tells us that the majority (about 3 out of 4) of those who improve while in treatment will stay improved after treatment is completed. However, about 1 out of 4 who experience an improvement with treatment will have the depression come back in the year after treatment ends. Some people may return for a few booster sessions months or years after treatment is completed, usually because of new challenges in life.

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### **How much does counseling or therapy cost?**

- Some therapy or counseling is provided at no cost through public agencies and health care facilities such as hospitals or primary care clinics.
- Services for students may be available through the special services available in most public schools (Grades 1 to 12) or the counseling services of most educational programs (colleges and universities).
- Counseling and therapy provided by family doctors and specialists in psychiatry are covered by the provincial health plan, so there is no charge for the service.
- Some community agencies provide services at no or low cost depending on income.
- Private services are available and are covered by some insurance plans. The cost for private counseling or therapy can range from \$50 to \$155 or more for a one-hour session.

**Employee Assistance Plans (EAPs):** Many large employers have EAPs that provide counseling or therapy for employees and their family members on a confidential basis. Often you can make an appointment within a week or two of the first contact. There is often no charge for the service, although the total number of sessions may be limited. Plans provide different numbers of sessions so ask about this at the start. EAP staff comes from a variety of different professional groups, so ask about the counselor's qualifications and experience with the problems you are concerned about.

**Supplemental health insurance:** Many families have coverage for psychology services (and in some cases other types of counseling or therapy services) through supplementary health insurance plans they have through work or school.

Dependent and unmarried young adults may be covered by a parent's plan until age 21 or until age 25 if they are full time students. Children who became disabled before age 21 (or before age 25 if in full time studies) may be covered for a longer period. Young people may be covered by both parent's plans. Many plans require a referral from a physician (such as a family doctor) and will not pay if there is no referral before services are provided. Coverage differs from plan to plan so check your plan brochure or the plan website to find coverage details.

As an example, some plans cover a percentage (often 80% to 100%) of the cost of therapy up to a specified limit. Coverage can be as little as \$300 and as much as \$1000 per year.

Health care spending accounts: Some employers provide these accounts, covering a range of health services, including counseling and therapy, by qualified practitioners. If you have a plan, be sure to check the amount of coverage and what is covered.

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### **Tips to manage the cost of counseling or therapy (if there is a cost):**

- Ask about managing the cost. A well-trained professional will be happy to help you to manage the cost of treatment.
- Don't wait for a crisis: Many problems respond more quickly if you catch them early and at a time when you are not in crisis. If you notice a problem limits your happiness and success, or holds you back in life, planning ahead to deal with it can allow you to take advantage of insurance coverage or services with lower or no cost. Examples of problems that can lead to depression are: ongoing problems with worry, nervousness, or anxiety; recurring problems in relationships; troubles finishing your work; and problems with periods of low mood.
- There are excellent books available about depression (including those discussed in the self-help section that follows) that may allow you to work on the problem more quickly.
- Devote the time to work on homework between sessions to reduce the number of sessions required.

- Once treatment has the desired effect, appointments can be spread out to reduce the costs. It may also be possible to schedule briefer appointments or telephone appointments.
  - Inquire about charges for missed or cancelled appointments. If you have to miss an appointment, be sure to call as soon as you know.
  - Payment: Some therapists require payment at the time you are seen; others will bill your insurance plan directly. Methods of payment may be cash, cheque, credit card or debit card.
  - Plan when to use insurance coverage. If you don't use your coverage for this year, it won't carry over to the next year.
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## **What are the risks of therapy?**

Each treatment that is widely used for depression has benefits and risks. Most people who seek psychotherapy or counseling for problems with depression improve, and those who improve usually feel that the benefits outweigh the risks. However, 1 out of 10 people will experience a worsening of their condition when they are having counseling or therapy. For some, this is a result of their problem worsening (unrelated to the treatment). For others, the deterioration is related to the therapy or the therapist they are seeing.

If your depression is getting worse or not improving after a reasonable time, be sure to discuss this with your therapist. You may benefit from a change to another therapist, another form of therapy, or to a medication treatment.

Persistence is important. If you try a treatment, it is important to stick with it to allow time to see if it helps. If you do not benefit from the first treatment you try, there is still a good chance your problem will respond to a different treatment.

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## **Medication treatments section**

The following pages contain information about:

- Medication treatment for depression
- How long does it take for the medication to work?
- How long should you keep taking the medication?

- What happens when the medication is gradually reduced and eventually stopped?
- How much does medication treatment cost?
- What are the common risks or side effects of medication treatment?

## **Medication treatments for depression**

Medication has been used for many years and is generally safe and effective. The medications used for depression are called antidepressants, and are also used for several other health problems. The medication is usually taken at least once a day — it is important to not miss any doses. Most people are treated by their family doctor.

Typically, after assessing the problem and your general health, your doctor will start you on a low dose of medication. This dosage is gradually increased over a period of several weeks, while you and your doctor watch for signs that the medication is starting to help with depression. You both also watch to ensure the medication is not causing undesirable side effects.

A “therapeutic dose” refers to the point when the dosage is increased enough to produce a marked improvement in depression. The therapeutic dose differs among people. There is no advantage to staying at a low dose if the medicine does not produce improvement. In fact, many people whose symptoms do not improve with a medication will show improvement if the doctor prescribes a higher dose. It usually takes three weeks on a therapeutic dose to see real improvement for symptoms of depression, so it is important to continue with treatment, even if you do not notice much change at first.

About 6 out of 10 people notice that they feel a lot less depressed on the first medication they try. If there is not improvement, sometimes the solution is a different medication or adding a second medication to make the first medication work better.

If it is hard to find a medication that helps, your family doctor may refer you to psychiatrist, who can talk to you about your depression and give advice about other medications and other treatment options.

---

## **How long till the medication starts to work?**

You will need to take your medication for at least two to three weeks to notice some improvement. The dose may have to be increased several times over a period of weeks to reach a therapeutic dose. You may need to be at the therapeutic dose level for four weeks or more to notice the maximum level of improvement.

## **How long do you keep taking the medication?**

It is generally recommended that you continue on the treatment at the therapeutic dose for at least 12 months once you have found that your depression is much better.

If the problem has been a difficult one and you have had difficulty with depression over a number of periods in your life, the doctor may recommend that you stay on the medication for a longer period or even indefinitely. Medications for depression are generally safe when used over long periods, and most people who stay on the treatment continue to feel a lot less depressed.

It is important to stay with the therapeutic dose — don't reduce the dose once you feel better. Reducing the dose often results in the depression returning.

For problems with depression, a rough guideline is to continue on the medication treatment for the following times after you are feeling well:

- One year if there has been one episode of depression. (An "episode" is a period of time in your life.)
- Two years if there have been two episodes
- Indefinitely if there have been three episodes or more.

If you are considering reducing the dose or stopping the medicine it is important to discuss your preferences with the doctor prescribing the medicine. Your doctor may have some helpful advice about this.

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## **What happens when the medication is gradually reduced and eventually stopped?**

If you want to stop your medication, it is important to discuss this decision with your doctor and not stop the treatment suddenly. Doctors recommend that you gradually reduce the treatment over a period of weeks or months. It is best to choose a period of lower stress in life when there are not a lot of changes going on (including positive changes such as a new job or a new relationship) so that if your depression returns, it is not too hard to handle.

Some people who suddenly stop taking their medication experience symptoms such as anxiety, headache, flu-like symptoms, shock-like sensations down the arms or neck, and stomach distress. These symptoms may begin 24 hours after a medication has been reduced or stopped and can last five to seven days. These symptoms may occur less frequently if medication is reduced gradually. While these symptoms are uncomfortable, they are not harmful.

When medication is stopped, there is a risk of the depression symptoms coming back over the following months. Of those who improve with treatment, about half (5 out of 10) will see a return of their depression symptoms in the months after their medication is stopped.

Some people get counseling or therapy at the same time as medication treatment. These people may have less difficulty with the depression symptoms rebounding when the medication is stopped.

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## **How much does medication treatment cost?**

Medications used to treat depression range in cost from \$30 to \$200 per month. Your family doctor or pharmacist will be able to provide more information about the costs of different medications and about coverage through provincial health plans.

### **Insurance coverage for medication costs:**

The provincial drug plan and private insurance plans may cover part or all of your medication costs. These plans usually have a deductible that you must pay before your coverage starts, and some have a maximum dispensing fee that they will cover and then the patient pays the remainder. Most medicines are covered by

insurance, but newer medicines may not be. Your doctor or pharmacist will be able to tell you if a medication is covered by your insurance plan. Private plans usually cover the same medicines as provincial plans do, but this may not always be the case.

**Provincial health plans:** All Canadian provinces and territories have public plans that cover some of the costs of medications for qualified persons. Manitoba's Pharmacare plan will pay 100 percent of eligible prescription drug expenses after the family pays a yearly deductible amount. The deductible depends on total family income as declared on income tax forms. As examples, with a total family income of \$20,000, the yearly deductible is \$273; for \$30,000 it is \$774; and for \$40,000 it is \$1,284. The minimum deductible is \$100. If a family has high medication costs and the deductible is a financial problem, arrangements can be made to pay the deductible in monthly instalments. After they turn 18, young adults are considered to be on their own and their eligibility is calculated based on their income and drug expenses. Details about the plan are available on the Manitoba Health website or through pharmacies. All approved prescribed drugs are covered for persons receiving Employment/Income Assistance.

**Brand name and generic drugs:** Brand name drugs are produced by the company that developed that drug and are generally more costly. Once a drug has been available for a number of years, it may be reproduced by a generic brand company. Generic brands have the same composition for the active ingredient but may have different components for other ingredients (like coloring or binding agents). Generic brands are generally less costly.

**Supplemental health insurance:** Many families have coverage for medications through supplementary health insurance plans offered through work or school. Many plans require you to pay a portion of the total prescription cost or a set deductible amount. Dependents and unmarried young adults may be covered by a parent's plan until age 21 or until age 25 if they are full-time students. Some plans only cover the generic version of a drug if the generic form is available. Some newer medicines may not be covered. Coverage differs from plan to plan so it is wise to check the plan brochure or the information on the plan's website to find the insurance coverage details.

As an example only, one widely-used plan in Manitoba covers 80 percent of the first \$375 of eligible medication expenses and 50 percent of the next \$300 to a maximum of \$450 per year (for the whole family). Unmarried dependent children up to age 21 and up to age 25 if they are full time students are covered. Children

who became disabled before age 21 (or before age 25 if in full time studies) may be covered for a longer period. This may vary from plan to plan.

**Health care spending accounts:** Some employers provide these accounts, which cover a wide range of health services, including medication costs not covered by other insurance. If you have a plan, be sure to check what is covered and the amount of coverage.

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### **Tips to manage the costs of medication treatment:**

- **Ask your doctor or pharmacist about the cost:** There are a variety of medications available for most problems. Ask your doctor and pharmacist about the cost and advantages of different medicines, especially if you do not have insurance coverage. Most doctors are quite happy to answer your questions about the cost of treatment.
- **Be careful about sample packages from your doctor:** Be aware that the sample packages of medication you may receive from your doctor as a "starter dose" are usually for newer, more expensive medicines. Newer medications are often more costly than older ones, and they are often no more effective. Some newer medications are not covered by insurance plans. Starting with such a sample medicine may lead to taking a more costly medicine over a long period of time. Switching to a less costly medicine is possible, but this takes extra time and there is a risk of having more symptoms while you switch medications. Therefore, it is usually less expensive to pay for a medicine right from the start, rather than beginning on a more expensive medication through sample packs from your doctor.
- **Use one pharmacy consistently:** There is an advantage here because your pharmacy has a record of the medicines that you are taking.
- **Check the cost of dispensing fees:** Pharmacies charge a dispensing fee for each prescription. This pays for the services the pharmacy provides, including keeping records, preparing the prescription, and providing advice about the medicine, other medicines you may be taking, and your health. Dispensing fees and mark-up costs can vary considerably between pharmacies. In Manitoba, dispensing fees usually range from \$4.49 to \$12.99. Check the dispensing fee by visiting or phoning the pharmacy.

- **Arrange the prescription for a three-month period:** Once you have taken a medicine for a while, are on a stable dose, and find it helpful, you can reduce the cost of the dispensing fee by asking your doctor to write a prescription covering a longer period. Usually the longest period supported by insurance plans is about three months (90 to 100 days). The dispensing fee is usually the same whether you get a prescription for three weeks or three months of medication.

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## **What are the common side effects of medication treatment?**

When considering treatment, many people want to know about possible side effects. Every treatment has advantages and disadvantages.

If you look at possible side effects of common medicines such as Aspirin or Tylenol, the list of potential side effects is long. Some people worry about side effects so much they avoid taking treatments that could really help them. Keep in mind that a wide range of medications are used in health care, with many beneficial effects and limited problems with side effects.

Still, it is helpful to have information about any possible side effects when making decisions about treatment choices. Side effects vary depending on the medication, its dose and treatment duration, and how quickly the dose is increased or decreased. Other factors such as age, sex, health and the use of other medications can also influence side effects. Side effects are one factor that doctors and patients consider in choosing the best medicine.

The sections that follow have information about early side effects, longer term side effects, and uncommon but serious side effects. The side effects that are most important vary depending on each situation and health status. The information provided here is general in nature. More specific information is available from your family doctor or pharmacist.

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## **Tables: What are the common side effects of medication treatment?**

### **Early side effects:**

Some side effects may start shortly after starting a medication. Many of these may decrease or stop after you have been taking the medication for a few weeks. Others

may go away only when you stop taking the medicine or reduce the dosage. About 6 out of 10 people will experience at least one side effect. Your doctor may be able to suggest ways to manage side effects. Common side effects of the most widely-used medications for treatment of depression and anxiety are shown in the following two tables. Information about other medicines used for treatment of depression and their side effects may be obtained from your family doctor or psychiatrist.

**Table 1A: Common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Less than 1 out of 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect				
	Nausea	Diarrhea	Constipation	Dry Mouth	Sweating
<b>SSRI Group</b>					
citalopram (Celexa)	■■	■	-	■■	■■
escitalopram (Ciprolex)	■■	■	■	■	■
fluoxetine (Prozac)	■■	-	-	■■	■
fluvoxamine (Luvox)	■■■	■	■■	■■	■■
paroxetine (Paxil)	■■	■■	■■	■■	■■
sertraline (Zoloft)	■■■	■■	■	■■	■
<b>SNRI Group</b>					

venlafaxine (Effexor)	■■■	■	■■	■■	■■
desvenlafaxine (Pristiq)	■■	■■	■	■■	■■
duloxetine (Cymbalta)	■■■	■	■■	■■	■
<b>Other antidepressants</b>					
bupropion (Wellbutrin)	■■	-	■■	■■	■
mirtazapine (Remeron)	-	-	■■	■■	-

Note: SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

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**Table 1B: Other common side effects of antidepressant medications.**

Medication	Side Effect				
	Daytime sleepiness	Trouble sleeping	Headache	Shakiness	Dizziness
<b>SSRI Group</b>					
citalopram (Celexa)	■■	-	-	■	-
escitalopram (Ciprolex)	■■	-	-	■	■
fluoxetine (Prozac)	■■	■■	-	■■	-
fluvoxamine (Luvox)	■■■	■■	■■■	■■	■■
paroxetine (Paxil)	■■	■■	■■	■	■■
sertraline (Zoloft)	■■	■■	■■■	■■	■■
<b>SNRI Group</b>					
venlafaxine (Effexor)	■■	■■	■■	■	■■
desvenlafaxine (Pristiq)	■	■■	■■	■	■■

duloxetine (Cymbalta)	■	■■	■	■	■
<b>Other antidepressants</b>					
bupropion (Wellbutrin)	-	■■	-	■	■
mirtazapine (Remeron)	■■■■	-	-	■	■

Note: Tables adapted from RW Lam, SH Kennedy, S Grigoriadis, RS McIntyre, R Milev, R Ramasubbu, SV Parikh, SB Patten, AV avindran. Canadian Network for Mood and Anxiety Treatments (CANMAT) Clinical guidelines for the management of major depressive disorder in adults. III. Pharmacotherapy, Journal of Affective Disorders 117 (2009) S26–S43. SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

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## **Long-term side effects**

Two longer-term side effects are common with anti-depressant medications: sexual problems and weight gain. These are more problematic with some medications than others.

- **Sexual side effects:** There is often already a reduction in sexual functioning when people experience depression, but reduced sexual function is also a side effect of many antidepressants. Sexual interest, ability to become aroused and ability to have an orgasm may be affected. About 2 out of 10 people who take antidepressant medications report sexual side effects. More problems with sexual side effects are reported with paroxetine (Paxil), while fewer problems are reported with bupropion (Wellbutrin).

- **Weight gain:** For many of the medications in this group, weight gain comes later in treatment. There may even be weight loss early in treatment, then weight gain later in treatment. More problems with weight gain are reported with mirtazapine (Remeron) and paroxetine (Paxil) than most of the other medications in this group. Fewer problems are reported with bupropion (Wellbutrin).

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## **Uncommon but serious side effects**

- **Drug Interactions:** Serious effects can occur if you take these antidepressants with other medicines that affect some of the same body systems. It is important to tell your doctor all of the medicines you are taking, including any herbal or natural medicines (such as St. John's Wort or tryptophan). If you consider starting another medicine, tell the doctor before starting it to see if there are possible drug interactions with the new medicine. Medicines that may interact with antidepressants include other antidepressants, some migraine medicines, some prescription pain medicines, and some over-the-counter cough medicines. Your doctor or a pharmacist can provide information about drug interactions.
- **Suicidal thoughts:** Persons struggling with depression sometimes experience thoughts of suicide. There was considerable concern in the year 2000, when researchers in a study of depression treatment noted that adolescents and young adults reported thoughts of suicide more often once they began taking an antidepressant medication. Problems with these thoughts occurred in 8 out of 100 people as compared to 4 out of 100 people who took a placebo (a pill with no medication). This problem was evaluated intensively, and it turned out that while there was a higher number reporting suicidal thoughts, there was not a higher rate of suicide attempts or completed suicide. Recent research indicates that treatment with antidepressant medication reduces the rate of suicide attempts. Nevertheless, it is important to keep track of any increase in thoughts of suicide and seek extra support if this occurs.
- **Excessively high mood:** Occasionally, people who take an antidepressant can experience a fairly sudden change in their mood. The depression may be replaced by a feeling of higher than normal energy, with rapid thoughts and higher than normal mood or irritability. If this change occurs, it should be assessed by a professional as soon as possible, and the treatment may be changed. People with higher than normal mood may make decisions and take actions that can be harmful to themselves and the people around them.

### **Alcohol**

When you are taking these medications, it is a good idea to avoid using alcohol or to use very little alcohol. Heavy alcohol use is a risk factor for anxiety and depression. The use of any alcohol reduces the ability to drive safely and when mixed with anti-depressants the risk of unsafe driving is higher.



**Allergic reaction**

There is a small chance of an allergic response to any new medication. Common symptoms include a skin rash. If this happens, speak to your doctor before taking any more of the medicine.

**The importance of persistence**

Most people who keep taking their medication until they have been at a therapeutic dose for a few weeks find the medication helps with their depression. If you try a medication, it is important to stick with it to allow enough time to see if it is helpful. When a medication is effective, it is usually continued for at least 12 months. See the section on duration of treatment for more information.

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**What about combining medication treatment and psychotherapy or counseling?**

Medication treatment and treatment with counseling or psychotherapy are effective for depression in most people when they are used alone (not combined). So, many people do well with just one type of treatment.

Combined medication and therapy may be effective in a somewhat larger proportion of people. It is not known at this time whether combined treatment is more effective in the long term if the medication is stopped.

There are advantages if you choose the single treatment you prefer (and is available) first. Taking one treatment at a time is simpler and less costly. One advantage of trying one treatment at a time is that when there is improvement, it will be clear which treatment led to the improvement. If you don't see enough improvement after trying the first treatment for the recommended time, you may find better results by adding the other form of treatment.

If you prefer combined treatment from the start, this can be arranged.

When people gradually reduce and stop medication, especially if they have had a number of periods of depression over the years, there is a risk the depression will return over the following months. Receiving psychotherapy focused on reducing the risk of relapse lowers this risk for some people, especially those who continue to have some symptoms of depression.

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## **Self-help treatments**

Some people prefer to manage problems with depression on their own if they can. There are a number of books and websites that you can use on your own or with a therapist's or counselor's help. Well-designed self-help materials can be helpful for problems with depression especially if you work through the program a step at a time. Self-help materials may also provide more information about the treatments that are available.

Working on depression without any outside help, however, does not benefit as many people as treatment involving professional help and guidance. Self-help programs that involve an assessment of the problem at the start (by a professional or by a web-based program) and some level of follow up have been found to be more effective even if the professional is not directly involved in providing treatment. We are not sure why, but it may be that the process of an assessment and some follow-up contact creates more commitment to the program.

Self-help programs can be combined with therapy and medication treatments.

In some parts of the country there are self-help groups which provide very useful help also. One way to find out about the programs available is to contact the provincial mood disorders association ([www.depression.mb.ca](http://www.depression.mb.ca)).

If you are having thoughts suicide or of harming yourself it is important to seek professional help.

### **Helpful books:**

*Feeling Good: The New Mood Therapy.* By D. Burns. (1999). New York: Avon.

*Mind Over Mood: A Cognitive Therapy Treatment Manual for Clients.* By D. Greenberger, & C.A. Padesky. (1995). New York: Guilford Press.

*Your Depression Map: Find the Source of Your Depression and Chart Your Own Recovery.* By Randy J. Patterson (2002). Oakland, CA: New Harbinger Press.

### **Web-based help:**

<http://moodgym.anu.edu.au/welcome> - This Australian website for depression has been evaluated in more research than any other web program available.

<http://www.depressioncenter.net/Default.aspx> - This Canadian website has an extensive program for depression.

[www.myselfhelp.com](http://www.myselfhelp.com) – This U.S. website is well-designed and available for a small monthly fee. Programs are available for depression, stress, insomnia, eating disorders, self-esteem, guilt, and grief.

[www.changeways.com](http://www.changeways.com) - Click on “self-care depression program” to access this Canadian website with its well-developed program.

**Thank-you!**

**Appendix H: Study 2 Decision Aid Content:**

***What is depression?***

**Feelings of sadness are a normal part of life. Our emotions are important because they help us understand and respond to important experiences and events in our life.**

**For many people, however, there are times in life when feelings of sadness are so intense and last so long (two weeks or more) that they start to interfere with life. We refer to this problem as 'clinical depression', or, more simply put, 'depression'.**

**These are key characteristics of clinical depression that are present most of the day, nearly every day, for at least two weeks:**

- **Depressed mood and/or**
- **Greatly reduced interest or pleasure in most activities.**

**Additionally, several of these characteristics are present nearly every day:**

- **Decrease or increase in appetite compared to usual**
- **Sleeping much less or more than usual**
- **Having problems concentrating or making decisions**
- **Feeling extremely tired and weak, or feeling very low on energy**
- **Feeling worthless or guilty (not just guilt about feeling depressed)**
- **Feeling restless or slowed down - so much that other people notice it**
- **Thinking a lot about suicide and/or death (not just fear of death).**

**Other common experiences during periods of depression are:**

- **Increased irritability**
- **Decreased motivation**
- **Withdrawal from usual activities**
- **Feeling less interested in sex.**

**More than 1 in 20 people will have serious problems with depression in any year and 1 in 6 will cope with depression at some point in their lifetime.**

**Depression becomes more common during the teenage years and is especially common in young adult years when people are going through many life changes. Twice as many women as men report problems with depression. It is a common problem throughout the adult years.**

**Reference(s):**

**American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders*. (4<sup>th</sup> ed. Text revision). Washington, D.C.: Author.**

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### ***What are the risk factors for depression?***

**When a person has problems in one of the following areas, his/her risk of having depression increases. The more risk factors, the greater the risk of depression. It is important to know also that many people experience these risk factors and do not have problems with depression. Others have no risk factors and still have problems with depression.**

**1. Family history: Many traits that make up who we are run in families, including positive traits such as good health and negative ones such as health problems. This is also true with depression. Men and women with many close relatives who have experienced depression are more likely to experience depression themselves. This does not mean that someone with a strong family history of depression is certain to have problems with depression. But it does tell us that there is an increased risk, especially when the person has other risk factors.**

**2. Stressful experiences during childhood can increase the risk for depression later in life, including:**

- **conflict in the home**
- **parents who are separated or divorced and the stress that may go along with this**
- **family stress such as a serious illness or death of a loved one**
- **a parent who struggles with depression or other emotional problem**
- **not being emotionally close to parent(s) or caregivers**
- **emotional, physical or sexual abuse.**

**3. Life stress during the adult years can lead to an increased risk for depression. Depression can be more likely if a person has events such as:**

- **a break up in a relationship**
- **disruption in relationships with family and friends (for example, marital or family conflict)**
- **death or serious illness of someone close**
- **a traumatic experience such as being injured in an accident, assaulted, or seeing a very upsetting event**
- **a difficult health problem**
- **serious disappointment at work or school (for example, a lost job or a failed exam)**
- **difficulty achieving important goals in life such as satisfying relationships and satisfying activities.**

**4. Chronic stresses such as financial pressure, long-term illness, excessive work, and conflict in relationships also increase the risk of depression.**

**5. Misuse of alcohol or other drugs: Use of alcohol or recreational or illegal drugs is a risk factor for the development of depression and other problems such as anxiety. Frequent use of alcohol or drugs increases the risk.**

**Reference(s):**

**Kendler, K.S., & Prescott, C.A. (2007). Genes, Environment, and Psychopathology: Understanding the Causes of Psychiatric and Substance Use Disorders. New York: Guilford Press.**

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### ***What happens to depression without treatment ?***

**Brief bouts of depression happen to many people, often when they are faced with stresses such as ending a relationship, losing a job, or having troubles solving a problem. Often, people can get over depression with their own coping approaches, especially if the depression does not go on for too many weeks. Some people prefer to handle their own problems without seeing a professional.**

**Research suggests that if people do not seek treatment for depression (which has lasted for at least two weeks):**

- About 5 out of 10 will have recovered within three months of the start of the depression.**
- 6 out of 10 people will have recovered within six months.**
- However, for those who continue to experience depression beyond 6 months without treatment, recovery after this point is more limited.**
- About 2 out of 10 people will still be depressed two years later.**

**It can be more difficult to overcome depression on your own if the depression goes on for many weeks, or if it seems severe and interferes with your everyday life. It is usually better to get help early rather than waiting until the problem has gone on for a long time. This reduces the chance of more serious problems developing.**

**Depression is also more of a problem if you have had more than one period of depression over the years. In these situations, it can be very helpful to speak with someone about treatments for depression.**

**If you have repeated periods of depression over the years, treatment may reduce problems with depression in the future.**

**It is especially important to seek help if you start to feel hopeless, that life is not worth living, or if you have serious thoughts of ending your life.**

**There are many people you can speak to about depression, including your family doctor, another health care provider, a school counsellor, someone with the Mood Disorders Association or a telephone help line. It can be difficult to speak**

to someone about personal problems, but many people are familiar with depression and how to get help.

**Reference(s):**

**Patten, S. B., Wang, J. L., Williams, J. V. A., Lavorato, D. H., Khaled, S. M., & Bulloch, A. G. M. (2010). Predictors of the longitudinal course of major depression in a canadian population sample. *The Canadian Journal of Psychiatry / La Revue Canadienne De Psychiatrie*, 55(10), 669-676.**

**Posternak, M. A., Solomon, D. A., Leon, A. C., Mueller, T. I., Shea, M. T., Endicott, J., & Keller, M. B. (2006). The naturalistic course of unipolar major depression in the absence of somatic therapy. *Journal of Nervous and Mental Disease*, 194(5), 324-329.**

**Spijker, J., De Graaf, R., Bijl, R. V., Beekman, A. T. F., Ormel, J., & Nolen, W. A. (2002). Duration of major depressive episodes in the general population: Results from the netherlands mental health survey and incidence study (NEMESIS). *The British Journal of Psychiatry*, 181(3), 208-213.**

### ***Treatments for depression***

**People who receive treatments that are known to be effective usually see a great reduction in feelings of depression. They also see improvement in their quality of life, relationships, ability to work and be productive, and sense of health and well-being. While treatment involves time, cost and effort, most people who receive effective treatment find it very helpful.**

**The two approaches to treatment that have been most carefully studied and evaluated are:**

- **Medication treatments**
- **Counseling or psychotherapy**

**There are many medications available for the effective treatment of depression. The main groups are the anti-depressant medications and another group of medicines called mood stabilizers.**

**Counseling or psychotherapy is also effective in treating depression. In this approach, you work with a trained professional to develop strategies to overcome**



depression. Therapists often use aspects of more than one form of therapy to help their clients overcome depression. Some therapies shown to be effective with depression include:

- Cognitive behavior therapy (commonly referred to as CBT) focuses on understanding how thoughts and actions affect emotions
- Emotion-focused therapy identifies a person's emotional and self-critical patterns linked to depression
- Interpersonal therapy deals with problems in relationships that may be related to the development of depression
- Problem-solving therapy develops helpful approaches to understand and manage life problems
- Short-term psychodynamic therapy focuses on troubling feelings that stem from unresolved painful events.

More information is provided about medication and counseling/psychotherapy in the following pages.

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### *Medication treatments section*

The following pages contain information about:

- Medication treatment for depression
- How long does it take for the medication to work?
- How long should you keep taking the medication?
- What happens when the medication is gradually reduced and eventually stopped?
- How much does medication treatment cost?
- What are the common risks or side effects of medication treatment?

### Medication treatments for depression

Medication has been used for many years and is generally safe and effective. The medications used for depression are called antidepressants, and are also used for several other health problems. The medication is usually taken at least once a

day — it is important to not miss any doses. Most people are treated by their family doctor.

Typically, after assessing the problem and your general health, your doctor will start you on a low dose of medication. This dosage is gradually increased over a period of several weeks, while you and your doctor watch for signs that the medication is starting to help with depression. You both also watch to ensure the medication is not causing undesirable side effects.

The therapeutic dose refers to the point when the dosage is increased enough to produce a marked improvement in depression. The therapeutic dose differs among people. There is no advantage to staying at a low dose if the medicine does not produce improvement. In fact, many people whose symptoms do not improve with a medication will show improvement if the doctor prescribes a higher dose. It usually takes three weeks on a therapeutic dose to see real improvement for symptoms of depression, so it is important to continue with treatment, even if you do not notice much change at first.

About 6 out of 10 people notice that they feel a lot less depressed on the first medication they try. If there is not improvement, sometimes the solution is a different medication or adding a second medication to make the first medication work better. It is important to stick with it until you find a treatment that helps.

If it is hard to find a medication that helps, your family doctor may refer you to psychiatrist, who can talk to you about your depression and give advice about other medications and other treatment options.

**Reference(s):**

Anderson, I. M., Ferrier, I. N., Baldwin, R. C., Cowen, P. J., Howard, L., Lewis, G., et al. (2008). Evidence-based guidelines for treating depressive disorders with antidepressants: A revision of the 2000 British Association for Psychopharmacology guidelines. *Journal of psychopharmacology (Oxford, England)*, 22(4), 343-96.

National Institute for Health and Clinical Excellence (NICE). (2009). *Depression: The treatment and management of depression in adults – National clinical practice guideline*. London: Author.

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### ***How long till the medication starts to work?***

**You will need to take your medication for at least two to three weeks to notice some improvement. The dose may have to be increased several times over a period of weeks to reach a therapeutic dose. You may need to be at the therapeutic dose level for four weeks or more to notice the maximum level of improvement.**

### **The importance of persistence**

**Most people who keep taking their medication until they have been at a therapeutic dose for a few weeks find the medication helps with their depression. If you try a medication, it is important to stick with it to allow enough time to see if it is helpful. If you are not sure if the medicine is working, it is best to speak to your doctor about this.**

### **How long do you keep taking the medication?**

**It is generally recommended that you continue on the treatment at the therapeutic dose for at least 12 months once you have found that your depression is much better.**

**If the problem has been a difficult one and you have had difficulty with depression over a number of periods in your life, the doctor may recommend that you stay on the medication for a longer period or even indefinitely. Medications for depression are generally safe when used over long periods, and most people who stay on the treatment continue to feel a lot less depressed. It is important to stay with the therapeutic dose — don't reduce the dose once you feel better. Reducing the dose often results in the depression returning.**

**For problems with depression, a rough guideline is to continue on the medication treatment for the following times after you are feeling well:**

- **One year if there has been one episode of depression. (An "episode" is a period of time in your life.)**
- **Two years if there have been two episodes**
- **Indefinitely if there have been three episodes or more.**

**If you are considering reducing the dose or stopping the medicine it is important to discuss your preferences with the doctor prescribing the medicine. Your doctor may have some helpful advice about this.**

**Reference(s):**

**Anderson, I. M., Ferrier, I. N., Baldwin, R. C., Cowen, P. J., Howard, L., Lewis, G., et al. (2008). Evidence-based guidelines for treating depressive disorders with antidepressants: A revision of the 2000 British Association for Psychopharmacology guidelines. *Journal of psychopharmacology (Oxford, England)*, 22(4), 343-96.**

**Bockting, C. L. H., Spinhoven, P., Koeter, M. W. J., Wouters, L. F., & Schene, A. H. (2006). Prediction of recurrence in recurrent depression and the influence of consecutive episodes on vulnerability for depression: A 2-year prospective study. *Journal of Clinical Psychiatry*, 67(5), 747-755.**

**National Institute for Health and Clinical Excellence (NICE). (2009). *Depression: The treatment and management of depression in adults – National clinical practice guideline*. London: Author.**

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***What happens when the medication is gradually reduced and eventually stopped?***

**If you want to stop your medication, it is important to discuss this decision with your doctor and not stop the treatment suddenly. Your doctor may be able to recommend how long you should continue the treatment.**

- **If you decide to stop your medication, doctors usually recommend that you gradually reduce the medication over a period of weeks or months.**
- **It is best to choose a period of lower stress in life when there are not a lot of changes going on (including positive changes such as a new job or a new relationship) so that if your depression returns, it is not too hard to handle.**
- **Some people who suddenly stop taking their medication experience symptoms such as anxiety, headache, flu-like symptoms, shock-like sensations down the arms or neck, and stomach distress. These symptoms may begin 24 hours after a medication has been reduced or stopped and can last five to seven days.**

- These symptoms may occur less frequently if medication is reduced gradually. While these symptoms are uncomfortable, they are not harmful.

Most people see considerable improvement with treatment. Those who have no or minimal symptoms of depression at the end of treatment are most likely to maintain this progress if they stop the treatment.

- When medication is stopped, there is a risk of the depression symptoms coming back over the following months and years.
  - The risk is greatest for those with repeated periods of depression in the past.
  - Of those who improve with treatment, about half (5 out of 10) will see a return of their depression symptoms in the year after their medication is stopped.
  - There continues to be a risk of the return of depression over the following months and years.
  - Some people get counseling or therapy at the same time as medication treatment. These people may have less difficulty with the depression symptoms returning when the medication is stopped.
  - Having some counselling around the time that you are coming off the medicine, focused on preventing depression and dealing with any symptoms of depression that return, may be helpful.
- *If you find that symptoms of depression are returning, it is important to see someone for help with this quickly (possibly the person who helped you before). Starting a treatment again may reduce the amount of interference caused by depression and help you to overcome any problems caused by depression.*

**Reference(s):**

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- Fava, G., Rafanelli, C., Grandi, S., Canestrari, R., & Morphy, M. A. (1998b). Six-year outcome for cognitive behavioural treatment of residual symptoms in major depression. *American Journal of Psychiatry, 155*(10), 1443-1445.
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### ***How much does medication treatment cost?***

Medications used to treat depression range in cost from \$30 to \$200 per month. Your family doctor or pharmacist will be able to provide more information about the costs of different medications and about coverage through provincial health plans.

#### **Insurance coverage for medication costs:**

The provincial drug plan and private insurance plans may cover part or all of your medication costs.

- These plans usually have a deductible that you must pay before your coverage starts, and some have a maximum dispensing fee that they will cover and then the patient pays the remainder.
- Most medicines are covered by insurance, but newer medicines may not be.
- Your doctor or pharmacist will be able to tell you if a medication is covered by your insurance plan.
- Private plans usually cover the same medicines as provincial plans do, but this may not always be the case.

**Provincial health plans:** All Canadian provinces and territories have public plans that cover some of the costs of medications for qualified persons.

- Manitoba's Pharmacare plan will pay 100 percent of eligible prescription drug expenses after the family pays a yearly deductible amount.
- The deductible depends on total family income as declared on income tax forms. As examples, with a total family income of \$20,000, the yearly deductible is \$273; for \$30,000 it is \$774; and for \$40,000 it is \$1,284. The minimum deductible is \$100.
- If a family has high medication costs and the deductible is a financial problem, arrangements can be made to pay the deductible in monthly instalments.
- After they turn 18, young adults are considered to be on their own and their eligibility is calculated based on their income and drug expenses.
- Details about the plan are available on the Manitoba Health website or through pharmacies.

- All approved prescribed drugs are covered for persons receiving Employment/Income Assistance (the provincial plan for low income families and persons).

**Brand name and generic drugs:** Brand name drugs are produced by the company that developed that drug and are generally more costly.

- Once a drug has been available for a number of years, it may be reproduced by a generic brand company.
- Generic brands have the same composition for the active ingredient but may have different components for other ingredients (like coloring or binding agents).
- Generic brands are generally less costly.

**Supplemental health insurance:** Many families have coverage for medications through supplementary health insurance plans offered through work or school.

- Many plans require you to pay a portion of the total prescription cost or a set deductible amount.
- Dependents and unmarried young adults may be covered by a parent's plan until age 21 or until age 25 if they are full-time students.
- Some plans only cover the generic version of a drug if the generic form is available.
- Some newer medicines may not be covered.
- Coverage differs from plan to plan so it is wise to check the plan brochure or the information on the plan's website to find the insurance coverage details.
- As an example only, one widely-used plan in Manitoba covers 80 percent of the first \$375 of eligible medication expenses and 50 percent of the next \$300 to a maximum of \$450 per year (for the whole family).
- Unmarried dependent children up to age 21 and up to age 25 if they are full time students are covered.
- Children who became disabled before age 21 (or before age 25 if in full time studies) may be covered for a longer period.
- This varies from plan to plan.

**Health care spending accounts:** Some employers provide these accounts, which cover a wide range of health services, including medication costs not covered by other insurance. If you have a plan, be sure to check what is covered and the amount of coverage.

**First Nations plans:** A plan by Health Canada covers prescription drug expenses for First Nations people that are not covered by other plans. The plan covers the

best priced alternative for prescription drugs. Most drugs are covered - a pharmacist or doctor will have information about what drugs are covered.

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***Tips to manage the costs of medication treatment:***

- **Ask your doctor or pharmacist about the cost:** There are a variety of medications available for most problems. Ask your doctor and pharmacist about the cost and advantages of different medicines, especially if you do not have insurance coverage. Most doctors are quite happy to answer your questions about the cost of treatment.
  - **Be careful about sample packages from your doctor:** Be aware that the sample packages of medication you may receive from your doctor as a "starter dose" are usually for newer medicines. Newer medications are often more costly than older ones, and they are often no more effective. Some newer medications are not covered by insurance plans. Starting with such a sample medicine may lead to taking a more costly medicine over a long period of time. Switching to a less costly medicine is possible, but this takes extra time and there is a risk of having more symptoms while you switch medications. Therefore, it is usually less expensive to pay for a medicine right from the start, rather than beginning on a more expensive medication through sample packs from your doctor.
  - **Use one pharmacy consistently:** There is an advantage here because your pharmacy has a record of the medicines that you are taking.
  
  - **Check the cost of dispensing fees:** Pharmacies charge a dispensing fee for each prescription. This pays for the services the pharmacy provides, including keeping records, preparing the prescription, and providing advice about the medicine, other medicines you may be taking, and your health. Dispensing fees and mark-up costs can vary considerably between pharmacies. In Manitoba, dispensing fees usually range from \$4.49 to \$12.99. Check the dispensing fee by visiting or phoning the pharmacy.
  - **Arrange the prescription for a three-month period:** Once you have taken a medicine for a while, are on a stable dose, and find it helpful, you can reduce the cost of the dispensing fee by asking your doctor to write a prescription covering a longer period. Usually the longest period supported by insurance plans is about three months (90 to 100 days). The dispensing fee is usually the same whether you get a prescription for three weeks or three months of medication.
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### ***What are the common side effects of medication treatment?***

When considering treatment, many people want to know about possible side effects. Every treatment has advantages and disadvantages.

If you look at possible side effects of common medicines such as Aspirin or Tylenol, the list of potential side effects is long. Some people worry about side effects so much they avoid taking treatments that could really help them. Keep in mind that a wide range of medications are used in health care, with many beneficial effects and limited problems with side effects.

Still, it is helpful to have information about any possible side effects when making decisions about treatment choices. Side effects vary depending on the medication, its dose and treatment duration, and how quickly the dose is increased or decreased. Other factors such as age, sex, health and the use of other medications can also influence side effects. Side effects are one factor that doctors and patients consider in choosing the best medicine.

The sections that follow have information about early side effects, longer term side effects, and uncommon but serious side effects. The side effects that are most important vary depending on each situation and health status. The information provided here is general in nature. More specific information is available from your family doctor or pharmacist.

When you receive a new prescription your pharmacy will provide important information about the medicine and side effects. It is helpful to read that information carefully.

### ***Tables: What are the common side effects of medication treatment?***

#### **Early side effects:**

Some side effects may start shortly after starting a medication. Many of these may decrease or stop after you have been taking the medication for a few weeks. Others may go away only when you stop taking the medicine or reduce the dosage. About 6 out of 10 people will experience at least one side effect. Your doctor may be able to suggest ways to manage side effects.

Common side effects of the most widely-used medications for treatment of depression and anxiety are shown in the following two tables. Your doctor or pharmacist will have information about other medicines used for treatment of depression.

#### **Table 1A: Common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Fewer than 1 out of 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect				
	Nausea	Diarrhea	Constipation	Dry Mouth	Sweating
<b>SSRI Group</b>					
citalopram _(Celexa)	■■	■	-	■■	■■
escitalopram _(Ciprolex)	■■	■	■	■	■
fluoxetine _(Prozac)	■■	-	-	■■	■
fluvoxamine _(Luvox)	■■■	■	■■	■■	■■
paroxetine _(Paxil)	■■	■■	■■	■■	■■
sertraline _(Zoloft)	■■■	■■	■	■■	■
<b>SNRI Group</b>					
Venlafaxine _(Effexor)	■■■	■	■■	■■	■■
desvenlafaxine _(Pristiq)	■■	■■	■	■■	■■
duloxetine _(Cymbalta)	■■■	■	■■	■■	■
<b>Other antidepressants</b>					
bupropion _(Wellbutrin)	■■	-	■■	■■	■
mirtazapine _(Remeron)	-	-	■■	■■	-

Note: SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

**Table 1B: Other common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Fewer than 1 in 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect				
	Daytime sleepiness	Trouble sleeping	Headache	Shakiness	Dizziness
<b>SSRI Group</b>					
citalopram _(Celexa)	■ ■	-	-	■	-
escitalopram _(Ciprolex)	■ ■	-	-	■	■
fluoxetine _(Prozac)	■ ■	■ ■	-	■ ■	-
fluvoxamine _(Luvox)	■ ■ ■ ■	■ ■	■ ■ ■ ■	■ ■	■ ■
paroxetine _(Paxil)	■ ■	■ ■	■ ■	■	■ ■
Sertraline _(Zoloft)	■ ■	■ ■	■ ■ ■ ■	■ ■	■ ■
<b>SNRI Group</b>					
Venlafaxine _(Effexor)	■ ■	■ ■	■ ■	■	■ ■
desvenlafaxine _(Pristiq)	■	■ ■	■ ■	■	■ ■
duloxetine _(Cymbalta)	■	■ ■	■	■	■
<b>Other antidepressants</b>					
bupropion _(Wellbutrin)	-	■ ■	-	■	■
mirtazapine _(Remeron)	■ ■ ■ ■ ■	-	-	■	■

Note: SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

Tables adapted from RW Lam, SH Kennedy, S Grigoriadis, RS McIntyre, R Milev, R Ramasubbu, SV Parikh, SB Patten, AV Avindran. Canadian Network for Mood and Anxiety Treatments (CANMAT) Clinical guidelines for the management of major depressive disorder in adults. III. Pharmacotherapy, *Journal of Affective Disorders* 117 (2009) S26–S43.

### *Long-term side effects*

Two longer-term side effects are common with anti-depressant medications: sexual problems and weight gain. These are more problematic with some medications than others.

- Sexual side effects: There is often already a reduction in sexual functioning when people experience depression, but reduced sexual function is also a side

effect of many antidepressants. Sexual interest, ability to become aroused and ability to have an orgasm may be affected. About 2 out of 10 people who take antidepressant medications report sexual side effects. More problems with sexual side effects are reported with paroxetine (Paxil), while fewer problems are reported with bupropion (Wellbutrin).

- Weight gain: For many of the medications in this group, weight gain comes later in treatment. There may even be weight loss early in treatment, then weight gain later in treatment. More problems with weight gain are reported with mirtazapine (Remeron) and paroxetine (Paxil) than most of the other medications in this group. Fewer problems are reported with bupropion (Wellbutrin).

**Reference(s):**

Clayton, A.H., & Montejo, A.L. (2006). Major depressive disorder, antidepressants, and sexual dysfunction. *Journal of Clinical Psychiatry, 67(6), 33-37.*

Kennedy, S. H., & Rizvi, S. (2009). Sexual dysfunction, depression, and the impact of antidepressants. *Journal of Clinical Psychopharmacology, 29(2), 157-164.*

Serretti, A., & Mandelli, L. (2010). Antidepressants and body weight: A comprehensive review and meta-analysis. *Journal of Clinical Psychiatry, 71(10), 1259-1272.*

Zimmerman, M., Posternak, M. A., Attiullah, N., Friedman, M., Boland, R. J., Baymiller, S., . . . Chelminski, I. (2005). Why isn't bupropion the most frequently prescribed antidepressant? *Journal of Clinical Psychiatry, 66(5), 603-610.*

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### *Uncommon but serious side effects*

**Drug Interactions:** Serious effects can occur if you take these antidepressants with other medicines that affect some of the same body systems.

- It is important to tell your doctor all of the medicines you are taking, including any herbal or natural medicines (such as St. John's Wort or tryptophan).
- If you consider starting another medicine, tell the doctor before starting it to see if there are possible drug interactions with the new medicine.
- Medicines that may interact with antidepressants include other antidepressants, some migraine medicines, some prescription pain medicines, and some over-the-counter cough medicines.
- Your doctor or a pharmacist can provide information about drug interactions.

**Suicidal thoughts:** Persons struggling with depression sometimes experience thoughts of suicide.

- There was considerable concern in the year 2000, when researchers in a study of depression treatment noted that adolescents and young adults reported thoughts of suicide more often once they began taking an antidepressant medication. Problems with these thoughts occurred in 8 out of 100 people as compared to 4 out of 100 people who took a placebo (a pill with no medication). This problem was evaluated intensively, and it turned out that while there was a higher number reporting suicidal thoughts, there was not a higher rate of suicide attempts or completed suicide.
- Recent research indicates that treatment with antidepressant medication reduces the rate of suicide attempts.
- Nevertheless, it is important to keep track of any increase in thoughts of suicide and to be sure to seek extra support from a health care provider if this occurs.

**Excessively high mood:**

- Occasionally, people who take an antidepressant can experience a fairly sudden change in their mood. The depression may be replaced by a feeling of

higher than normal energy, with rapid thoughts and higher than normal mood or irritability.

- If this change occurs, it should be assessed by a professional as soon as possible, and the treatment may be changed.
- People with higher than normal mood may make decisions and take actions that can be harmful to themselves and the people around them.

### Alcohol

When you are taking these medications, it is a good idea to avoid using alcohol or to use very little alcohol. Heavy alcohol use is a risk factor for anxiety and depression. The use of any alcohol reduces the ability to drive safely and when mixed with anti-depressants the risk of unsafe driving is higher.

### Allergic reaction

There is a small chance of an allergic response to any new medication. Common symptoms include a skin rash. If this happens, speak to your doctor before taking any more of the medicine.

### Reference(s):

Barbui, C., Esposito, E., & Cipriani, A. (2009). Selective serotonin reuptake inhibitors and risk of suicide: A systematic review of observational studies. *Canadian Medical Association Journal*, 180(3), 291-297.

Dudley, M., Goldney, R., & Hadzi-Pavlovic, D. (2010). Are adolescents dying by suicide taking SSRI antidepressants? A review of observational studies. *Australasian Psychiatry*, 18(3), 242-245.

Stone, M., Laughren, T., Jones, M. L., Levenson, M., Holland, P. C., Hughes, A., . . . Rochester, G. (2009). Risk of suicidality in clinical trials of antidepressants in adults: Analysis of proprietary data submitted to US food and drug administration. *BMJ: British Medical Journal*, 339(7718)

Vitiello, B., Silva, S. G., Rohde, P., Kratochvil, C. J., Kennard, B. D., Reinecke, M. A., . . . March, J. S. (2009). Suicidal events in the treatment for adolescents with depression study (TADS). *Journal of Clinical Psychiatry*, 70(5), 741-747.

### *Psychotherapy or counseling for depression*

The following pages contain information about:

- **Counseling or psychotherapy**
- **Who provides treatment for depression?**
- **Working effectively in counseling or therapy**
- **How long does treatment continue?**
- **What happens when therapy is completed?**
- **How much does counseling or therapy cost?**
- **What are the common risks of counseling or therapy?**

**Treatment with psychotherapy or counseling**

**Counseling has been used for years and is a safe and effective form of treatment. Different professionals provide different forms of therapy, depending on their training and where they work. Treatment may be offered on an individual basis (you alone with a therapist) or group basis (you participate with a therapist along with others, who are all working to overcome problems with depression). Some individual and group treatments focus on specific themes such as relationships, dealing with traumatic experiences, and dealing with the death of someone close.**

**About 6 out of 10 people will feel much less depressed after eight to 20 sessions of psychotherapy or counseling. If you do not feel better, talk to your therapist about making changes to the therapy approach. You may consider a different therapist or type of treatment (including medication).**

**Confidentiality: What you say to your therapist is kept between the two of you, and will not be shared with anyone else without your permission. Your therapist or counselor should explain the nature of confidentiality and its limits at the beginning of therapy.**

**Reference(s):**

**Dobson, K. S., Hollon, S. D., Dimidjian, S., Schmaling, K. B., Kohlenberg, R. J., Gallop, R. J., . . . Jacobson, N. S. (2008). Randomized trial of behavioral activation, cognitive therapy, and antidepressant medication in the prevention of relapse and recurrence in major depression. *Journal of Consulting and Clinical Psychology, 76*(3), 468-477.**

**Hollon, S. D., & Ponniah, K. (2010). A review of empirically supported psychological therapies for mood disorders in adults. *Depression and Anxiety, 27*(10), 891-932.**

**National Institute for Health and Clinical Excellence (NICE). (2009). *Depression: The treatment and management of depression in adults – National clinical practice guideline*. London: Author.**

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### ***Who provides counseling or psychotherapy?***

Counseling or psychotherapy is provided by a range of professionals (described below) who provide different forms of treatment. Some counselors or therapists specialize in certain problems or work with specific groups of people (such as younger or older people). To find out whom you may want to see for help, you can speak to your family doctor, check on resources in your community through the Canadian Mental Health Association or the Mood Disorders Association, or check with the organizations for the professionals described below.

When you consider seeing someone, ask any questions that are important to you, such as:

- What is the training and experience of the person whom you will be seeing?
- What types of problems are treated?
- What is the cost of the service, if any?
- What approaches to treatment are used?
- How long does treatment usually last?
- What times are appointments scheduled?
- Is there a waiting list to be seen?

#### **Professionals who provide counseling or psychotherapy (presented in alphabetical order):**

Family doctors typically have a bachelor's degree, plus four years training in medicine and two years of training in family medicine (Qualification: MD and Fellowship in Family Medicine, CCFP). Some family doctors have training in counseling and a few of them practice psychotherapy as a major part of their work. The amount of training they have in these areas varies. This work is usually covered by provincial health plans, so there is no cost.

Nurses have two to four years of training in nursing through a college or university (Qualification: R.N. or B.N. or R.P.N. for registered psychiatric nurse). Some have additional training in counseling or therapy or more advanced university training. Services by nurses are provided with no charge by some hospitals or community health services.

Psychiatrists usually have a bachelor's degree, plus four years of training as a medical doctor. After this, they take five years of specialized training in psychiatry, covering treatment of a range of different health and mental health problems with medication and/or psychotherapy (Qualification: MD and Fellowship in Psychiatry, FRCPC). Their work is covered by provincial health plans so there is no cost for these services. Many psychiatrists focus on assessment and consultation, where they see a patient for one or two sessions, then make recommendations for treatment to the family doctor.

Psychologists have a bachelor's degree plus six or seven years of graduate university training in psychology (Qualification: Ph.D. (doctorate) in Psychology [masters degree in a few provinces]; and registration as a psychologist



**[C.Psych.]). Specialized training in clinical, counseling, applied or educational psychology covers treatment of a range of different health and mental health problems with counseling or therapy. Services by psychologists are provided with no charge by some hospitals or community health services. Many psychologists work in a private practice setting where there is a charge for the service. Psychology services are often partially covered by some extended health insurance plans.**

**Social workers have four (for bachelor's level) or six years (master's level) of training in social work and related fields (Qualification: B.S.W. or M.S.W.) Training often covers counseling or therapy with individuals, families, and groups with a range of health and mental health problems. Social work services are provided by some hospitals and many community agencies with no or minimal charge. Private social work services are partially covered by some extended health insurance plans.**

**Therapists or counsellors. This term is not regulated in most Canadian provinces so people with different kinds of background may use this term. Many have training in education, psychology, social work, marriage and family therapy, occupational therapy, or the clergy. Services by counsellors are provided with no charge by some hospitals or community health services. A small number of people practicing in this area have very limited training. Ask about the person's training and experience when arranging to see a counsellor or therapist. The province of Ontario is developing a College of Registered Psychotherapists and Mental Health Therapists that will register and regulate these groups in Ontario.**

### ***Working effectively in counseling or psychotherapy***

**What to expect in the first meeting:**

**The first visit is a consultation meeting, when you and the therapist will get to know each other and plan for your work together. Your therapist may ask what brings you to therapy, your concerns, and any symptoms you experience and may ask you to complete some questionnaires.**

**Your therapist may want to learn about your background, including your childhood, education, work history, current relationships, and long term goals. Don't feel pressured to talk about topics that are uncomfortable for you. Opening up can be hard, and it may take time for you to trust your therapist. Your thoughts, feelings and experiences will help your therapist's understanding of your difficulties and how to best help you, so it is important that you feel comfortable enough to be open with your therapist and say what is on your mind.**

**A good "fit" with your therapist is key to successful therapy. Your first therapy sessions are an opportunity for you to decide if his or her approach and personality will work for you. If, after two or three sessions, you do not feel comfortable or you don't feel you have a good working relationship with your therapist, it may be best to try someone else.**

**What to expect during the following meetings:**

**The rest of therapy is devoted to helping you understand and resolve current difficulties, and help you achieve the changes you want. Therapy can be quite different, depending on the approach used by the therapist. Some will take a directive role, providing feedback on your progress, homework exercises to practice some of the techniques learned in therapy or suggestions of what he/she thinks might be helpful. Others will give you more space to draw your own conclusions and direct the course of therapy. Therapists may be willing to adapt their style to your needs, so it is important to discuss your preferences.**

**Improvement is faster if your therapist can understand and relate positively to you, and you can work together on goals you both agree on. A good therapist will guide and support you, and challenge you when you are ready to be challenged. It is normal to disagree with your therapist from time to time. When this happens, it is important to honestly share any feelings or concerns you have about how therapy is going. This will give your therapist a chance to address your needs and maximize the benefits you can receive from therapy.**

**Keep in mind that therapy is designed to equip you with long-term solutions rather than a quick fix. Any change in life involves time and effort. Your commitment to attend appointments regularly, courage to look at yourself honestly, and willingness to make some difficult changes in your life will be important assets.**

***What are the results over time?***

**How long does it take before psychotherapy starts to work?**

**Often people start to feel less depressed within the first few weeks of treatment. Many feel better once they know they are doing something to deal with their problem.**

**How long does psychotherapy continue?**

**The length of treatment depends on your situation, including the seriousness of your depression. Most people require eight to 20 treatment sessions in order to see great improvement. Sessions are usually started on a weekly basis, then**

spread over longer periods of time (for example, once every other week) to allow time between the sessions to work on the problem.

### **What happens when psychotherapy is completed?**

It is important to discuss with the counselor or therapist when and how to complete the treatment. It is best not to stop treatment suddenly without discussing this.

Most people see considerable improvement with treatment. Those who have no or minimal symptoms of depression at the end of treatment are most likely to maintain this progress.

- Once treatment is completed, there is a risk of the depression symptoms coming back over the following months and years.
- The risk is greatest for those with repeated periods of depression in the past.
- Research tells us that the majority (about 3 out of 4) of those who improve while in treatment will stay improved in the year after treatment. However, about 1 out of 4 will have the depression come back during this year.
- There continues to be a risk of the return of depression over the following months and years.
- If you find that symptoms of depression are returning, it is important to see someone for help with this (possibly the person who helped you before) quickly.

· *Some people find it helpful to return for a few booster sessions months or years after treatment is completed, usually because of new challenges in life or more problems with symptoms.*

· *If you find that symptoms of depression are returning, it is important to see someone for help with this quickly (possibly the person who helped you before). Starting a treatment again may reduce the amount of interference caused by depression and help you to overcome any problems caused by depression.*

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Reference(s):

Bockting, C. L. H., Spinhoven, P., Wouters, L. F., Koeter, M. W. J., & Schene, A. H. (2009). Long-term effects of preventive cognitive therapy in recurrent depression: A 5.5-year follow-up study. *Journal of Clinical Psychiatry, 70*(12), 1621-1628.

Vittengle, J. R., Clark, L. A., Dunn, T. W., & Jarrett, R. B. (2007). Reducing relapse and recurrence in unipolar depression: A comparative meta-analysis of cognitive-behavioural activation's effects. *Journal of Consulting and Clinical Psychology, 75*(3), 475-488.

Vittengle, J. R., Clark, L. A., & Jarrett, R. B. (2009). Continuation-phase cognitive therapy's effects on remission and recovery from depression. *Journal of Consulting and Clinical Psychology, 77*(2), 367-371.

### *How much does counseling or psychotherapy cost?*

- Some therapy or counseling is provided at no cost through public agencies and health care facilities such as hospitals or primary care clinics.
- Services for students may be available through the special services available in most public schools (Grades 1 to 12) or the counseling services of most educational programs (colleges and universities).
- Counseling and therapy provided by family doctors and specialists in psychiatry are covered by the provincial health plan, so there is no charge for the service.
- Some community agencies provide services at no or low cost depending on income.
- Private services are available and are covered by some insurance plans. The cost for private counseling or therapy can range from \$50 to \$155 or more for a one-hour session.

**Employee Assistance Plans (EAPs):** Many large employers have EAPs that provide counseling or therapy for employees and their family members on a confidential basis.

- Often you can make an appointment within a week or two of the first contact. There is often no charge for the service, although the total number of sessions may be limited.
- Plans provide different numbers of sessions so ask about this at the start.

- EAP staff comes from a variety of different professional groups, so ask about the counselor's qualifications and experience with the problems you are concerned about.

**Supplemental health insurance:** Many families have coverage for psychology services (and in some cases other types of counseling or therapy services) through supplementary health insurance plans they have through work or school.

- Dependent and unmarried young adults may be covered by a parent's plan until age 21 or until age 25 if they are full time students.
- Children who became disabled before age 21 (or before age 25 if in full time studies) may be covered for a longer period.
- Young people may be covered by both parent's plans.
- Many plans require a referral from a physician (such as a family doctor) and will not pay if there is no referral before services are provided.
- Coverage differs from plan to plan so check your plan brochure or the plan website to find coverage details.
- As an example, some plans cover a percentage (often 80% to 100%) of the cost of therapy up to a specified limit. Coverage can be as little as \$300 and as much as \$1000 per year.

**Health care spending accounts:** Some employers provide these accounts, covering a range of health services, including counseling and therapy, by qualified practitioners. If you have a plan, be sure to check the amount of coverage and what is covered.

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***Tips to manage the cost of counseling or therapy (if there is a cost):***

- **Ask about managing the cost. A well-trained professional will be happy to help you to manage the cost of treatment.**
- **Don't wait for a crisis: Many problems respond more quickly if you catch them early and at a time when you are not in crisis.**
- **If you notice a problem limits your happiness and success, or holds you back in life, planning ahead to deal with it can allow you to take advantage of insurance coverage or services with lower or no cost.**
- **Examples of problems that can lead to depression are: ongoing problems with worry, nervousness, or anxiety; recurring problems in relationships; troubles finishing your work; and problems with periods of low mood.**
- **There are excellent books available about depression (including those discussed in the self help section that follows) that may allow you to work on the problem more quickly.**
- **Devote the time to work on homework between sessions to reduce the number of sessions required.**
- **Once treatment has the desired effect, appointments can be spread out to reduce the costs. It may also be possible to schedule briefer appointments or telephone appointments.**
- **Inquire about charges for missed or cancelled appointments. If you have to miss an appointment, be sure to call as soon as you know.**
- **Payment: Some therapists require payment at the time you are seen; others will bill your insurance plan directly. Methods of payment may be cash, cheque, credit card or debit card.**
- **Plan when to use insurance coverage. If you don't use your coverage for this year, it won't carry over to the next year.**

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***What are the risks of psychotherapy?***

**Each treatment that is widely used for depression has benefits and risks. Most people who seek psychotherapy or counseling for problems with depression improve, and those who improve usually feel that the benefits outweigh the**

risks. However, 1 out of 10 people will experience a worsening of their condition when they are having counseling or therapy. For some, this is a result of their problem worsening (unrelated to the treatment). For others, the deterioration is related to the therapy or the therapist they are seeing.

If your depression is getting worse or not improving after a reasonable time, be sure to discuss this with your therapist. You may benefit from a change to another therapist, another form of therapy, or to a medication treatment.

Persistence is important. If you try a treatment, it is important to stick with it to allow time to see if it helps. If you do not benefit from the first treatment you try, there is still a good chance your problem will respond to a different treatment.

**Reference(s):**

Kraus, D. R., Castonguay, L., Boswell, J. F., Nordberg, S. S., & Hayes, J. A. (2011). Therapist effectiveness: Implications for accountability and patient care. *Psychotherapy Research, 21*(3), 267-276.

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***What about combining medication treatment and psychotherapy or counseling?***

Medication treatment and treatment with counseling or psychotherapy are effective for depression in most people when they are used alone (not combined). So, many people do well with just one type of treatment.

Combined medication and therapy may be effective in a somewhat larger proportion of people. It is not known at this time whether combined treatment is more effective in the long term if the medication is stopped.

There are advantages if you choose the single treatment you prefer (and is available) first.

- Taking one treatment at a time is simpler and less costly.
- One advantage of trying one treatment at a time is that when there is improvement, it will be clear which treatment led to the improvement.
- If you don't see enough improvement after trying the first treatment for the recommended time, you may find better results by adding the other form of treatment.
- If you prefer combined treatment from the start, this can be arranged.

When people gradually reduce and stop medication, especially if they have had a number of periods of depression over the years, there is a risk the depression will

return over the following months. Receiving psychotherapy focused on reducing the risk of relapse lowers this risk for some people, especially those who continue to have some symptoms of depression.

**Reference(s):**

Bockting, C. L. H., Spinhoven, P., Wouters, L. F., Koeter, M. W. J., & Schene, A. H. (2009). Long-term effects of preventive cognitive therapy in recurrent depression: A 5.5-year follow-up study. *Journal of Clinical Psychiatry, 70*(12), 1621-1628.

Otto, M. W., Smits, J. A. J., & Reese, H. E. (2005). Combined Psychotherapy and Pharmacotherapy for Mood and Anxiety Disorders in Adults: Review and Analysis. *Clinical Psychology: Science and Practice, 12*(1), 72-86.

Pampallona, S., Bollini, P., Tibaldi, G., Kupelnick, B., & Munizza, C. (2004). Combined pharmacotherapy and psychological treatment for depression: a systematic review. *Archives of General Psychiatry, 61*(7), 714-9.

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### ***Self-help treatments***

Some people prefer to manage problems with depression on their own if they can.

There are a number of books and websites that you can use on your own or with a therapist's or counselor's help. Well-designed self-help materials can be helpful for problems with depression especially if you work through the program a step at a time. Self-help materials may also provide more information about the treatments that are available.

Using self-help program will help you to have a much better understanding of depression. Self-help programs are widely available, free or low in cost (books cost in the range of \$20), and help you develop strategies to manage the problem. If you work through the program regularly, a step at a time, you are more likely to see positive results.

Working on depression without any outside help, however, does not benefit as many people as treatment involving professional help and guidance. Self-help programs that involve an assessment of the problem at the start (by a professional or by a web-based program) and some level of follow up have been found to be more effective even if the professional is not directly involved in providing treatment. We are not sure why, but it may be that the process of an assessment and some follow-up contact creates more commitment to the program.



**Self-help programs can be combined with therapy and medication treatments.**

**In some parts of the country there are self-help groups which provide very useful help also. One way to find out about the programs available is to contact the provincial or national mood disorders association ([www.depression.mb.ca](http://www.depression.mb.ca)). Attending the educational or support programs of these associations may help you feel more supported in dealing with the problem.**

**These associations or your doctor or therapist may have advice about recommended self-help programs.**

**If you are having thoughts suicide or of harming yourself it is important to seek professional help.**

**Recommended self-help books: These books may be available in your local library or bookstore and may be ordered through internet book sellers.**

***Feeling Good: The New Mood Therapy.* By D. Burns. (1999). New York: Avon.**

***Mind Over Mood: A Cognitive Therapy Treatment Manual for Clients.* By D. Greenberger, & C.A. Padesky. (1995). New York: Guilford Press.**

***Your Depression Map: Find the Source of Your Depression and Chart Your Own Recovery.* By Randy J. Patterson (2002). Oakland, CA: New Harbinger Press.**

**Web-based self-help:**

**<http://moodgym.anu.edu.au/welcome> - This Australian website for depression has been evaluated in more research than any other web program available.**

**<http://www.depressioncenter.net/Default.aspx> - This Canadian website has an extensive program for depression.**

**[www.myselfhelp.com](http://www.myselfhelp.com) – This U.S. website is well-designed and available for a small monthly fee. Programs are available for depression, stress, insomnia, eating disorders, self-esteem, guilt, and grief.**

**[www.changeways.com](http://www.changeways.com) - Click on “self-care depression program” to access this Canadian website with its well-developed program.**

**Reference(s):**

**Vincent, N., Walker, J. R., & Katz, A., Self-administered treatments in primary care. In P. L. Watkins, & G. A. Clum (Eds.) (2008) *Handbook of self-help therapies*. New York: Taylor & Francis Group, pp. 387-417.**

Appendix I: Study 1 Recruitment Ad:

**Decision Aid About  
Treatment of Depression**

This is a chance for your opinions and experience to help improve the lives of people who are suffering some of the same hardships as you have suffered.

***What?*** It's a study about a new decision aid for depression. This aid can help young people make wise decisions about getting the right kind of help. We need your help to improve the information in the decision aid. You must be able to attend an interview in Winnipeg, Manitoba.

***Who?*** If you are 18 to 25 years old and you have faced a decision about treatment for depression, you may qualify to participate in this research.

*People who participate will receive a cash honorarium of \$25 in recognition of the time they spend completing a 60-90 minute interview.*

They will also receive a copy of the decision aid to refer to in the future.

**Please contact: Brad Zacharias, Ph.D. Student, Department of Psychology, University of Manitoba (This research is being conducted by Brad as part of a Ph.D. thesis in clinical psychology at the University of Manitoba).**

**Phone:** (a confidential voicemail can be left with your name and phone number).

**Email:**

*Thank you!*

## Appendix J: Study 1 Telephone Script:

*(Have copies of recruitment ad, consent form, “HELPING RESOURCES FOR MENTAL HEALTH CONCERNS” SHEET, and MINI at the ready)*

“Hello, my name is Brad Zacharias. I am a PhD student in Clinical Psychology at the University of Manitoba. How are you today? You expressed interest in participating in my research project by [PHONE MESSAGE OR EMAIL]. Is this a convenient time to talk about that, or, would you rather I call you back at another time?”

The study you contacted me about concerns young adults’ opinions regarding a new decision aid regarding depression and its treatment. This research is part of my Ph.D. thesis in Clinical Psychology at the University of Manitoba. To participate, you must be aged 18 to 25 and have personally faced a decision (that is, you were depressed or thought you might be depressed) and explored options about treatment for depression such as counselling or medication. You will receive a \$25.00 cash honorarium for your participation. The honorarium will be paid even if you do not answer each question or complete the interview. It will be paid to you immediately after you have arrived for your interview and have signed the consent form.

Before I describe the study in any detail or collect any personally identifying information, I need to ask a few questions on an anonymous basis about your experiences related to depression. Is this alright with you?”

[IF NO]: “Thank you for your consideration. Unfortunately, without this information, I cannot proceed to include you in the study. I will continue the study over the next few months, so if you change your mind and are interested in participating in the near future, please feel free to contact me again. If you prefer, I can also call you back in the next few weeks.”

[IF YES: ADMINISTER DEPRESSION AND HYPOMANIA/MANIA SECTIONS OF THE MINI: IF CODE “NO” FOR DEPRESSIVE EPISODE]:

“It would appear that, although you may have experienced some problems with low mood, you may not have had what is termed a major depressive episode. Therefore, I’m sorry to tell you we cannot include you in this study. Thank-you very much for your interest.”

[If CODE “YES” FOR DEPRESSIVE EPISODE AND CODE “YES” FOR MANIC/HYPOMANIC EPISODE(S)]:

“Often it is the case that people with problems with depression will also go through an extreme ‘up’ or ‘hyper’ time like you’ve just described. However, my study focuses specifically on people with a history of depression and without those extreme ‘up’ experiences. So, I’m sorry to tell you we cannot include you in this study.”

[IF CODE “YES” FOR DEPRESSIVE EPISODE AND CODE “NO” FOR MANIC/HYPOMANIC EPISODES]:

“Thanks for answering these questions. You are eligible to participate in this study.

If you ultimately decide to participate, you will come in for an interview where you will be asked about your decision making for depression treatment such as counselling, medication, or self-help treatments. You will also be asked to read passages from a decision aid regarding depression and some of the ways it is treated. A decision aid is a tool (in this case, a written

tool) intended to provide information to members of the public about options they have for dealing with a health problem so they can make informed decisions. In this case, the decision aid describes depression and some of the common treatments available to help with depression. After you read sections of the information, I will ask questions about your views of the information you just read. The appointment will take place in a private office at the Mood Disorders Association of Manitoba at a convenient time for you and it will take approximately 60 to 90 minutes to complete. Any questions about that so far?” [ANSWER QUESTIONS.]

[IF THERE ARE ANY CONCERNS ABOUT ATTENDING AT THE ABOVE LOCATION]: “Later, we can discuss other locations that will also work well.

The interview will be audio-recorded so that the information you provide can be typed and summarized at a later time. By participating, you will have the opportunity to learn more about depression and treatment. You will also receive a \$25.00 cash honorarium for your help and you will receive a printed copy of the decision aid to take home with you. Your feedback will help me understand some of the concerns involved in treatment decision making and also help me make improvements to the decision aid.

Are there any questions you have about the study?”

[ANSWER ANY QUESTIONS THAT COME UP AT THIS POINT.]

“Would you be interested in participating in the study?”

[IF NO] “Thank you for your consideration. I will continue the study over the next few months, so if you change your mind and are interested in participating in the near future, please feel free to contact me again. If you prefer, I can also call you back in the next few weeks.”

[IF YES]: “Can I schedule a time for you to come in for the interview? What days and times work best for you?”

[SET DATE AND TIME.]

[SET LOCATION.] “Now I’d like to arrange for a convenient place to meet for the interview. I have been doing my interviews at a private office at the Mood Disorders Association of Manitoba. Would this be satisfactory to you? [IF NO, DISCUSS OTHER OPTIONS SUCH AS THE OFFICE IN THE DUFF ROBLIN BUILDING AT THE UNIVERSITY OF MANITOBA. LOCATION AGREED UPON: \_\_\_\_\_.]

[ALSO, PROVIDE MY EMAIL ADDRESS IF THEY WANT TO CONTACT ME DIRECTLY AND/OR THEY DO NOT ALREADY HAVE IT.]

“I would like to send you a copy of the consent form so you can review it before our appointment. Do you have a confidential email address that I can send it to?”

[IF YES]”What is that address?”

[OBTAIN THEIR EMAIL ADDRESS TO SEND CONSENT FORM. IF POSTAL MAIL PREFERRED, OBTAIN POSTAL ADDRESS].

“Thanks again. I look forward to meeting you on: [APPOINTMENT DATE, TIME, AND LOCATION]. Good-bye.”

[IF HE OR SHE PREFERS NOT TO HAVE CONSENT FORM SENT OUT]: “Thanks again. I look forward to meeting you on: [APPOINTMENT DATE, TIME, AND LOCATION]. Good-bye.”

**Appendix K: Study 1 Helping Resources:****Department of Psychology**

190 Dysart Road  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-  
9338  
Fax (204) 474-7599

**RESOURCES FOR HELP FOR ADULTS WITH DIFFICULTY WITH STRESS,  
ANXIETY, AND DEPRESSION**

If you are in crisis, you can call Klinik Crisis Line: 786-8686/1-877-435-7170 (toll free Manitoba). They have trained counselors available 24 hours per day/7 days per week. If you are feeling like you might be a danger to yourself or someone else, you should go to the emergency room of the nearest hospital immediately.

So many people have difficulties with stress, anxiety, and depression that only a small proportion of them can or should be served in specialized clinics. Many mental health professionals (psychiatrists, psychologists, and trained counselors) have experience helping people deal with these problems and the personal problems associated with them. Consequently, a person is likely to be able to obtain help with wherever mental health services can be arranged. A list of some of the available services is provided below. The best way of finding out if a therapist or counselor has experience in this area is to discuss it with him or her. Your family doctor may be able to suggest other appropriate services.

**RESOURCES AVAILABLE THROUGH THE WORKPLACE:** Many people have access to benefits through their work that would provide for counseling or therapy services that cover themselves, their partner and their children.

- Employee Assistance Programs (EAP) are available with many employers. They provide counseling services that cover a wide range of personal and family problems including stress, anxiety and depression. The service is confidential and the employer does not know which employees are using the service and for what reasons. Service is usually provided in an office away from the work site. The programs often allow for a certain number of appointments per calendar year. You can refer yourself to an EAP. It is best to obtain a copy of the brochure describing the plan to see what services are provided as different programs provide different services.
- Extended health insurance is a benefit in many workplaces. Often the employee pays a monthly premium. This program covers services such as ambulance, physiotherapy, and clinical psychology services. The insurance plan often has rules about when services will be

covered. It is best to obtain a copy of the brochure describing the plan to see what services will be covered and what dollar amount is covered per year. For example, some plans require a referral from a physician in order for the cost of the visits to be covered. Generally the services obtained through these plans are confidential and the employer does not receive information about who is using the plan and what services they are using. The names of psychologists who provide services covered by many extended health insurance plans are listed in the yellow pages section of the phone book.

- Some employees have access to both an Employee Assistance Program and extended health benefits and they may use both if they wish.

***SERVICES PROVIDED THROUGH SCHOOLS AND EDUCATIONAL FACILITIES:***

***Many educational programs have counseling services available for students and some of these may cover problems with stress, anxiety, and depression. Public schools and high schools have access to counselors and other specialist services. Universities and colleges have student counseling and support services. For information about these it is best to check with the administration of the program.***

COMMUNITY SERVICES: For most of the services listed below, individuals may refer themselves. A referral from a doctor is not necessary, although it is welcomed.

**Counseling Services:** A range of organizations provide counseling services in the Winnipeg Region. It is necessary to call the service to see whether they have openings. A good place to get an extensive list of the counseling services available is the Mental Health Resource Guide for Winnipeg available on the Internet at: [http://www.cmha.ca/data/1/rec\\_docs/867\\_Mental-Health-Guide-10th%20Edition%202006.pdf](http://www.cmha.ca/data/1/rec_docs/867_Mental-Health-Guide-10th%20Edition%202006.pdf)

**Access Centres and Community Health Centres:** Many of the health centres in Winnipeg have counseling services. Contact the centre to see what services are available. As an example, Klinik Health Centre at 870 Portage Ave. phone 784-4059 has a range of services available including a drop in service on particular days. This Centre has special services for people with a history of abuse.

Health Access Centres such as Access River East (938-5000) and Access Transcona (938-5555) serve particular areas of Winnipeg.

FAMILY ORIENTED SERVICES: The following services may be especially helpful in situations in which family difficulties are a source of concern.

**Aurora Family Therapy Centre:** at the University of Winnipeg (786-9251)



<http://aurora.uwinnipeg.ca/clinic.shtml>

**Family Centre of Winnipeg:** 401-393 Portage Avenue (Portage Place), Winnipeg, 947-1401  
[www.familycentre.mb.ca](http://www.familycentre.mb.ca)

**SELF HELP:** Self-help associations can provide excellent information about services and many offer group programs that can help people cope with and overcome personal problems.

**Anxiety Disorders Association of Manitoba:** 100 - 4 Fort St., Winnipeg 925-0600 (outside Winnipeg, phone 1-800-805-8885). There are several regional offices around the province. A self-help association that provides a variety of resources including educational groups (available at a modest cost) to help members learn to cope with problems with panic disorder, social anxiety disorder, and other anxiety problems. Support groups are available year round.  
[www.adam.mb.ca](http://www.adam.mb.ca)

**The Obsessive Compulsive Disorder Centre Manitoba (OCDC):** 100-4 Fort St., 942-3331. A self-help organization offering education and support to persons suffering from obsessive compulsive disorder (OCD) as well as their families. In addition to a library of education and self-help materials, the centre offers a support group, an education group for family members, and a group focused on setting goals to assist in overcoming OCD. [www.ocdmanitoba.ca](http://www.ocdmanitoba.ca)

**Mood Disorders Association of Manitoba:** 100-4 Fort St., Winnipeg, 786-0987. A self-help association that provides a variety of resources including educational groups to help members learn to cope with problems with mood disorders such as depression and bipolar disorder.  
[www.depression.mb.ca](http://www.depression.mb.ca)

**PRIVATE PRACTITIONERS:** Health service providers in a number of different specialty areas serve people with problems with stress, anxiety, and depression. The professional association may be able to give you the names of professionals who provide services to people with specific problems. Some practitioners request a letter of referral from your family doctor. Only psychiatrists in private practice are covered by Medicare. With other service providers it is a good idea to ask about the cost of services before you arrange for your first appointment. The service provider should willingly provide information about the cost of the service and the number of sessions that people might use for typical problems so that you can have a reasonable idea about the cost of service.

**Psychiatrists:** Names are listed in the Yellow Pages or telephone the College of Physicians and Surgeons, 774-4344.

**Psychologists:** Extended health benefit plans through employment often provide coverage. Consult the Yellow Pages or telephone the Psychological Association of Manitoba, 487-0784.  
[www.cpmc.ca](http://www.cpmc.ca)

**Registered Psychiatric Nurses:** Some nurses provide private services. Contact the College of Registered Psychiatric Nurses of Manitoba, 888-4841

**Social Workers:** Blue Cross and other private health plans may provide some coverage. Contact the Manitoba Institute of Registered Social Workers, 888-9477.

## Appendix L: Study 1 Greeting Script:

[HAVE ALL WRITTEN MATERIALS AND EQUIPMENT READY]

[GREET THE PARTICIPANTS]:

“Hello, are you here to participate in an interview with Brad Zacharias today?”

[IF NO]: “Sorry, have a nice day”.

[IF YES]: “I’m Brad Zacharias. Can I ask your name?” [CONFIRM CORRECT PARTICIPANT NAME]

“Thanks for coming in today.”

[BE SEATED WITH PARTICIPANT IN PRIVATE OFFICE]:

“Are you comfortable? Would you like some water?” [HAVE WATER READY AND PROVIDE IF DESIRED].

“We are meeting today for an interview as I talked about on the phone the other day. The first thing I want to do is review the purpose of the study, then we’ll go over the consent form and ask you to sign it, give you the \$25.00 honorarium, have you fill out a brief questionnaire, conduct the interview, and provide you with a research feedback form as well as a copy of the decision aid. Feel free to ask questions at any time. Any questions so far?”

[ANSWER ANY QUESTIONS].

“The main purpose of this study is to understand your thoughts and opinions about the information in a new decision aid for depression. The way I want to do that is to have you read through sections of information and then to ask you questions about the information you just read. At any time, you are free to ask questions about the information or offer suggestions on how the information might be improved. I also would like to know a bit about your past experience and how you found information about depression treatment. Do you have any questions about that? Now, what we need to do is review the consent form.”

[IF THEY HAVE RECEIVED THE CONSENT FORM IN ADVANCE]:

“Did you read the consent form already?”

[IF NO, SKIP TO PROCEDURE IMMEDIATELY FOLLOWING THIS ONE, INTENDED FOR THOSE REVIEWING THE CONSENT FORM FOR FIRST TIME].

[IF YES]: “Did you have any questions about any of the information in the consent form?”

[ANSWER ALL QUESTIONS, ENSURE ITEMS ARE CLEARLY CHECKED AT END OF FORM, AND OBTAIN SIGNATURE].

[IF THEY ARE REVIEWING THE CONSENT FORM FOR THE FIRST TIME]: “Here is the consent form. It is very important that you take your time reading it in full and checking off the items at the end of it. Once you have read it, I will answer any questions you have about it before you will be asked to sign it.” [ALLOW AMPLE TIME FOR READING CONSENT FORM. ANSWER ALL QUESTIONS AND ENSURE ALL ITEMS ARE CLEARLY CHECKED AT END OF FORM, AND OBTAIN SIGNATURE].

[PROVIDE PARTICIPANT WITH \$25.00 HONORARIUM].

[PROVIDE DEMOGRAPHICS QUESTIONNAIRE AND K 6 AND ASK PARTICIPANT TO COMPLETE]. [SEAT PARTICIPANT AT COMPUTER; HAVE RECORDING DEVICE, NOTE PAD READY FOR INTERVIEW]:

**Appendix M: Study 1 Consent Form:****Department of Psychology**

190 Dysart Road  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-9338  
Fax (204) 474-7599

**Consent Form**

**Project title:** Evaluation of the Informational Component of a Web-Based Decision Aid for Depression

**Principal Investigator:** Bradley D. Zacharias, M.A., Ph.D. Student  
Department of Psychology, University of Manitoba  
Phone:  
Email:

**Research Supervisors:** Dr. John R. Walker, C. Psych, Associate Professor,  
Department of Psychology, University of Manitoba  
Phone:  
Email:

Dr. Diane Hiebert-Murphy, C. Psych, Professor  
Department of Psychology, University of Manitoba  
Phone:  
Email:

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This research is being conducted by me, Bradley Zacharias, as part of a Ph.D. thesis in Clinical Psychology under the supervision of Dr. John Walker and Dr. Diane Hiebert-Murphy at the University of Manitoba. The primary goal of the project is to better understand young adults' views about the information contained in a new decision aid for depression. We are interested in the opinions of young adults (18-25 years of age) who have decided about receiving some form of treatment for depression in the past.

You are being invited to be interviewed by me, the principal investigator (Bradley Zacharias). You will be asked a series of questions about your experience deciding on a

treatment for depression as well as other topics related to the decision making process. You will also be asked to read information about depression and several forms of treatment for depression and to provide your opinions regarding the information. With your consent, the interview will be audio recorded and later typed into a written record. Your opinions will help make improvements to the decision aid. You will also be asked to complete some questions pertaining to your demographic background such as your education, your parent(s)' education, and your parent(s)' postal code(s). The reason for collecting information regarding parents' education and postal codes is to gain a better understanding of your family's social and economic background.

Interviews will be held in a private office in the Mood Disorders Association of Manitoba. The interview could also be conducted at another location that provides reasonable privacy and is agreeable to both of us. The interview is not expected to exceed 90 minutes in length. This research is being carried out independently of the Mood Disorders Association of Manitoba and their staff will be unaware of whether you agree or decline to participate. Your decision about participating will have no effect on current and/or future services you may receive from the Mood Disorders Association of Manitoba.

You will be compensated with a \$25.00 cash honorarium for your time and any other costs you may incur related to the interview, such as transportation and child care. The honorarium will be paid even if you do not answer each question or complete the interview. It will be paid to you immediately after you have arrived for your interview and have signed this consent form.

Please note that talking about one's history of depression and process of decision making for treatment for depression carries with it a slight risk of experiencing emotional distress. With this possibility in mind, a list of counseling resources in Winnipeg has been attached to this consent form for your assistance. There may be some direct benefits to you in terms of learning more about the nature of depression and depression treatments. Besides the \$25.00 honorarium for your participation, you will also be given a paper copy of the decision aid to take home with you. We hope that a greater understanding of adults' opinions regarding the decision aid will help us provide the most beneficial information and decision support to aid adults looking for help for depression.

Following the interview, I may need to contact you for further information or clarification, which would only involve brief a conversation(s) over email or telephone. This contact will be optional and I will ask separately for your consent to do so. At the end of the project, which will be in October, 2012, you will have the option of receiving a brief summary of the findings. Also, with your consent, I may wish to contact you for future research projects on the opinions of young adults regarding the information contained in the decision aid. However, you are under no obligation to agree to be contacted for this purpose. Additionally, agreeing to be contacted does not obligate you to participate in research that I contact you about. However, this does require that you authorize me to keep personally identifying information on file for contact purposes. Procedures

intended to protect the confidentiality of this and other personal information are described below.

At the end of the project, I will be presenting the findings of this study at a meeting with my dissertation committee at the University of Manitoba. In addition, I plan to publish the findings in scientific journals and/or present them at professional conferences. However, in all cases I will do so without revealing identifying characteristics such as names or addresses and results will be reported for all study participants as a group, not for individuals. I will only use quotations from the interviews after removing identifying details, so they cannot be attributed to any single person.

Information from the interview will be audio-recorded and stored on a password protected computer. Your name or other identifying information will not be associated with your responses and will be kept only on a list of participants and code numbers held by Dr. John Walker and me in a locked area at St. Boniface General Hospital. The only persons (other than potentially two external agencies, noted below) who will have access to information collected in the project are members of the research team which includes Dr. Walker, Dr. Hiebert-Murphy, project research assistants, and me. Audio recordings and hand-written notes will also be stored in a locked cabinet at St. Boniface General Hospital. I will transcribe interviews and, in the process, remove all personal identifiers. Data containing personal identifiers will be destroyed immediately after the study period has ended (October, 2012). At that time, all audio recordings and documents including the key linking your identifying information to your responses will also be shredded and/or deleted. If you give permission, we may contact you to see if you are interested for future follow-up research related to this study.

There are only two external agencies that may have access to our research records. One external agency is the University of Manitoba Research Ethics Board(s) which includes a representative(s) of the University of Manitoba Research Quality Management /Assurance office who may require access to your research records for safety and quality assurance purposes. The other external organization that may have access to our research records is a professional transcription agency. In both the above cases, precautions will be taken to protect your confidentiality and the confidentiality of the data. For example, in the event that recordings are sent to a transcription agency, confidentiality will be maintained by allowing only the codes (assigned to each recording) to leave the premises; participants' names would remain at St. Boniface Hospital. The audio files would then be password protected and sent on a medium such as Compact Disc. The researchers will not discuss individual responses with anyone outside the research team. The data will be destroyed (i.e., paper form will be shredded; electronic files will be deleted; digital recordings will be erased) five years after publication (approximately in the year 2018).

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researcher from his legal and professional responsibilities. You are free to withdraw from the study at any time and/or

refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

This research has been approved by the University of Manitoba Psychology/Social Research Ethics Board (Protocol #P2011:099). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

Please check the “yes” box if you agree to each of the following and the “no” box if you do not agree:

I have read or had read to me the details of this consent form.  Yes  No

My questions have been addressed.  Yes  No

I, \_\_\_\_\_(print name), agree to participate in this study.  Yes  No

I agree to have the interview audio-recorded.  Yes  No

I agree to be contacted by phone or e-mail if further information is required after the interview  Yes  No

I agree to have the findings (which may include quotations) from this project published or presented in a manner that does not reveal my identity.  Yes  No

I agree to be contacted for future research on decision aids conducted by the researcher.  Yes  No

**IF YES:**

I consent to the researcher keeping my personal information on file  Yes  No

Do you wish to receive a summary of the findings?  Yes  No

**IF YES:**

How do you wish to receive the summary?  E-mail  Surface mail

Email: \_\_\_\_\_

Surface Mailing Address: \_\_\_\_\_

Participant's Signature \_\_\_\_\_

Date \_\_\_\_\_

Researcher's Signature \_\_\_\_\_

Date \_\_\_\_\_

**Appendix N: Study 1 Research Feedback Sheet:****Department of Psychology**

190 Dysart Road  
 Winnipeg, Manitoba  
 Canada R3T 2N2  
 Telephone (204) 474-9338  
 Fax (204) 474-7599

**Interview Study – Feedback:**

This study explores young adults' opinions and preferences concerning information in a new decision aid regarding the nature of depression and some of the common treatments for depression.

We also are interested in aspects of past decision making process when looking for help for depression. Also, we want to know whether and how the information in the decision aid might have helped them in the process of seeking help had it existed at that time.

The results of this study will be used to make changes to the decision aid so that we can test it out on the Internet in the coming months. That way, many others can read the information and give us similar feedback on how to improve the materials in the decision aid.

The results of the final project will be available beginning in October, 2012. If you indicated that you would like information about the results of the study, we will send a summary of findings to you.

Questions or concerns about this study can be directed to Mr. Bradley Zacharias at \_\_\_\_\_ or Dr. John Walker at \_\_\_\_\_. If you have any complaints about this project, you may contact the above-named persons or the Human Ethics Secretariat at 474-7122 or via email to [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).

Thank you for participating in this study.





1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
Strongly Mildly Strongly  
disagree disagree agree

**3. How reasonable are the conclusions of the findings? Your rating: \_\_\_\_\_**

1-----2-----3-----4-----5-----6-----7-----8-----9-----10  
Not at all Moderately Very  
reasonable reasonable reasonable

**4. Please note any other comments/suggestions about the findings.**

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**Thank-You!**

**If you have any questions or comments about the study, feel free to email at:**

\_\_\_\_\_

Sincerely,

*Brad Zacharias, M.A.  
Clinical Psychology Graduate Student  
Department of Psychology  
University of Manitoba*

## **Appendix P: Study 1 Member Checking Summary:**

### **Brief Summary**

**Background:** This interview sought to gather young adults' opinions about the clarity, balance, amount, familiarity, trustworthiness, and helpfulness of a developing decision aid for depression. We also were interested in whether or not they would recommend the decision aid to someone suffering from depression, and what formats they thought would be most effective for users of the decision aid. Ten participants (5 men and 5 women) ranging in age from 18-25 years took part in the interviews between February and April of 2012. The interviews took place at the offices of the Mood Disorders Association of Manitoba.

### ***Reactions to the Decision Aid***

#### ***Familiarity of the information***

Most of the topics of the decision aid were described as familiar to participants. However, there were five main areas of *unfamiliarity*:

- (1) Rates of recovery from depression, without any treatment, and with the first trial of medication treatment.
- (2) The cost of treatment.
- (3) Some treatment side effects described in the text or in tables (especially on the page: "Tables: What Are the Common Side Effects of Medication Treatment?").
- (4) Therapy training for different types of therapists.

#### ***Amount of information***

Most of the pages were described as containing about the right amount of information. The exceptions were:

- (1) “Long-Term Side Effects” page, where some thought a bit more could be added and some thought there was a bit too much information.
- (2) “What Are the Risks of Psychotherapy and Counselling?” page, where most expressed an interest for more information.
- (3) “Tables: What Are the Common Side-Effects of Medication Treatment?” page where, although most thought the amount of information was acceptable, there was acknowledgement from some participants that it was a lot of information. For example, one of the female participants said:  
*I think it's good... obviously not everybody's going to like read the whole thing and know all those things, but it's a good reference to just look up you know about things you've heard of.*
- (4) “Uncommon but Serious Side Effects” page where some felt there was noticeably less information compared with the other side effects pages. For example, one of the male participants said:  
*It seems alright, it's just... the amount of information per section seems a little unbalanced, I don't know if that's just sort of a, a visual thing...when you look at alcohol, people mixing medication with alcohol is probably as common as all the other sections, but it's so much smaller.*
- (5) “Self-Help Treatments” page was acceptable to most; however, one of the men felt quite strongly that it was too brief: “Um but yeah, so this definitely needs to be longer.” This participant expounded that self-help treatment is important because there are no other treatments that can provide 24-hour, day-to-day care because they rely on someone other

than yourself: “Uh and it, and it really addresses the day to day stuff...And the only person that can be with you all the time is yourself...”

### ***Clarity***

Overall, both men and women felt that the decision aid was very clear, with no areas of real concern or confusion. One male participant commented:

*Oh yeah...again the whole short attention span thing like doubles as a compliment. If I can understand it then it's like probably five times...easier to read for everyone else.*

Although he believed the decision aid was quite clearly written, one of the men suggested developing two versions of the decision aid: the current version as well as one written in more plain language. Another overall suggestion to improve clarity was to increase the use of bullet points, especially where there were longer paragraphs and pages.

### ***Balance***

Most felt that the decision aid was well balanced. A number of participants commented that they appreciated that the information described a range of different treatments and indicated that some but not all of those taking a particular treatment benefited from it. Some also commented that the material did not seem to be pushing a particular treatment but rather presented treatment options for the reader to consider. One woman commented:

*...Actually showing all the like different sides and how they can be combined and like how it works for some people, it doesn't work for other people...*

One of the male participants felt the decision aid could be more balanced in its portrayal of treatments and available resources. One of the female participants noted that there is more information on medications than other treatments, thereby creating a type of imbalance. However, she also thought this was as an understandable and natural imbalance:

*No, I mean there's definitely way more information about medication but that's because there's way more that people want to and need to know about it...So I think it just makes sense. It's the amounts of information are appropriate to the subjects.*

### **Trustworthiness**

Most agreed that the overall decision aid seemed fairly trustworthy. However, several participants noted the lack of references to other source materials and felt this decreased their sense of trustworthiness of the material. As one female participant put it:

*Well it doesn't really say where this information came from so...maybe if there was some kind of citing of where this information came from, 'cause I guess anybody can really find information on the Internet and then kind of put it how they want, I guess.*

All participants saw the Combined Treatment/Self-Help Treatment section as generally trustworthy. However, several participants noted a relative lack of “facts” and research findings that reduced the relative trustworthiness. For example, one woman said:

*...it seemed more like kind of opinionated...not like facts and information, but just kind of like this is another way... it didn't have like the, as many facts...like the other pages...*

### **Helpfulness**

The general opinion was that the overall decision aid offered helpful information.

Reasons for perceived helpfulness included:

- (1) How informative it is—how it broadens one's perspective.
- (2) How it reduces confusion.
- (3) How it can contribute to realistic expectations.
- (4) How mind-opening it is.
- (5) How practical it is for someone making decisions about depression treatment.

## (6) How empowering it is.

One of the men emphasized the helpfulness of increased knowledge and empowerment, as well as broadened perspective. He said:

*...It would have been, I would have had more of a broad perspective on depression...because at the time it was limited to me, 'cause I didn't have, there was not much pamphlets...there was not much professional help, there, there was like oh here's some pills down your throat... .*

One of the women explained that the information could have been helpful if she could have referred to it after seeing her doctor. A man felt it would have helped him decide to find a new therapist sooner than he did, and another man thought it would have better prepared him for psychotherapy, particularly in terms of expectations. One man said he thought it would have helped him while particularly confused in his depressed state, especially in terms of the decision to do something.

One of the women believed that the material was too “dry” and that this would have been prohibitive to reading through the material:

*Um it would have been kind of, like I think it may have, I probably feel like the way I was would have read like maybe a couple of pages and then just been like, I don't want to read anymore so, just 'cause it's so like dry, it's dry material so. If I read it, it probably would have been helpful but I couldn't say I'd probably read it.*

**Recommend the decision aid?**

Most agreed that they would recommend this decision aid to someone they thought was suffering from depression. The rationale for recommending the decision aid was similar to how

they saw the aid as helpful for themselves and included how it was informative and empowering.

One woman explained:

*...It just gives a really good overall look at kind of this world...and the comfort you're going to get there is knowing what's going on and feeling like you're in control...and feeling like there are things you can do about it...and I mean it's perfect.*

One of the male participants felt he would wait till the suggested improvements had been made:

*I think I would trust it more if there was a lot more done to it...Um and I would refer it to a friend of mine and I have tons of friends that have depression...and they could really use something like this...it will help them realize there's a whole different world out there.*

### ***Format Suggestions***

Participants suggested the following formats for making this information available to people:

- (1) Website.
- (2) Personal presentations (e.g., schools and self-help organizations).
- (3) A brief summary of information in a pamphlet with reference to the full decision aid on a website.
- (4) Pamphlets placed in primary care offices, pharmacies, schools, and universities.

The most common suggestion was to make the decision aid available on a website. For example, one woman said:

*I think like internet would be the best...because...I guess for my age group...and for like teenagers because no one really opens books and reads them, like maybe for older adults*



*it would be good in like a book or something but for like the young adult or teen population everything we do is on the Internet...*

### ***Suggestions for Improvement***

The interviews provided many helpful suggestions for revising and improving the decision aid. There were several suggestions to slightly revise wording to increase understanding and/or correct typos. The format change suggestions primarily focused on presenting information more concisely and/or using bullets to present information and to make the material more appealing to young adults. Suggestions for added content were most numerous and included suggestions to include contact information for therapists, to add more to the “Self-Help Treatment” page, to add the suggestion that readers obtain medication information sheets from pharmacists, and to describe a variety of available psychotherapy groups. Suggestions to present material differently included using warmer language, representing probabilities differently, and making slight organizational changes (e.g., move a paragraph to another page).

### ***How your feedback was used***

After this interview study was done and the changes were made, the revised decision aid was launched in a web-survey format with a larger group of young adults who also provided their opinions on the content of the aid. Once again, many helpful suggestions from these young adults resulted in further improvements.

### **THANK-YOU FOR MAKING A DIFFERENCE!!**

As you can see by this brief report, your contribution to the development of this information was substantial. You have helped to develop information to inform

and empower others who may be needing information about depression for themselves or for loved ones.

If you want to take a look at the most recent version of the decision aid (including changes you and others have suggested), follow the link:

<http://depression.informedchoices.ca/>

**Appendix Q: Study 2 Consent Webpage:**

**Department of Psychology**

190 Dysart Road  
 Winnipeg, Manitoba  
 Canada R3T 2N2  
 Telephone (204) 474-9338  
 Fax (204) 474-7599

*Information and Consent Form*

**Project title: Evaluation of a New Web-Based Decision Aid for Depression**

**Principal Investigator: Bradley D. Zacharias, M.A., Ph.D. Student**  
 Department of Psychology, University of Manitoba  
 Phone:  
 Email:

**Research Supervisors: Dr. John R. Walker, C. Psych, Professor (Research Advisor)**  
 Department of Clinical Health Psychology, University of Manitoba  
 Phone:  
 Email:

**Dr. Diane Hiebert-Murphy, C. Psych, Professor**  
 Department of Psychology, University of Manitoba  
 Phone:  
 Email:

**This consent form, a copy of which you may save or print for your records and reference at this time, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to contact us. Please take the time to read this carefully and to understand any accompanying information. Note that the consent form may be printed after you review this page but it will not be available on later webpages. However, email requests for an electronic copy of the consent form may be sent to Bradley Zacharias (above) until December 31, 2012.**

**Bradley Zacharias is conducting this study as his Ph.D. Thesis in Clinical Psychology at the University of Manitoba, under the supervision of Drs. Hiebert-Murphy and Walker (above). The purpose of the project is to understand young adults' views about the information contained in a new decision aid for depression. Decision aids are tools intended**

**to inform and empower healthcare consumers in their treatment decision making. You will be asked to read information about depression and several forms of treatment for depression and to provide your opinions regarding the information. Your opinions will help make improvements to the decision aid. You will also be asked to complete some questions about your background such as your education, your parent(s)' education, and your parent(s)' postal code(s). The reason for collecting information regarding parents' education and postal codes is to gain a better understanding of your family's social and economic background. You will also be asked whether you have experienced depression and sought treatment. You will also be asked to complete a brief questionnaire (six items) regarding your current emotional distress.**

**Our preliminary testing indicates it should take a maximum time of 120 minutes to complete the survey. Please note that reading about depression carries with it a risk of experiencing emotional distress (especially if you have personal memories of being depressed). A list of local helping resources that you can download and/or print is located at the end of the survey. Participation may afford some direct benefits to you in terms of learning more about the nature of depression and depression treatments. You will also receive 4 research participation credits, which will be awarded to you within 2 weeks of participation. You will also be given the opportunity to download and/or print a copy of the decision aid. It is hoped that a greater understanding of young adults' opinions regarding the decision aid will help to provide the most beneficial information and decision support to aid adults looking for help for depression for themselves or for people they know. Your participation in this study is completely voluntary. Should you choose to withdraw from the study at any point or feel that you would rather leave some question(s) unanswered, you may do so without any penalty (e.g., you will still receive 4 research participation credits).**

**All the information you provide will be collected and saved on an anonymous basis. That is, once you click on the web address provided, you will be given a random participant identification number. This way, there will be no way of linking your responses to your student number. It will only be apparent THAT you participated (and have earned research participation credits); it will not be known WHICH responses you gave. Although this on-line survey tool transmits your responses in an encrypted form (similar to on-line banking), and stores it on a highly secure password-protected off-campus server, there is always the risk (anytime the Internet is used for anything), however small, that someone could either legally access the data (e.g., law enforcement agencies) or illegally access the data (e.g., "hackers"). However, you can be assured that every feasible precaution is taken to protect the data.**

**A brief summary (1-3 pages) of the results of this study will be available by February, 2013. If you would like to receive a summary, please follow the link at the end of the survey. This will redirect you to a site where you can provide your name and address, which will be kept completely separate from your survey responses. You only need to provide this information if you wish to receive a summary of the results; you are not required to provide this information to receive credit for your participation. The electronic file with the list of names and email addresses will be password protected and will be stored on a password**

protected computer in our research lab at St. Boniface General Hospital. Only the research team members will have access to this file. Once all the data are collected and analyzed for this project, the plan is to share this information with the research community through seminars, conferences, presentations, and journal articles. As the study is part of Bradley Zacharias' Ph.D. thesis, the results will also be presented to his thesis committee members and others who may attend his oral defense. Copies will also be provided to the Department of Psychology and Faculty of Graduate Studies at the University of Manitoba. When presenting the results of this research, no information that would reveal the identity of individual participants will be provided.

Clicking “yes” at the bottom of this page indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. If you wish to withdraw, simply close the browser window at any time. If you do choose to withdraw from this study, any data provided to that point will be saved on an anonymous basis and included in the analysis. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba Research Ethics Board(s) and a representative(s) of the University of Manitoba Research Quality Management/Assurance office may also require access to your research records for safety and quality assurance purposes. This research has been approved by the Psychology/Sociology Research Ethics Board (#P2012: 052). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. If you have read the information presented in this form and do not have any questions about this study, please click “I agree” when you are ready to begin. You should only click “I agree” if you agree to participate with full knowledge of the study presented to you in this information and consent form and of your own free will.

We suggest that you be in a quiet place, when you have up to 120 minutes free, and where you can complete this survey on your own and without interruption. We would appreciate it if you could turn off all instant messaging programs, as well as any other programs, currently running on your computer before continuing. Thank you for your consideration. We strongly encourage you to save or print a copy of this consent form now for your records. [Click here](#) to download this Consent Document in .pdf form, which may then be printed. If you do not wish to participate in this study now, please close your web browser. You may return to participate at a later date and time. You have 72 hours to complete this survey from the date and time of your signing up. Thank you for considering participating.

*Do you wish to continue?\**

Yes

No

## Appendix R: Study 2 Demographics Questions:

### *A Few Questions about You:*

**What is your University Student Number?\***

---

(\*=required item)

**For each question, please click the response that best describes you or fill in the text box:**

*Your gender:*

Male

Female

**Your age:**

---

*Your first language:*

English

French

Other

*YOUR Education: How many years of education have you completed in the following areas?*

	0	1	2	3	4	5	6	7	8	9	10	11	12	13
Grade School 1 – 12 (or 13):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apprenticeship:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
College, technical, business, vocational, nursing (non-university):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
University program:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*In which faculty are you registered?*

University 1

Architecture



*Mother's Education: How many years of education has your MOTHER completed in the following areas?*

	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b>
Grade School 1 – 12 (or 13):	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )
Apprenticeship:	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )
College, technical, business, vocational, nursing (non-university):	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )
University program:	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )

*Please fill in the postal code(s) of parents in the blanks below OR SKIP QUESTION IF YOU DON'T KNOW:*

Parents residing together:: \_\_\_\_\_

Mother:: \_\_\_\_\_

Father:: \_\_\_\_\_

**What do you expect your total debt to be for post-secondary education when you have completed your program?**

\_\_\_\_\_

*Marital status:*

- ( ) Single/Never married
- ( ) Married/Common-law
- ( ) Separated
- ( ) Divorced

**When people think of past experiences, they may remember periods in their life when they were having difficulty with depression.**

*Was there a period in the past when you were having problems with depression that was causing a lot of distress or interfering with your everyday life?*

- ( ) Yes
- ( ) No
- ( ) Not sure



*Have you ever had counselling for problems with depression?*

- Yes
- No
- Not sure

*Have you ever had medication treatment for problems with depression?*

- Yes
- No
- Not sure

*Have you ever taken medication and counseling at the same time for problems with depression?*

- Yes
- No
- Not sure

**[INSERT K6]**

**Appendix S: Study 2 Webpage Questions:**

*Was the amount of information on this topic?*

- much too little
- too little
- just right
- too much
- way too much

*The information on this topic seems clear and understandable*

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

*The information on this topic seems trustworthy.*

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

*How familiar are you with this topic information?*

- very familiar
- somewhat familiar
- unsure
- somewhat unfamiliar
- very unfamiliar

**Do you have any suggestions for improving the information on this page or for other things that should be included?**

**Appendix T: Study 2 Overall Questions:****Overall Questions:**

**Now considering all of the information in the decision aid (all of the topics), how would you rate the decision aid as a whole?**

*The amount of information in the decision aid was:*

- much too little
- too little
- just right
- too much
- way too much

*The information in the decision aid is clear and understandable.*

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

*The information in the decision aid appears trustworthy.*

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

*How familiar or unfamiliar are you with the information in the decision aid?*

- very familiar
- somewhat familiar
- unsure
- somewhat unfamiliar
- very unfamiliar

*How balanced was the information in the decision aid?*

- slanted towards trying counselling or psychotherapy
- slanted towards trying medications
- slanted towards trying combined treatment
- slanted towards trying self-help strategies
- balanced descriptions of treatments

*For those who have had difficulties with depression and looked for treatment in the past (all others click "Not Applicable"):*

*This decision aid would have been helpful for me when I was looking for treatment for depression*

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree
- Not Applicable

*For those who have NOT had problems with depression (all others click on "Not Applicable"):*

*This decision aid would be helpful to me IF I was having problems with depression and looking for treatment*

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree
- Not Applicable

*I would recommend this decision aid to a friend or family member if I thought he/she was having problems that looked like depression*

- Strongly disagree
- Disagree
- Neutral

- Agree
- Strongly agree

**Do you have any overall suggestions that you did not describe previously for improving the information in the decision aid?**

**Appendix U: Study 2 Recruitment Announcement:**

Department of Psychology

190 Dysart Road  
*Winnipeg, Manitoba*  
*Canada R3T 2N2*  
*Telephone (204) 474-9338*  
*Fax (204) 474-7599*

**Study Name:** Evaluation of the Informational Component of a New Web-Based Decision Aid for Depression

**Principal Investigator:**

Bradley D. Zacharias, M.A., Ph.D. Student  
 Department of Psychology, University of Manitoba  
 Phone:  
 Email:

**Research Supervisors:**

Dr. Diane Hiebert-Murphy, C. Psych, Professor  
 Department of Psychology, University of Manitoba  
 Phone:  
 Email:

Dr. John R. Walker, C. Psych, Associate Professor,  
 Department of Psychology, University of Manitoba  
 Phone:  
 Email:

**Brief Abstract:** An online study examining your opinions on the information in a decision aid regarding depression. Decision aids are tools intended to inform and empower healthcare consumers in their treatment decision making.

**Detailed Description:** This online study is being conducted by Bradley Zacharias, M. A., as part of a Ph.D. thesis in Clinical Psychology at the University of Manitoba under the supervision of Drs. Hiebert-Murphy and Walker (above). The purpose of the study is to examine the opinions of young adults of the information in the decision aid. That feedback will be analyzed and used to make changes to the information so as to increase the clarity and usability of the information for other young adults in the community. The study requires you to participate in one data collection session at a time of your convenience between now and the conclusion of the data collection period (ending in January, 2013). Once you sign up, you will be emailed a link to the survey. You can complete the survey as soon as you receive this link and up to 72 hours after

the sign-up system date/time. You will be asked to complete some questions pertaining to your demographic background such as your education, your parent(s)' education, and your parent(s)' postal code(s). The reason for collecting information regarding parents' education and postal codes is to gain a better understanding of your family's social and economic background. You will also be asked if you have ever been depressed and/or tried medication or psychotherapy for depression. The session will take up to 120 minutes to complete so you will receive 4 experimental credits. Once you have completed the survey, you will have the opportunity to download and/or print the decision aid. There is a chance that in reading about depression and depression treatments, you may feel distressed. A list of helping resources will be provided to participants.

**Eligibility Requirements:** Must be 18-25 years of age.

**Pre-Test Restrictions:** None

**Duration:** 1 data collection session of up to 120 minutes.

**Credits:** 4.

**Appendix V: Helping Resources Webpage:*****Helping Resources Page***

**Please note that reading about depression carries with it a risk of experiencing emotional distress (especially if you have personal memories of being depressed).**

**[Click here](#) for a list of local helping resources that you can download and/or print. There is another copy of this list included with a printable/downloadable copy of the Decision Aid at the end of the survey.**



**Appendix W: Study 2 Helping Resources:****Department of Psychology**

190 Dysart Road  
 Winnipeg, Manitoba  
 Canada R3T 2N2  
 Telephone (204) 474-9338  
 Fax (204) 474-7599

**RESOURCES FOR HELP FOR ADULTS WITH DIFFICULTY WITH STRESS, ANXIETY, AND DEPRESSION**

If you are in crisis, you can call Klinik Crisis Line: 786-8686/1-877-435-7170 (toll free Manitoba). They have trained counselors available 24 hours per day/7 days per week. If you are feeling like you might be a danger to yourself or someone else, you should go to the emergency room of the nearest hospital immediately.

Difficulties with stress, anxiety, and depression are common. Many mental health professionals (e.g., psychiatrists, psychologists, and trained counselors) have experience helping people deal with these problems. Consequently, a person is likely able to obtain help with wherever mental health services can be arranged. A list of some of the available services is provided below. The best way of finding out if a therapist or counsellor has experience in this area is to discuss it with him or her. Your family doctor may be able to suggest other appropriate services.

**UNIVERSITY OF MANITOBA COUNSELLING RESOURCES:**

There are a number of counseling services available to **University of Manitoba students**. A major source of a variety of services is the Student Counselling and Career Centre. To assist students in obtaining appropriate information and services, staff members of the Student Counselling and Career Centre have provided a variety of web pages (visit their homepage for more web addresses: <http://umanitoba.ca/student/counselling/>).

Students are encouraged to contact the Student Counselling and Career Centre offices located on either the Fort Garry or the Bannatyne campuses if they need additional information.

**Fort Garry Campus**  
 474 University Centre  
 (204) 474-8592

**Bannatyne Campus**  
 S207 Basic Medical Science  
 Building (204) 789-3857 or  
 (204) 474-8592

The Student Counselling and Career Centre is staffed by professional counsellors whose primary goal is to facilitate the personal, social, academic, and vocational development of university students. To fulfill this role, the Student Counselling and Career Centre provide the following programs and services:

**PERSONAL COUNSELLING** - Counsellors are available to provide supportive and problem-solving assistance for emotional difficulties, interpersonal problems, or stressful life situations.

**GROUP DEVELOPMENT** - Group programs that provide support, develop skills, and aid in self-improvement in specialized areas are announced and offered throughout the year. Educational and informational programs are also part of the Student Counselling and Career Centre's activities. There is a nominal registration fee for some group programs.

**CAREER COUNSELLING** - Career planning and counselling are available on an individual and group basis. Testing and assessment of interests, abilities, and personality are available as well. There is a nominal charge for testing services.

**CAREER RESOURCE CENTRE (CRC)** - To complement the career planning process, the Career Resource Centre maintains information on more than 230 occupations, a selection of university and community college calendars and career-related resource books and materials. The CRC is organized on a self-help basis, but a resource person is available to assist you on a drop-in basis.

**CAREER MENTOR PROGRAM** - The Career Mentor Program provides an opportunity to meet with a professional working in a specific field. Most of our mentors are University of Manitoba alumni. The program involves exploring the world of work to gain a realistic view of a specific career.

**REFERRAL AND CONSULTATION** - In addition to providing direct service to students, counsellors are available to provide referral information and consultation service to other members of the university community.

**TRAINING** - The Student Counselling and Career Centre provides placements and supervision of students who are pursuing counselling as a profession. Therefore, during the regular academic session, students assist our professional staff in the provision of direct service to students. Students are encouraged to call the Student Counselling and Career Centre or drop by the main office to inquire about programs and services. Students who have not seen a counsellor before may come during our drop-in times to see a counsellor for a short introductory interview. Students will then be directed to individual or group counselling, career services, or referred elsewhere.

**Personal Counselling Scheduled Drop-in Times:**

(Regular Session September - April): Monday, Tuesday, Thursday, Friday 9:30 am – 10:30 am 1:30 pm – 2:30 pm Wednesdays 1:30 pm – 2:30 pm The office is open 8:30 - 4:30, Monday to Friday. You are encouraged to call their office (474-8592) for the summer drop-in times (May-August)

**KLINIC COMMUNITY HEALTH CENTRE:**

Klinik Community Health Centre offers a Drop-In Counselling Program available in various communities (See website for more information and links: <http://www.klinik.mb.ca/dropin.htm>):

**Central/Downtown** 545 Broadway, R3C 0W3 (Klinik on Broadway) Mondays & Wednesdays Noon – 7:00 p.m. Tuesdays, Fridays & Saturdays Noon – 4:00 p.m.

**Transcona/River East/Elmwood** 845 Regent Avenue West, R2C 3A9 (Access Transcona) One block west of Plesis Road Tuesdays Noon – 7:00 p.m.

Times subject to change. Please call the Drop-In Line (204-784-4067) for current times and site closures or e-mail them at: [dropin@klinik.mb.ca](mailto:dropin@klinik.mb.ca).

**RESOURCES AVAILABLE THROUGH THE WORKPLACE:**

Many people have access to benefits through their work that would provide for counselling or therapy services that cover themselves, their partner and their children. If one of your parents has one of these benefits and you are living with them, you may be covered. It is best to check the details of the plan with your parents.

- Employee Assistance Programs (EAP) are available with many employers. They provide counseling services that cover a wide range of personal and family problems including stress, anxiety and depression. The service is confidential and the employer does not know which employees are using the service and for what reasons. Service is usually provided in an office away from the work site. The programs often allow for a certain number of appointments per calendar year. You can refer yourself to an EAP. It is best to obtain a copy of the brochure describing the plan to see what services are provided as different programs provide different services.
- Extended health insurance is a benefit in many workplaces. Often the employee pays a monthly premium. This program covers services such as ambulance, physiotherapy, and clinical psychology services. The insurance plan often has rules about when services will be covered. It is best to obtain a copy of the brochure describing the plan to see what services will be covered and what dollar amount is covered per year. For example, some plans require a referral from a physician in order for the cost of the visits to be covered. Generally the services obtained through these plans are confidential and the employer does not receive information about who is using the plan and what services they are using. The names of psychologists who provide services covered by many extended health insurance plans are listed in the yellow pages section of the phone book.
- Some employees have access to both an Employee Assistance Program and extended health benefits and they may use both if they wish.

**COMMUNITY SERVICES:** For most of the services listed below, individuals may refer themselves. A referral from a doctor is not necessary, although it is welcomed.

**COUNSELLING SERVICES:** A range of organizations provide counseling services in the Winnipeg Region. It is necessary to call the service to see whether they have openings. A good place to get an extensive list of the counseling services available is the Mental Health Resource Guide for Winnipeg available on the Internet at: [http://www.cmha.ca/data/1/rec\\_docs/867\\_Mental-Health-Guide-10th%20Edition%202006.pdf](http://www.cmha.ca/data/1/rec_docs/867_Mental-Health-Guide-10th%20Edition%202006.pdf)

**ACCESS CENTRES AND COMMUNITY HEALTH CENTRES:** Many of the health centres in Winnipeg have counseling services. Contact the centre to see what services are available. As an example, Clinic Health Centre at 870 Portage Ave. phone 784-4059 has a range of services available including a drop in service on particular days. This Centre has special services for people with a history of abuse.

Health Access Centres such as Access River East (938-5000) and Access Transcona (938-5555) serve particular areas of Winnipeg.

**FAMILY ORIENTED SERVICES:** The following services may be especially helpful in situations in which family difficulties are a source of concern.

**Aurora Family Therapy Centre:** at the University of Winnipeg (786-9251)  
<http://aurora.uwinnipeg.ca/clinic.shtml>

**Family Centre of Winnipeg:** 401-393 Portage Avenue (Portage Place), Winnipeg, 947-1401  
[www.familycentre.mb.ca](http://www.familycentre.mb.ca)

**SELF HELP:** Self-help associations can provide excellent information about services and many offer group programs that can help people cope with and overcome personal problems.

- **Anxiety Disorders Association of Manitoba:** 100 - 4 Fort St., Winnipeg 925-0600 (outside Winnipeg, phone 1-800-805-8885). There are several regional offices around the province. A self-help association that provides a variety of resources including educational groups (available at a modest cost) to help members learn to cope with problems with panic disorder, social anxiety disorder, and other anxiety problems. Support groups are available year round.  
[www.adam.mb.ca](http://www.adam.mb.ca)
- **The Obsessive Compulsive Disorder Centre Manitoba (OCDC):** 100-4 Fort St., 942-3331. A self-help organization offering education and support to persons suffering from obsessive compulsive disorder (OCD) as well as their families. In addition to a library of education and self-help materials, the centre offers a support group, an education group for family members, and a group focused on setting goals to assist in overcoming OCD.  
[www.ocdmanitoba.ca](http://www.ocdmanitoba.ca)
- **Mood Disorders Association of Manitoba:** 100-4 Fort St., Winnipeg, 786-0987. A self-help association that provides a variety of resources including educational groups to help members learn to cope with problems with mood disorders such as depression and bipolar disorder.  
[www.depression.mb.ca](http://www.depression.mb.ca)

**PRIVATE PRACTITIONERS:** Health service providers in a number of different specialty areas serve people with problems with stress, anxiety, and depression. The professional association may be able to give you the names of professionals who provide services to people with specific problems. Some practitioners request a letter of referral from your family doctor. Only psychiatrists in private practice are covered by Medicare. With other service providers it is a good idea to ask about the cost of services before you arrange for your first appointment. The service provider should willingly provide information about the cost of the service and the number of sessions that people might use for typical problems so that you can have a reasonable idea about the cost of service.

**Psychiatrists:** Names are listed in the Yellow Pages or telephone the College of Physicians and Surgeons, 774-4344.

**Psychologists:** Extended health benefit plans through employment often provide coverage. Consult the Yellow Pages or telephone the Psychological Association of Manitoba, 487-0784. [www.cpmb.ca](http://www.cpmb.ca)

**Registered Psychiatric Nurses:** Some nurses provide private services. Contact the College of Registered Psychiatric Nurses of Manitoba, 888-4841

**Social Workers:** Blue Cross and other private health plans may provide some coverage. Contact the Manitoba Institute of Registered Social Workers, 888-9477.

**Appendix X: Study 2 Instructions Webpage:**

**This decision aid contains information about depression and the treatment of depression. In this survey, you will read the information one section at a time, and then give your opinions about the information provided. At the end of the decision aid, there are a few more questions regarding your opinions about the overall decision aid.**

**Please read each section carefully and answer the questions at the end of the section. After you have answered the questions, please click the 'next' button. At the end of the survey, you will be able to download a copy of the decision aid (without the questions) and the scientific references we used to assemble this information.**

**We suggest that you be in a quiet place, when you have up to 120 minutes free, and where you can complete this survey on your own and without interruption. With 120 minutes to complete the survey, you should have ample time to carefully read the materials and provide suggestions for improvement.**

**We would appreciate it if you could turn off all instant messaging programs, as well as any other programs, currently running on your computer before continuing.**

**Thank you for your consideration.**

**Appendix Y: Study 2 Feedback:****STUDY FEEDBACK**

**Thank you for participating in this study!**

**This study explores young adults' opinions and preferences concerning information in a new decision aid regarding the nature of depression and some of the common treatments for depression.**

**Results from a previous study using data from in-person interviews with young adults informed improvements to the information that was then presented to you in this survey. The results of this survey will be used to make further improvements to the decision aid so as to further increase its acceptability and benefit to young adults interested in information about depression and its treatment.**

**The results of the final project will be available beginning in February, 2013. If you indicated that you would like information about the results of the study, we will send a summary of findings to you at that time.**

**Questions or concerns about this study can be directed to Mr. Bradley Zacharias at \_\_\_\_\_, or, Dr. John Walker at \_\_\_\_\_ or \_\_\_\_\_.**

**If you have any complaints about this project, you may contact the above-named persons or the Human Ethics Secretariat at 474-7122 or via email to [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).**

## Appendix Z: Study 2 Results Summary for Participants:

### EVALUATION OF A WEB-BASED DEPRESSION DECISION AID STUDY SUMMARY

This study explored young adults' opinions and preferences concerning information in a new decision aid focused on depression and some of the common treatments for depression. We examined participants' opinions about the amount, familiarity, trustworthiness, clarity, balance, and helpfulness of the decision aid. We also explored participants' ratings in light of demographic backgrounds. Finally, we wanted to observe how time spent on the different web-pages varied and if it varied according to any demographic variables like gender.

The results of this study have been used to make changes to the decision aid which now exists as a web-based information tool (<http://depression.informedchoices.ca/>).

Below is a summary of the results of the project in which you participated.

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- There was a large degree of variation on ratings of **familiarity** with half of participants rating the overall decision aid as familiar and about 37% rating it as unfamiliar. One of the more familiar topics was “What is Depression?” and one of the most unfamiliar topics was “Tables: What Are the Common Side Effects of Medication?” (“Tables”).
- Most participants (75%) rated the decision aid as having a *just right amount* of information. One topic rated as *too little* by 45% of participants was “What are the Risks of Counselling or Psychotherapy?”, and one topic rated as *too much* was “Tables”.
- Most participants (91%) rated the overall decision aid as **clear**.
- A minority of participants (40%) rated the decision aid as **balanced**, whereas 26% rated it as *slanted toward trying psychotherapy or counselling* and 21% rated it as *slanted toward trying medications*. Very few participants rated the



decision aid as *slanted toward trying combined treatment* (11%) or *slanted toward trying self-help treatment* (2%).

- A large majority of participants (93%) rated the information as **trustworthy**.
- The majority of participants rated that the decision aid either would have been **helpful** in a past decision he/she made about depression treatment (77%), or would be helpful if a participant became in the future depressed and needed to decide on treatment (80%).
- The majority of participants (81%) reported that they would also recommend the decision aid to someone they thought was struggling with depression.
- There was very little variation of opinions based on demographic data. First, a larger proportion of women (52%) versus men (34%) rated the overall decision aid as portraying a **balanced** description of treatments. Second, although providing similarly high helpfulness ratings, those who reported higher maternal education and no personal history of depression reported the decision aid as slightly less helpful in a hypothetical future decision.
- The mean **time** (standardized to seconds per 100 words) spent on the overall decision aid was 37 seconds, and topic based times ranged from 21-57 seconds, which are in line with established reading times within the “reading for learning” and “reading for comprehension” times (Carver, 1992). Participants’ demographic background information did not vary with time spent on the overall decision aid or on separate topics. Topics logging highest mean times were “What Is Depression?”, “Treatments for Depression”, “What Are the Risks of Psychotherapy or Counselling?” and “What Are the Common Side Effects of

Medication Treatments?” and pages with lowest mean times were “Self-Help Treatments” and “Uncommon but Serious Side Effects”.

- Participants also completed some **open text boxes** for suggestions for improving the decision aid. The most common themes in the comments were suggestions to add information (73 responses) and suggestions that we handle or present the information in a different way (69 responses). Prominent examples of the former include the suggestion that we “use more examples” (10 responses) and the suggestion that we add information that helps normalize depression and its treatment so as to decrease stigma (7 responses). Major examples of the latter include suggestions to “be more specific” (16 responses) and that we combine topic pages (12 responses). Another common theme was the suggestion to add or update references (24). However, there were also many positive comments made about the decision aid (43). There were only 2 comments made suggesting that this format of informing a potentially depressed person about depression and treatment would be inappropriate for such a person (i.e., too lengthy to expect him/her to read through it). The summarized comments were reviewed by members of the development team to consider which would be useful in strengthening the content of the decision aid. Revisions were then made to the decision aid.

### **Once again, thank-you for your participation!**

Questions or concerns about this study can be directed to Mr. Bradley Zacharias at \_\_\_\_\_ or Dr. John Walker at \_\_\_\_\_. If you have any complaints about this project, you may contact the above-named persons or the Human Ethics Secretariat at 474-7122 or via email to [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).

Appendix AA: Study 1 Version of the “Tables” Page:

**Tables: What are the common side effects of medication treatment?**

**Early side effects:**

Some side effects may start shortly after starting a medication. Many of these may decrease or stop after you have been taking the medication for a few weeks. Others may go away only when you stop taking the medicine or reduce the dosage. About 6 out of 10 people will experience at least one side effect. Your doctor may be able to suggest ways to manage side effects. Common side effects of the most widely-used medications for treatment of depression and anxiety are shown in the following two tables. Information about other medicines used for treatment of depression and their side effects may be obtained from your family doctor or psychiatrist.

**Table 1A: Common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Less than 1 out of 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect				
	Nausea	Diarrhea	Constipation	Dry Mouth	Sweating
<b>SSRI Group</b>					
citalopram (Celexa)	■■	■	-	■■	■■
escitalopram (Ciprolex)	■■	■	■	■	■

fluoxetine (Prozac)	■ ■	-	-	■ ■	■
fluvoxamine (Luvox)	■ ■ ■	■	■ ■	■ ■	■ ■
paroxetine (Paxil)	■ ■	■ ■	■ ■	■ ■	■ ■
sertraline (Zoloft)	■ ■ ■	■ ■	■	■ ■	■
<b>SNRI Group</b>					
venlafaxine (Effexor)	■ ■ ■	■	■ ■	■ ■	■ ■
desvenlafaxine (Pristiq)	■ ■	■ ■	■	■ ■	■ ■
duloxetine (Cymbalta)	■ ■ ■	■	■ ■	■ ■	■
<b>Other antidepressants</b>					
bupropion (Wellbutrin)	■ ■	-	■ ■	■ ■	■
mirtazapine (Remeron)	-	-	■ ■	■ ■	-

Note: SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

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**Table 1B: Other common side effects of antidepressant medications.**

Medication	Side Effect				
	Daytime Sleepiness	Trouble sleeping	Headache	Shakiness	Dizziness
<b>SSRI Group</b>					
citalopram (Celexa)	■ ■	-	-	■	-
escitalopram (Ciprolex)	■ ■	-	-	■	■
fluoxetine (Prozac)	■ ■	■ ■	-	■ ■	-
fluvoxamine (Luvox)	■ ■ ■	■ ■	■ ■ ■	■ ■	■ ■

paroxetine (Paxil)	■ ■	■ ■	■ ■	■	■ ■
sertraline (Zoloft)	■ ■	■ ■	■ ■ ■	■ ■	■ ■
<b>SNRI Group</b>					
venlafaxine (Effexor)	■ ■	■ ■	■ ■	■	■ ■
desvenlafaxine (Pristiq)	■	■ ■	■ ■	■	■ ■
duloxetine (Cymbalta)	■	■ ■	■	■	■
<b>Other antidepressants</b>					
bupropion (Wellbutrin)	-	■ ■	-	■	■
mirtazapine (Remeron)	■ ■ ■ ■	-	-	■	■

Note: Tables adapted from RW Lam, SH Kennedy, S Grigoriadis, RS McIntyre, R Milev, R Ramasubbu, SV Parikh, SB Patten, AV Avindran. Canadian Network for Mood and Anxiety Treatments (CANMAT) Clinical guidelines for the management of major depressive disorder in adults. III. Pharmacotherapy, *Journal of Affective Disorders* 117 (2009) S26–S43. SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

Appendix BB: Study 2 version of the “Tables” Page:

**Tables: What are the common side effects of medication treatment?**

**Early side effects:**

Some side effects may start shortly after starting a medication. Many of these may decrease or stop after you have been taking the medication for a few weeks. Others may go away only when you stop taking the medicine or reduce the dosage. About 6 out of 10 people will experience at least one side effect. Your doctor may be able to suggest ways to manage side effects.

Common side effects of the most widely-used medications for treatment of depression and anxiety are shown in the following two tables. Your doctor or pharmacist will have information about other medicines used for treatment of depression.

**Table 1A: Common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Fewer than 1 out of 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect				
	Nausea	Diarrhea	Constipation	Dry Mouth	Sweating
<b>SSRI Group</b>					
citalopram (Celexa)	■■	■	-	■■	■■
escitalopram (Ciprolex)	■■	■	■	■	■
fluoxetine (Prozac)	■■	-	-	■■	■
fluvoxamine (Luvox)	■■■	■	■■	■■	■■
paroxetine (Paxil)	■■	■■	■■	■■	■■
sertraline (Zoloft)	■■■	■■	■	■■	■
<b>SNRI Group</b>					
Venlafaxine (Effexor)	■■■	■	■■	■■	■■
desvenlafaxine	■■	■■	■	■■	■■

(Pristiq)					
duloxetine (Cymbalta)	■■■	■	■■	■■	■

**Other antidepressants**

bupropion (Wellbutrin)	■■	-	■■	■■	■
mirtazapine (Remeron)	-	-	■■	■■	-

**Note:** SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.

**Table 1B: Other common side effects of antidepressant medications.**

**Symbols:**

- Very few people report this symptom
- Fewer than 1 in 10 people report this symptom
- 1 to 3 out of 10 people report this symptom
- 3 to 5 out of 10 people report this symptom
- 5 out of 10 or more people report this symptom

Medication	Side Effect					
	Daytime sleepiness	Trouble sleeping	Headache	Shakiness	Dizziness	
<b>SSRI Group</b>						
citalopram (Celexa)	■■	-	-	■	-	
escitalopram (Ciprolex)	■■	-	-	■	■	
fluoxetine (Prozac)	■■	■■	-	■■	-	
fluvoxamine (Luvox)	■■■	■■	■■■	■■	■■	
paroxetine (Paxil)	■■	■■	■■	■	■■	
Sertraline (Zoloft)	■■	■■	■■■	■■	■■	
<b>SNRI Group</b>						
Venlafaxine (Effexor)	■■	■■	■■	■	■■	
desvenlafaxine (Pristiq)	■	■■	■■	■	■■	
duloxetine (Cymbalta)	■	■■	■	■	■	
<b>Other antidepressants</b>						
bupropion (Wellbutrin)	-	■■	-	■	■	
mirtazapine	■■■■	-	-	■	■	

(Remeron)

**Note: SSRI= selective serotonin reuptake inhibitors, SNRI= selective norepinephrine serotonin reuptake inhibitors.**

**Tables adapted from RW Lam, SH Kennedy, S Grigoriadis, RS McIntyre, R Milev, R Ramasubbu, SV Parikh, SB Patten, AV Avindran. Canadian Network for Mood and Anxiety Treatments (CANMAT) Clinical guidelines for the management of major depressive disorder in adults. III. Pharmacotherapy, Journal of Affective Disorders 117 (2009) S26–S43.**