

Running head: IMPACT OF NEWS OF RISK



*Te Whare Wānanga o Ōtāgo*

# **The Acute Impact of Risk Information for Schizophrenia: Ethical Implications of Psychometric Screening**

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### Abstract

**Background:** In the psychometric high-risk paradigm, contrary to the principle of informed consent, participants are not usually informed of their risk status. One argument for this nondisclosure is that risk information may engender significant distress.

**Objective:** The aims were to investigate this argument and to examine the reactions of non-help seeking individuals to disclosure of personally relevant information about risk for schizophrenia. It was expected that the impact of news of risk for schizophrenia would be similar to that associated with cancer and greater than that associated with depression and a neutral control condition. It was also expected that stigma consciousness and health locus of control would predict distress arising from the news.

**Method:** Participants ( $N = 160$ ) underwent screening in a deception paradigm (thioamine acetylase enzyme deficiency) during which the participants were led to believe they had an enzyme deficiency that was benign (neutral control) or associated with elevated risk for schizophrenia, cancer, or depression. Participants provided subjective mood ratings, salivary cortisol pre- and post-manipulation, and rated beliefs about stigmatisation and health locus of control.

**Results:** Low levels of subjective and objective distress were observed. There was no evidence that the impact of news differed across groups or that health locus of control predicted distress. Greater expectations of being stigmatised predicted greater deterioration in self-reported mood.

**Conclusions:** The study helps to progress the research available on schizotypy screening and contributes to the debate surrounding this area. Given the findings, it is possible that the concern participants could experience distress upon receiving news of risk may not be well-founded.

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**List of Abbreviations**

CE	Catastrophic Events
CI	Cortisol Impact score
CPR	Cardiopulmonary Resuscitation
DNR	Do Not Resuscitate
EDSP	Early Developmental Stages of Psychopathology study
HD	Huntington's Disease
HIV	Human Immunodeficiency Virus
MHLC	Multidimensional Health Locus of Control scale
POMS	Profile of Mood States Questionnaire
PRI	Perceived Risk Impact Questionnaire
SCID-I	Structured Clinical Interview for the Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV-TR) Axis I Disorders
SCQ	Stigma Consciousness Questionnaire
SPD	Schizotypal Personality Disorder
SPQ	Schizotypal Personality Questionnaire
TAED	Thioamine Acetylase Enzyme Deficiency
TMDS	Change in POMS Total Mood Disturbance scores
TPSQ	Thinking and Perceptual Style Questionnaire

“Nondisclosure may be justifiable if the harmful effects of disclosure outweigh its benefits” (Linscott & Cross, 2009, p. 184).

The quotation above highlights the ethical implications of disclosure and nondisclosure in the context of research into psychometric risk for schizophrenia (schizotypy). It is not clear whether high-risk paradigm research into schizotypy is conducted in a manner consistent with the key principles of healthcare research, specifically in terms of informed consent, nondisclosure, and deception. Four principles form the foundation of ethical healthcare research practice. These are autonomy, beneficence, non-maleficence, and justice (Gillon, 1994). It is not uncommon to conduct general sample population screening studies and follow-up research that does not inform participating individuals about their risk status (for example, Kwapil, Miller, Zinser, Chapman & Chapman, 1997; Lenzenweger & Korfine, 1992; Linscott & Cross, 2009). Instead participants are told that the researchers are interested in such things as personality or attitudes (Linscott & Cross, 2009) as it is thought that risk information may engender significant distress. Screening for the purposes of the current research refers to large sample population testing, usually in order to define a particular population (Moum, 1995).

Another line of argument for the practice of nondisclosure is based on an aetiological theory of schizotypy that proposes the presence of a schizotypy taxon (Linscott & Cross, 2009; Meehl, 1990). It is reasoned that information about the existence of a schizotypy taxon could introduce significant stress that may increase the likelihood of an individual developing schizophrenia. The uncertainty about whether people would experience distress or not upon being told such information indicates an urgent need to conduct research in this area.

Until now there has been no consensus, or indeed little discussion, on whether nondisclosure is justifiable and if so under what circumstances (Beskow et al., 2001; Clayton &

Ross, 2006; Fernandez & Weijer, 2006; Miller, Christensen, Giacomini, & Robert, 2008). Even though legislation and ethical principles point towards disclosure within the context of informed consent (e.g., Health Information Privacy Code, 1994), the responsibility for ethical research practice lies with the researcher. This task is made more difficult by the lack of sufficient, relevant empirical evidence. The issue is also relevant in studies involving follow-up.

This study is designed to provide evidence that may support a scientifically sound and ethically justifiable decision in these matters. To achieve this, a version of a screening study for schizotypy is conducted comparing the effects of disclosure about being at risk for schizophrenia with disclosure of being at risk for other illnesses.

Initial research conducted by Linscott and Cross (2009) investigated peoples' responses to risk information. The study used a hypothetical paradigm to examine the impact that news of risk for the liability for schizophrenia had on non-help seeking individuals (Linscott & Cross, 2009). Undergraduate participants were asked to imagine that they were at increased risk for seven medical and psychological disorders, including schizophrenia. Participants then rated the impact they thought this imagined information would have on several aspects of their lives (felt distress, optimism, future lifestyle choices, coping, helplessness, and potential for survival). Participants thought that news of risk for schizophrenia would cause greater distress than risk for heart disease, arthritis, depression, and diabetes but less distress than risk for cancer and Alzheimer's disease.

There are two main limitations to the research of Linscott and Cross (2009). Firstly, using a hypothetical paradigm requires participants to imagine being at risk for a disorder, which is not the same as experiencing the outcome. Secondly, although the relative impact of different

disorders could be contrasted, the level of distress experienced, or anticipated by participants was not quantified in a way that had meaning beyond the study itself.

As with the Linscott & Cross (2009) research, the current study addresses the question of whether or not disclosure of risk engenders distress while addressing the limitations mentioned. To ensure the applicability of the findings a realistic paradigm is used in which the risk information is personally relevant to the participants for the time of participation. To achieve this it is necessary to base this paradigm on a deception approach, which is designed to be similar to a real-life screening process (Croyle & Ditto, 1990; Croyle & Ditto, 1995). Both subjective and objective measures are used to adequately measure the significance of participants' distress and account for the second limitation.

Firstly, the importance of schizophrenia and schizotypy will be discussed with several examples of the current research practice. Then a description of good ethical practice principles will be provided. The ethical issues of the current screening practice will be highlighted. After that, the available schizotypy research on these issues will be reviewed. Although there is little evidence specifically regarding ethical issues in schizotypy research, there is valuable information regarding this topic in literature on other pathologies including research on informed consent, research investigating the ethical debate behind genetic research, and stigma research. This information builds the basis of the methodical approach taken in this study and will therefore be discussed in more detail.

### **Importance of Schizophrenia and Schizotypy Research**

#### **Schizophrenia.**

In order to understand the importance of research in the area of schizophrenia and schizotypy, a definition of schizophrenia is firstly provided. Schizophrenia is a common and

debilitating mental illness that can have a significant effect on an individual's life. The disorder affects approximately 0.4% to 0.7% of adults worldwide with a variable course (American Psychiatric Association [APA], 2000). However, most people experience a prodromal phase in which several of the symptoms of the disorder gradually appear. People with schizophrenia then become either chronically ill or can experience exacerbations and remissions of the disorder (APA, 2000; Wan, Abel, & Green, 2008). The disorder is characterised by both positive (e.g., hallucinations, disorganised speech) and negative (e.g., affective flattening, alogia) symptoms and typically onsets in late adolescence or early adulthood (APA, 2000).

Given the significance of the problem, efforts to understand risk may help to reduce the burden of the disorder. Therefore, one focus of research has been defining the putative risk factors or prodromal symptoms of schizophrenia (Chapman, Chapman, Kwapil, Eckblad & Zinser, 1994; McGlashan et al., 2006; Yung & McGorry, 1996). Yung and McGorry (1996) have identified several of these factors including anxiety, depressed mood, and irritability. Table 1 provides a list of these commonly described prodromal features of schizophrenia. One benefit of schizotypy research is that it provides insight into the aetiology of schizophrenia and screening measures can then be developed. These measures provide an opportunity for researchers to investigate precipitating events and protective factors, both important for the development of early interventions (Chapman, Chapman & Kwapil, 1995; Clarke, 2003).

### **Theory of aetiology.**

Schizotypy is a low level liability state, often occurring before the prodromal state of schizophrenia. Meehl (1990) proposed that schizophrenia has a specific aetiology, namely that a genetic liability interacts with environmental contingencies (e.g., stress, social learning) to produce schizophrenia. There is also a key intermediate outcome of the liability, namely a

personality profile he referred to as schizotypal, a contraction of schizophrenic phenotype. Rado (1953) initially coined the term schizotypy. Schizotypal traits have been categorised into four areas with different manifestations in different individuals (Table 2) (Claridge et al., 1996).

Schizotypy therefore can be seen as the manifestation of predisposition for schizophrenia. It is important to note that not everyone who has schizotypy will develop schizophrenia. The prevalence of schizophrenia is estimated at 1%. The base rate of schizotypy in the general population is estimated at 10%, suggesting that just 10% of people with schizotypy will go on to experience schizophrenia (Clarke, 2003; Meehl, 1990). Accordingly, approximately 90% of people with schizotypy do not progress to schizophrenia.

Table 1  
*Commonly Described Prodromal Features of Schizophrenia*

Symptom Type	Specific outcomes
Neurotic Symptoms	Anxiety, restlessness, anger and/or irritability
Mood-related symptoms	Depression, anhedonia, guilt and/or suicidal ideas
Changes in volition	Mood swings, apathy, loss of drive, boredom, loss of interest, fatigue and/or reduced energy
Cognitive changes	Disturbance of attention and concentration, preoccupation, daydreaming, thought blocking and/or reduced abstraction
Physical symptoms	Somatic complaints, loss of weight, poor appetite and/or sleep disturbance
Attenuated or sub-threshold versions of psychotic symptoms	Perceptual abnormalities, suspiciousness, ideas of reference, change in sense of self and/or others, or the world
Other symptoms	Obsessive–compulsive phenomena, dissociative phenomena and/or increased interpersonal sensitivity
Behavioural changes	Deterioration in role functioning, social withdrawal, impulsivity, odd behaviour, aggressive and/or disruptive behaviour

*Note.* Adapted from “The Initial Prodrome in Psychosis: Descriptive and Qualitative Aspects,” by A. Yung and P. McGorry, 1996, *Australian and New Zealand Journal of Psychiatry*, 30, p. 587-599.

There is some evidence for the proposed higher rates of psychosis among those with schizotypy features (Klosterkotter, Hellmich, Steinmeyer, & Schultze-Lutter, 2001; Riecher-Rossler et al., 2006). One longitudinal study spanning 10 years found that people who scored highly on measures of schizotypy were more likely to develop schizotypy or psychosis itself (Chapman et al., 1994).

### **Impact of being schizotypal.**

Being schizotypal can have a significant affect on many areas of an individual's life, both positive and negative. Anhedonia is posited to be a significant feature of schizotypy that can have negative effects on an individual's functioning (see Table 2) (Clarke, 2003; Meehl, 1990). Research using a general adolescent population found that individuals with schizotypy are more likely to have greater levels of depressive symptomatology (Clarke, 2003).

People with schizotypal personality disorder (SPD) are found to have a poorer quality of life highlighting another negative outcome on general functioning (Cramer, Torgerson & Kringle, 2006). In one population study of 2066 Norwegian people it was found that a person will receive less support and have less contact with his or her family when they have more schizotypal traits (Cramer et al., 2006). It is important to note however that these links do not necessarily demonstrate a causal relationship and that SPD is more narrowly defined than schizotypy. Therefore these results may not be completely generalisable to schizotypy.

There is less evidence in the literature on positive associations with schizotypy. One study has found that schizotypy traits may be linked to creativity (Burch, Pavelis, Hemsley & Corr, 2006). When visual artists and non-artists were compared on several measures of schizotypy traits, higher levels of positive-schizotypy (e.g., unusual experiences, thought to be related to unusual ideas) and asocial schizotypy (social anxiety and disorganised thinking) were found for

artists (Burch et al., 2006). In summary, schizophrenia and schizotypy symptoms can have a significant impact on an individual's life. Consequently, it is important to fully understand the condition.

### **Current practice of screening for schizotypy.**

There are several methods of achieving information about the aetiology and impact of schizotypy. One way is through biological methods. That is, finding an individual with schizophrenia and following-up his or her children to assess whether they develop schizophrenia (Clarke, 2003). Other methods involve screening of clinical or general populations. For the purpose of the present research, the focus will be on general sample population screening as this is where the ethical issues discussed in the introductory paragraphs are most apparent. Specifically, examples of the current screening practice for schizotypy can be found in two areas, screening and follow-up research.

### ***General population screening research.***

Linscott and colleagues conducted a screening study with secondary school students to investigate the differences between races within a schizotypy taxon (Linscott, Marie, Arnott & Clarke, 2006). It was found that Maori New Zealanders were over-represented as examined by the Thinking and Perceptual Style Questionnaire (TPSQ), a schizotypy measure. The procedure followed here was to explain the research under the guise of a personality study with a general statement explaining that risk for different mental health outcomes would also be investigated. Participants then filled out the questionnaires. There was no follow-up other than a generic form sent thanking participants and explaining that small numbers had been found to have higher scores than others. Schizotypy was not mentioned (B. Clarke, personal communication, August 1, 2011).

Table 2  
*Commonly Described Symptoms of Schizotypy*

Symptom Type	Specific outcomes
Aberrant perceptions and beliefs	For example, hallucinations. Similar to positive symptoms of schizophrenia
Cognitive disorganisation with anxiety	Attentional difficulties, distractibility, social anxiety features
Asocial behaviour	Impulsiveness, mood-related disinhibition
Introvertive anhedonia	Solitariness, lack of feeling. Similar to negative symptoms of schizophrenia

*Note.* Adapted from “The Factor Structure of ‘Schizotypal’ Traits: A Large Replication Study,” by G. Claridge et al., 1996, *British Journal of Clinical Psychology*, 35, 103-115.

Korfine and Lenzenweger (1995) conducted a general population screening study with 1,684 participants and found support for the hypothesis that schizotypy has a low base rate of < .10. Korfine and Lenzenweger’s (1995) work was a replication of Lenzenweger and Korfine’s (1992) screening research, which had previously found the same results using 1140 participants. Similar to the research of Clarke (2003), schizotypy was not mentioned to the participants at all (M. Lenzenweger, personal communication, August 8, 2011). Instead, participants were told that a range of personality characteristics was being assessed.

Raine (1991) conducted screening research to develop the Schizotypal Personality Questionnaire (SPQ). The SPQ is a self-report scale that was modelled on the DSM-III-R criteria for schizotypal personality disorder. The SPQ has been used in several screening studies since it was developed (for example, Bergida & Lenzenweger, 2006; Chen, Hsiao & Chaucer, 1997).

The major focus of general population screening studies has been on adult populations. However, a children’s screening measure for schizotypal traits has also been developed and tested in a sample of children aged 11 to 15 years ( $N = 317$ ) (Cyhlarova & Claridge, 2005). The

questionnaire was administered as part of a larger study on children's cognitive functioning. No information was provided on the consent and debriefing procedures of this study.

*General population follow-up research.*

Kwapil, Miller, Zinser, Chapman and Chapman (1997) conducted a 10-year follow-up study of individuals previously assessed on psychometric psychosis measures. From an original sample of approximately 2000 individuals, 20 control participants and 28 participants who had obtained high scores on the measures were interviewed. Over the ten years, 2 participants in the high-risk group had developed psychotic disorders. The researchers concluded that they had found partial support for research conducted in 1994 by Chapman and colleagues, who found increased psychosis proneness in participants who had high scores on the same measures. It was also hypothesised that the social anhedonia aspect of schizotypy may have more negative effects on an individual's life as he or she gets older (Kwapil et al., 1997).

Gooding, Tallent and Matts (2005) conducted 5-year follow-up research on a sample of participants previously found to be at high-risk for psychotic disorders. The high risk scores were based on participants' psychometric scores on psychosis risk scales. They were able to recruit 75% of their original sample ( $N = 269$ ) with two at-risk groups and a control group. Their findings were unlike those of Kwapil and colleagues (1997) and Chapman and colleagues (1994) as they found that none of the high-risk participants met criteria for a psychotic disorder. However, given that Gooding and colleagues (2005) conducted their research at only five years follow-up not ten, the difference in findings may be due to this methodological reason.

Large scale psychosis screening research has been occurring in the Netherlands. Van Os and colleagues have screened 7000 participants several times over 3 years in various studies (van Os & Delespaul, 2003). This research was predominantly focused on non-clinical psychosis. In a

review of the research van Os and Delespaul commented that they were interested in aspects of continuity between non-clinical and clinical psychosis. They found this continuity in factors such as age, gender, and marital status. These findings and others are being investigated with further population research (van Os & Delespaul, 2003).

The Early Developmental Stages of Psychopathology (EDSP) study is ongoing and has been conducted over several years with more than 3000 adolescents (aged 14 – 24 years) (Spauwen, Krabbendam, Lieb, Wittchen, & van Os, 2003). After a baseline assessment the sample was followed-up twice in the subsequent 3-4 years. The general aim of the study is to investigate mental disorders and substance use in adolescence. Many different aspects of psychosis have been looked at in the EDSP. For example, results have supported the hypothesis that normal brain changes in adolescence may contribute to the development and expression of psychosis (Spauwen et al., 2003).

Usually the only procedure reported for screening research is the questionnaires that are administered. As can be seen from the researchers' comments on the screening studies above, the general procedure is to administer the screening measures and provide some form of reimbursement. The debriefing provided usually does not specifically mention that the purpose of the research was screening for schizotypy.

### **Good Ethical Practice**

When conducting research with human participants the first question that must be considered is, what equates to good ethical practice? The process of ethical committees provides an applied approach. One main focus of committees is that the participants of research do not experience any adverse effects. Table 3 provides a list of the University of Otago Human Ethics Committee's principles as an example of general ethical guidelines.

**Key ethical principles in healthcare research.**

There are also theoretical approaches for understanding good ethical practice. One such theory that specifically relates to healthcare research is known as the principles-oriented framework (Tsai, 1999). Within this framework four key principles have been posited to form the moral basis of ethical decision-making in healthcare research (Gillon, 1994). These principles are autonomy, beneficence, non-maleficence, and justice and do not provide rules for ethical practice but rather a framework for making decisions. Gillon (1994, 2003) states that all decisions ought to be able to be made within this approach.

***Autonomy.***

Autonomy can be defined as the degree of control a person has over his or her self and decision making (T. J. Sincock, personal communication, January 11, 2011). Autonomy in the medical context has been defined as “an individual's self determination” (Andorno, 2004, p. 436) and has been said to be closely related to informed consent (Corcoran et al., 2005). In relation to healthcare there has been a focus in recent years on patients’ right to know and decide about their treatment (Andorno, 2004). A person's right to know his or her genetic status is now also considered important, particularly as genetic testing and general population screening for disease is becoming more prevalent.

Biomedical law recognises the principle of a right not to know but there are still opposing views on allowing this right (Andorno, 2004). It is thought that allowing people the choice of whether or not they want to know their genetic status can either reduce or enhance autonomy (Andorno, 2004; Corcoran et al., 2005). One argument is that nondisclosure of genetic information is paternalistic and reduces or undermines autonomy (Moum, 1995). Conversely, the right to decide about disclosure improves autonomy by enabling choice (Andorno, 2004). As has

been succinctly stated by McGlashan “While it may be tempting to keep news of risk from a person to avoid distress, such ‘protection’ can also be seen as violating that person’s civil liberties and right to know” (McGlashan, 2001, p. 52).

***Beneficence.***

Beneficence has been defined as acting for the good of others (Beauchamp, 2008). When considering this principle, one observation is that it is difficult to determine what “good” is and which definition should be used. What may be “good” or of benefit for one person is not necessarily of benefit for another (Gillon, 1994).

***Non-Maleficence.***

Non-maleficence can be viewed as on a spectrum with beneficence and it can be difficult to consider one principle without the other (Kessel, 1998). Non-maleficence primarily means not causing harm (Gillon, 1994; Kessel, 1998). However, this principle does not necessarily imply the need for action; it is enough to not make a situation worse. What is often considered is the long-term beneficence principle over possible short-term harm. Gillon (1994) has stated that both the risk of harm and the probability of harm occurring need to be considered when making an ethical decision.

In a specific example of the non-maleficence principle, the New Zealand Code of Ethics has a principle relating to responsible caring. The first value statement of the principle is that “Psychologists recognise that a basic ethical expectation of our discipline is that its activities will benefit members of society or, at the very least, do no harm” (New Zealand Psychological Society, 2002, p. 9). This statement implies that psychologists will only proceed with an action if the potential benefits outweigh the potential harms, similar to Gillon’s ideas of beneficence and non-maleficence. In relation to schizotypy screening, this principle could be interpreted to imply

that if there may be more distress and harm from knowing the information than not knowing, it might not be necessary to disclose risk results.

***Justice.***

A full examination of the principle of justice is beyond the scope of the present research. Generally, equality is considered crucial to justice (Kessel, 1998). When considering medical ethics Gillon (1994) has divided justice into three relevant categories: distributive justice (fair allocation of social resources), rights based justice (respecting the rights of patients), and legal justice (having morally acceptable laws).

Table 3

*Ethical Principles from a Human Ethics Committee*

University of Otago Human Ethics Committee Principles

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Research or teaching merit

Participants' informed consent which is given free from any form of coercion

Respect for participants' rights of privacy and confidentiality

Minimisation of the risk of harm to participants

Special care for vulnerable participants

Limitation of, and justification for, any deception

Appropriately qualified supervision

Avoidance of any conflict of interest

Respect for societies and cultures of participants

Freedom to publish the results of research, while maintaining the anonymity of individuals

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*Note.* Adapted from “Ethical Practices in Research and Teaching Involving Human Participants,” by University of Otago, 2011, retrieved from

<http://www.otago.ac.nz/administration/academiccommittees/otago015522.html>

### **Ethical Issues with Current Schizotypy Screening Research**

Given the key principles of ethical research there are some serious issues that need consideration when examining the current practice of screening for schizotypy. In particular there are matters regarding informed consent, non-disclosure, and deception. Each of these will be discussed in more detail.

#### **Informed consent.**

A seminal set of guidelines on ethical requirements for research is the Nuremberg Code, originating after the Second World War in 1947. The code has ten principles for research (Wilson & Stanley, 2006). The first principle delineates the importance of obtaining voluntary informed consent. Therefore, the participant should have enough information about the experiment to make an informed choice. Specifically, information should be provided on “the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonable to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment” (Cottrell & McKenzie, 2011, p. 96).

The tenet of informed consent is seen in many other significant documents pertaining to research ethics, including the American Psychological Association Code of Ethics. New Zealand’s equivalent to this, as mentioned earlier, is the Code of Ethics for Psychologists working in Aotearoa/New Zealand (New Zealand Psychological Society, 2002). The Code of Ethics provides guidelines for ethical decision-making and practice.

Informed consent is not always straightforward particularly when different cultural values are considered. New Zealand is a multicultural nation and the indigenous population is Maori. The concept of whakapapa (genealogy or ancestry) is important to Maori culture and has

implications for informed consent, in particular for genetic research, because a large percentage of Maori share the same whakapapa (Hudson, Ahuriri-Driscoll, Lea & Lea, 2007). It is subsequently thought by some that it may not be possible to get the informed consent of everyone for whom the genetic research would be applicable (Hudson et al., 2007). The idea of reciprocity is also a very important part of Maori culture. Having a reciprocal relationship would mean a mutually beneficial relationship for both the researchers and those participating in the study. This reciprocal aspect is not usually considered in the context of experimental research (Hudson et al., 2007). Another example more relevant to the proposed research is Maori concern about taking part in genetic testing due to possible stigmatisation, for example on the basis of race. There is the potential for genetic information to be misused if it becomes public knowledge (Hudson et al., 2007). One scientist highlights a concern that there is a “need to think ahead and anticipate the uses and misuses to which information gathered by screening for disease prevention and detection may be put” (Moum, 1995, p. 212).

### **Deception.**

The use of deception in current screening practices for schizotypy also poses an ethical concern, largely because it goes against the seminal legislation on ethical research previously examined. The entire evidence base regarding deception is too large to be covered here. Therefore, some key points only will be discussed. Researchers have identified general issues with the use of deception. It is thought that deception may raise the suspicions of participants and increase distrust (Hetwig & Ortmann, 2008). Another hypothesis is that participants may attempt to guess what the true purpose is of the experiment (Hetwig & Ortmann, 2008).

However, there are proponents who do not believe that deception is harmful to participants and that without it the experiment would not reflect a real situation. For example,

Sharpe, Adair and Roese (1992) in a longitudinal study found evidence to show that participants were not more suspicious or negative towards psychologists or psychological research after experiencing deception in studies. It has been stated that in certain situations, such as when the experiment cannot be performed in situ, deception may be appropriate as long as a full debriefing is carried out (Mills, 1976).

### **Nondisclosure.**

Nondisclosure can be seen as opposing the various pieces of legislation discussed earlier as well as removing individual rights, as some researchers do not disclose the entire purpose of the study at the beginning of research (e.g., Clarke, 2003). Participants are also often not told of their risk status upon completion of the study (e.g., Korfine & Lenzenweger, 1995; Lenzenweger & Korfine, 1992). However, researchers do not arbitrarily decide not to disclose information about schizotypy. M. Lenzenweger (personal communication, August 8, 2011) has outlined reasons why nondisclosure in these circumstances can be considered acceptable. Screening measures are often fallible and have a lower level of reliability than would be considered appropriate for confirming risk status. There is also the possibility of harm to an individual's life from a false positive response (M. Lenzenweger, personal communication, August 8, 2011). Meehl's (1990) aetiological theory proposes that the number of people with schizotypy who go on to display schizophrenia is limited, therefore providing another possible reason for nondisclosure.

One concern expressed by researchers, particularly genetic researchers, is that extensive education would be necessary for a person to understand a disease and all the possible consequences of risk, making informed consent difficult. There would also be additional complex information required after the results were determined. An individual would then have many

elements to consider when making a decision (Moum, 1995). This reason for nondisclosure has been termed “medical information overload” (Moum, 1995, p. 210).

In practical terms of disclosing individual results, Fernandez, Kodish and Weijer (2003) have emphasised the potential impact on researchers in terms of time to prepare the results for disclosure as well the financial costs for research budgets. Other reasons for nondisclosure include the suggestion that there could be an emotional impact on both participant and researcher from disclosing any adverse results (Fernandez et al., 2003). Similar to this suggestion and relevant to schizotypy is the concern that the added stress and stigma of screening may result in increased risk and exacerbate any symptoms that are present (Linscott & Cross, 2009).

### **Evidence for Current Schizotypy Screening Practice**

#### **Evidence from schizotypy research.**

There is a scarcity of evidence relating to the ethics of the current schizotypy screening practice. The only available study specifically researching this area was conducted by Linscott and Cross (2009) using a hypothetical risk paradigm. Undergraduate participants ( $N = 114$ ) were asked to imagine being at increased risk for several medical and psychological disorders, including schizophrenia. Participants then rated the perceived impact of the risk news on their lives. Participants thought that news of risk for schizophrenia would cause greater distress than risk for heart disease, arthritis, depression, and diabetes but less distress than risk for cancer and Alzheimer's disease.

More evidence directly relating to schizotypy comes from the area of early intervention programmes for help-seekers. There are many advocates for early detection (Riecher-Rossler et al., 2006) supported by benefits found from early treatment of schizophrenia (Yung et al., 2006). McGlashan (2006) has discussed ongoing clinical trials in which he and colleagues are

implementing an early intervention of atypical neuroleptics in those persons displaying prodromal symptoms of schizophrenia. The trials are conducted with help-seeking participants who are classified at high-risk of developing schizophrenia in the next year (40% chance). These clinical trials are very useful in that they provide evidence to inform the debate around early interventions. Currently much of the research is focused on prodromal interventions, but it is likely that in the future the focus will be on transitions from schizotypy to prodromal states (Linscott & Cross, 2009).

### **Evidence from other pathologies.**

Evidence from research on other pathologies, for example, breast cancer, genetic research, and Huntington's Disease (HD) can provide useful information for the current debate on the screening practice for schizotypy. This evidence will be discussed in relation to the four key ethical principles previously mentioned.

#### ***Autonomy.***

Autonomy in the context of this research is related to personal choice about information. One study used a Psychiatric Genome Course to investigate whether mental health clinicians ( $N = 41$ ) thought people should have the right to know their genotypes (Mrazek et al., 2007). The course was educative about genetic variation and the associations of genes with psychiatric diagnoses. At the completion of the course nearly all participants (94%) believed that adults should have the right to know their genotype and the majority of participants (63%) believed parents should have the right to know their children's genotypes (Mrazek et al., 2007). These views are akin to those of lay persons (Shaw & Bassi, 2001). As an addition to Moum's (1995) ideas on "information overload", it appears that once information is provided, people can,

perhaps not surprisingly, more easily make decisions about complex issues. The same may be true for schizotypy information.

The concept of the therapeutic misconception becomes a complication when considering participant autonomy. The misconception held is that research has the same goals as clinical practice, that is, to help the patient or provide for the patient's best interests (Clayton & Ross, 2006). Clayton and Ross (2006) state that the goal of research is to "create generalizable knowledge" (p. 37). Therefore, providing individual results does not fall within the scope of this goal. In addition, general results may not be relevant for an individual. While a screening process can group individuals into levels of risk, for a particular individual within that group, risk may differ (Linscott & Cross, 2009).

*In principle vs. actual intent.*

An important point to note here is that although many people will say that they want to know their results, whether these relate to genetic or medical factors, often people who are at high risk do not actually want to know (Corcoran et al., 2005). Evidence for this comes from research into genetic testing for HD and breast cancer genes. This research shows that when there is an opportunity for testing, many people who previously had expressed interest have not participated in the testing (Corcoran et al., 2005). Croyle and Lerman (1995) followed up people who had been offered free testing for HD but had not accepted the offer after one year. The most common reasons for not undergoing testing were concerns over the risk for their children, the disease being incurable and a concern over a loss of health insurance (Quaid & Morris, 1993, as cited in Croyle & Lerman, 1995).

***Beneficence.***

To recap, beneficence is related to acting for the good of others. Fernandez, Kodish and Weijer (2003) have delineated several benefits when sharing research results with participants that are relevant for schizotypy research. Some important benefits include reducing the likelihood of participants feeling exploited by the researchers and allowing opportunities for early interventions (if available). It could then be considered for the good of an individual if they are told a result and are able to do something about this information.

Another possible benefit could result from telling individuals their results if they want to know, as seen in the research on help-seeking participants (McGlashan et al., 2006). Full informed consent would need to be obtained prior to a study for disclosure to be successful.

***Non-maleficence.***

As discussed earlier, non-maleficence relates to not harming participants without necessarily indicating the need for change. There have been concerns raised regarding the possibility of harm to participants if information is disclosed. One concern from sharing risk results is that there could be discrimination in employment or insurance if an individual is found to be at increased risk (Fernandez et al., 2003).

Another important factor when considering reactions to genetic research is the risk of suicide. Being informed of high risk of a physical or psychological illness, particularly when there is not adequate treatment available can have devastating effects on an individual's life (Almqvist, Bloch, Brinkman, Craufurd, & Hayden, 1999). Research has investigated the worldwide rate of catastrophic events (CE) (e.g., suicide, psychiatric hospitalisation) in individual's lives who have undergone predictive testing for HD. It was found that while the rate of CE was not as high as originally predicted, 0.97% of those individuals followed-up by health

centres experienced a CE. This result was considered to be a minimum estimate given that the sample did not include participants with no follow-up and the authors concluded that predictive testing could have serious risks (Almqvist et al., 1999).

***Justice.***

*Legal justice.*

Gillon defines legal justice as “respect for morally acceptable laws” (1994, p. 185). A specific bioethical example is described to illustrate the possibility of a law not being respected. Research has been conducted into the effects of do not resuscitate (DNR) orders. DNR orders are associated with medical professionals requesting less testing (from simple to complex procedures) and being less likely to perform cardiopulmonary resuscitation (CPR) (N. Pickering, personal communication, May 11, 2011). Use of CPR in emergency departments has been hypothesised to reflect the value society places on particular social groups’ lives. For example, those who are elderly or disabled have lower social value (Pickering, 2011). It is suggested that a DNR order provides an opportunity for ‘social death’ to become real death as health care professionals internalise discrimination and subconsciously decide who is worthy of living. In relation to screening research, one concern is that the person who is known to be at risk may be treated differently in many aspects of their life, socially and possibly even medically.

While the findings above do not illustrate a causal link, they do show an unintended impact of information in institutional settings. The DNR order example is not directly related to the impact of a person finding out about increased risk of schizotypy, precisely because he or she would decide with whom to share that information. It does suggest that concerns about individuals experiencing stigma is valid. Mitchell (2000) has also raised concerns that the actions

of others may change once a person is told of risk. For example, parents of a child at risk may be overprotective or hyper-sensitive to possible symptomatology.

*Distributive justice.*

To review, distributive justice relates to the distribution of resources in a reasonable manner, a concept particularly relevant for genetic research (Gillon, 1994). New predictors of risk are being researched and discovered and the genetic basis of more psychiatric disorders will become available as technology improves. In the future it is likely that whole genome information for each individual will be available. It is now possible for individuals to find out information about their genome such as their carrier status, disease risk, drug response, and traits simply by giving a saliva sample (for example, [www.23andme.com](http://www.23andme.com)) providing they have the available finances (23andMe, Inc., 2007). [www.23andme.com](http://www.23andme.com) currently provides information on 193 of the topics above. The site does include several disclaimers. It does not provide medical advice, nor diagnose disease or medical conditions, and makes it clear that consumers may find out uncontrollable information that may upset them (23andMe, Inc., 2007). The subject of finances raises another concern regarding the potential divide between those who can afford to pay for their information and those who cannot.

*Rights based justice.*

For the purposes of the present research, rights based justice is seen to relate most closely to stigma research. People with mental illness can experience stigma in all areas of their lives (Jenkins & Carpenter-Song, 2009). In particular, people without mental illness often perceive those with mental illness (particularly psychosis) to be dangerous (Penn, Kommana, Mansfield & Link, 1999). Two explanations for the negative views people hold about mental illness are a lack of knowledge about mental illness and the amount of contact a person has had with those with

mental illness (Penn et al., 1999). To investigate these explanations Penn and colleagues (1999) gave participants information regarding the reality of the relationship between violent behaviour and mental illness. They were also asked about their previous contact with individuals with mental illness. Penn and colleagues (1999) found that when participants read a description of an individual with schizophrenia, they were less likely to rate them as dangerous after they had received realistic information on dangerousness than when they had not. The more contact a participant had previously had with someone with a mental illness, the less likely they were to rate the description as dangerous (Penn et al., 1999).

Wahl (2003) postulates that the portrayal of mental illness in the mass media contributes to the negative stereotypes people hold about mental illness. Mental illness is often portrayed inaccurately through many different types of media (film, television, newspapers) in a way that either ridicules those with mental illness or portrays them as dangerous and violent as in the Penn and colleagues (1999) study. The frequency of these portrayals leads to a pervasive barrage of negative information about mental illness. In particular Wahl (2003) highlights the use of terms such as *schizophrenic* and *insane* to denote a mentally ill individual who is a danger to society. Although Wahl (2003) notes that there appears to be a shift towards more positive portrayals of people with mental illness, the majority of the media still portrays unfavourable stereotypes.

Given the lack of knowledge the public holds regarding schizotypy, someone who was at increased risk for schizotypy may be misunderstood to have a psychotic illness. There may then be increased connections made between that individual and violence because the condition is poorly understood.

It is also possible that given the frequency of negative depictions in the media, people with schizotypy may place these stereotypes and negative biases onto themselves. A study by

Jenkins and Carpenter-Song (2009) asked participants who had a diagnosis of schizophrenia or schizoaffective disorder for their perception of stigma across a variety of social settings. They found that stigma was pervasive for these individuals within their everyday experiences and particularly more so as they recovered. They called this the “paradox of stigma” (Jenkins & Carpenter-Song, 2009, p. 522). That is, as participants showed less symptomatology they reported becoming more aware of social stigma. They were also more likely to translate this stigma onto themselves.

There is evidence that stigma could be a potential moderating variable in anticipating and receiving risk news and also when considering treatment for mental illness (Jenkins & Carpenter-Song, 2009; Linscott & Cross, 2009). It is likely that if an individual believes he or she will be stigmatised as a result of mental illness they will experience a greater distress reaction upon receiving risk news. Pinel’s (1999) Stigma Consciousness Questionnaire (SCQ) has been found to be an effective way to measure quantitatively the extent to which a person believes they will be stigmatised. The SCQ has been used for many different populations including gay and lesbian.

To conclude the discussion of ethical literature, good ethical practice appears to necessitate a combination of the four key principles of autonomy, beneficence, non-maleficence, and justice. Data from a wide variety of pathologies suggest that in relation to screening research, evidence is divided about participants’ right to information and the impact of risk information. Without knowing how people will react to risk information it is difficult to determine whether the current screening practice, which raises problems regarding informed consent, nondisclosure, and deception, is an acceptable practice. As Marteau (1995) notes in her work on the psychological consequences of screening, continuing to investigate different experimental designs and psychological models could help elucidate people's responses to screening. Marteau's (1995)

conclusions are becoming more applicable as technology is improving and general population screening is becoming more prolific.

### **Evidence of Risk Impact**

How do people react to finding out they are at risk? There is an implicit assumption that people will react rationally (Croyle, 1995) but personal response to risk news is uncertain. Studies from a wide range of disorders show that responses vary depending on the disorder (Croyle, 1995; Croyle & Lerman, 1995; Lerman & Rimer, 1995; Marteau, 1995). For example, after one year, people who have tested positive for HD have been found to be no more distressed than those who tested negative (Croyle & Lerman, 1995). However, individuals who learn they are not at risk for the human immunodeficiency virus (HIV) often increase their risk behaviour (Jemmott, Sanderson & Miller, 1995).

There is evidence that disclosure of risk information has significant psychological consequences in some situations (Moum, 1995). Cancer is found to be a disease that causes significant distress. Supporting evidence can be seen in studies of women with breast cancer who have had positive results for an abnormal smear for cervical cancer (Marteau, 1995). The women with positive results for pre-cancerous cells exhibited high anxiety before undergoing the colposcopy examination, higher than women undergoing surgery for cervical cancer (Marteau, 1995).

It has been found that less distress is manifested for non-treatable conditions over time, for example, HD and HIV. People who tested HIV seropositive (i.e., the person had HIV antibodies when they were tested) experienced distress upon receiving the information but this reduced after a few weeks. There are, however, some qualifying factors for these results. The people involved in studies for HD and HIV are usually self-selected and want to know the

results. Therefore they may be prepared for the result (Marteau, 1995). Wanting to know and then receiving the results means that some uncertainty has gone, causing less distress. General population screening programs such as cervical and breast cancer screening are less likely to be self-selected and once an individual has found out they are at risk they may be in a state of uncertainty and more distress (Marteau, 1995). This example highlights a concern with schizotypy screening research. When news of risk is unexpected compared to being actively sought out, there may be greater distress.

However, the psychological impact of predictive genetic testing is an area that needs further research. In one systematic review of research on HD it was found that there was no reporting of cognitive or behavioural consequences and limited information on emotional consequences (Broadstock, Michie & Marteau, 2000). Factors identified that influenced the emotional consequences of testing included awareness of pre-test risk status and psychological coping mechanisms (for example, threat minimisation). Similarly, there is limited evidence of the psychological impact of news of risk for schizotypy.

One factor that could moderate reactions to risk news is the way an individual views his or her health. One way of measuring this factor is known as locus of control. The locus of control concept was introduced in the 1960's and came from social learning theory (Furnham & Steele, 1993). Locus of control has been defined as “a belief that a response will, or will not, influence the attainment of reinforcement” (Furnham & Steele, 1993, p.144). It is thought that individuals can have an internal or external locus of control (Furnham & Steele, 1993; Rotter, 1966; Wallston et al., 1976, Wallston, Wallston & DeVillis, 1978). People with an internal locus of control believe they have more influence and control over their own behaviours and environment while people with an external locus of control believe other people or social factors influence

their behaviour (Furnham & Steele, 1993; Wallston et al., 1976). These concepts can be applied to health behaviours and measured via health locus of control scales. An internal locus of control relates to beliefs that overt behaviour is connected with personal health. An external locus of control relates to views of health behaviour as a matter of chance or due to the influence of powerful others such as medical professionals. An individual's health locus of control could arguably also have an effect on how he or she seeks help for treatment.

### **Possible Areas of Future Research**

The main focus currently of schizophrenia research is on prodromal states and developing early interventions. As previously mentioned, it is likely that the screening focus will move from the prodromal stage to the precursor states of schizotypy (Linscott & Cross, 2009). The focus of screening research is already shifting from adults to adolescents and children (for example, Cyhlarova & Claridge, 2005).

Although valuable information can be drawn from research on other pathologies, there is much evidence missing to inform the debate on the ethics of general population screening and follow-up for schizotypy. Particularly, there is little or no evidence of the impact of disclosure versus non-disclosure of risk status results. That is, whether a participant falls in a high or low risk group and the impact this risk news would have on him or her.

There is also a lack of evidence on the impact of risk news of schizotypy on unsuspecting or non help-seeking individuals. There is some evidence from help-seekers (McGlashan et al., 2006; Yung et al., 2006). In addition, there is little evidence on whether people would want to know their results from screening studies.

Considering these gaps in the research there are several areas for possible further research that would inform the ethical debate on schizotypy screening. Firstly, how do individuals react to

risk news in general? Secondly, how do individuals react when news is unsuspected versus anticipated? Are there differences in immediate and long-term reactions? And are these differences then related to differing health behaviours? Is it possible that when people display distress after receiving risk information their help seeking behaviour may become more functional? Do differences in personality mediate these effects? Lastly, would people want to know their results if given the opportunity? Considering some of these different areas of enquiry, the question that will be addressed by the present research is, what are the reactions of non-help seeking individuals to risk information?

### **The Present Research**

The overall aim of the proposed research is to identify the reactions of non-help seeking individuals to disclosure of personally relevant information about risk for schizophrenia. The objectives are to firstly identify the impact of news of risk for schizophrenia relative to other diseases; secondly, to quantify reactions using both subjective (self-report) and objective (salivary cortisol levels) measures; thirdly, to determine the relationship of stigma and health locus of control to participants' reactions; and fourthly, to investigate the impact participants anticipate the risk information will have on several aspects of their lives.

In line with Marteau's (1995) comments on the need for different experimental designs, the present study uses a deception paradigm to investigate individuals' responses to risk news. The research will be based on an experimental paradigm known as the thioamine acetylase enzyme deficiency (TAED) paradigm (Croyle & Ditto, 1990; Croyle & Ditto, 1995). This paradigm is useful for revealing the immediate impact of risk information for disease. Participants are told that TAED is a risk factor for a particular disease (e.g., mild pancreatic disorders). They then self-administer a diagnostic test that involves dipping a chemically coated

test strip (actually a urinary glucose strip) in a mouth rinse sample. A colour change reaction occurs because participants have used a mouthwash (unknowingly) that contains dissolved glucose.

Research with the TAED paradigm has found that risk information has an impact on people's behaviour and responses (Croyle & Ditto, 1990; Croyle & Ditto, 1995). Specifically, if participants are told they have an increased risk for a disorder, they consistently judge the illness as less severe and threatening than participants who are told they do not have an increased risk. This pattern of results is known as the minimisation effect (Jemmott et al., 1995). Another way receiving risk information affects people is that they rate the test as less accurate. These results show the participants are reacting with a form of denial. This previous research emphasises the strengths of the TAED paradigm in revealing how people react to risk information (Croyle & Ditto, 1995). In addition, the paradigm is a realistic test and research has found low suspicion rates (Croyle & Ditto, 1990).

Another strength of the paradigm is that it allows for a high level of control while still being very flexible (i.e., it can be used as a fictitious risk factor for many diseases) (Croyle & Ditto, 1990). Therefore, the TAED paradigm will be modified for the proposed research and participants will be informed that TAED indicates an increased chance for developing schizophrenia, cancer, or depression, or in the control condition, indicates an enzyme deficiency only.

One concern regarding the TAED paradigm is the use of a fictitious rather than a real risk factor as it is thought that this may limit or change people's response. However, research that has screened participants for blood cholesterol and gum disease and then provided them with false feedback (i.e., positive results) has replicated the results found in the TAED paradigm research

(Croyle & Ditto, 1995); in particular, the minimisation effect. Participants who received a high blood cholesterol result rated this as a less serious threat to their health than participants who did not receive risk information. Similar results were found for false reports of gum disease after a standard dental check up (Croyle & Ditto, 1995).

As discussed earlier, the current research follows the hypothetical paradigm of Linscott and Cross (2009), which provides evidence to suggest that people anticipate receiving risk information for schizophrenia will have a significant impact. These results are consistent with the claim that significant psychological consequences may result from receiving risk information (Moum, 1995). One limitation of the Linscott and Cross research is that while using an imaginal paradigm is the first step in investigating the effects of risk news, imagining an adverse outcome is not the same as experiencing that outcome. As a result, participants may have had difficulty completely incorporating the risk status with other aspects of their lives (Linscott & Cross, 2009). If participants thought that the information was personally relevant they may experience greater impact from the risk information. The second limitation concerns a more methodological issue. The significance of the distress could not be adequately determined due to the measures used. Therefore, the proposed research aims to measure any distress with both a subjective and an objective measure. The TAED paradigm provides a useful way to address the limitations of the Linscott and Cross (2009) research.

Using a modified version of the TAED paradigm in the proposed research, participants will be assessed for TAED after completing screening and demographics questionnaires. They will be led to believe that the fictitious deficiency is associated with elevated risk for one other disorder, depending on group assignment (schizophrenia, cancer, depression, or TAED-only control).

Before and after the TAED procedure participants will complete a self-report measure of distress (Profile of Mood States [POMS], McNair, Lorr & Droppleman, 1992) and provide saliva samples for cortisol assaying (subjective and objective measures of distress respectively). Cortisol levels have been found to indicate a person's stress levels (Hausmann, Vleck & Farrar, 2007) and can be measured through blood plasma or saliva samples (Dickerson & Kemeny, 2004). Measures of stigma consciousness (SCQ; Pinel, 1999) and health locus of control (Multidimensional Health Locus of Control [MHLC]; Wallston et al., 1978) will also be administered, as will a perceived risk impact (PRI) questionnaire. A full debriefing will be conducted with each participant during which the deception will be revealed and the fictitious nature of TAED will be demonstrated.

It is expected that participants will react in a similar way to previous research using a hypothetical paradigm (Linscott, unpublished data). Therefore, the impact of news of risk for schizophrenia is expected to be similar to that associated with risk for cancer and greater than that associated with risk for depression and for the TAED condition.

It is also expected that participants will show changes in both measures of distress during the testing, namely, the self-report measure scores will be greater after the second administration. Cortisol levels are expected to decrease for all participants given the length of each experimental session but a lesser decrease is expected for the schizophrenia condition. It is expected that the measure of stigma will significantly predict the level of distress a person experiences. Because an individual's health locus of control may moderate the impact of risk news, the health locus of control measure is expected to be associated with people's reactions. Specifically it is expected those with an internal locus of control will show greater distress reactions relative to those with an external locus of control. Finally, it is expected that participants who are told of risk news of

schizophrenia, cancer and depression will anticipate the news to have a greater impact on their lives than the control condition.

## **Method**

### **Participants**

Undergraduate psychology students ( $N = 160$ ) at the University of Otago, Dunedin, were recruited through a participant pool run by the Department of Psychology. All participants were fluent in English. Age ranged from 19 to 45 years (53% male). All participants were in their second year studying psychology. The majority of participants identified with New Zealand European ethnicity (70%), smaller groups with Chinese (5.6%), Indian (5%), Maori (5%), Pacific Island (1.9%), and other ethnic groups (12.5%). Participants were randomly allocated to one of four conditions. Those in the control group were informed that TAED was a benign deficiency, whereas those in the experimental (treatment) conditions were informed that TAED was associated with a ten-fold increase in risk for schizophrenia (schizophrenia group), depression (depression group), or cancer (cancer group). Participants were excluded if they had a current or pre-existing psychological disorder. Exclusion also occurred if participants indicated that they had a family member with psychosis or had ever been told they had cancer or depression.

After completing the study, participants were eligible to receive a small amount of course credit by completing a brief worksheet about the design of the study. The University of Otago Human Ethics Committee approved the research. A condition of ethical approval was that the Ethics Committee closely monitored the progress of the study with specific focus on the outcomes of the first ten participants.

## Measures

The Pyramids and Palm Trees test (Howard & Patterson, 1992) was used as a filler task. Ordinarily this test is used to measure the integrity of semantic memory. In each item of the test participants are shown three stimuli, one at the bottom of the page and two at the top of the page (either one word and two pictures or one picture and two words). Participants then decide which stimulus on the top best matches the one below. There are 3 practice items after which the participant is told the correct answer with an explanation and 52 test items on which they are not told. This test was used as a filler task to distract the participants without causing extra distress primarily because it was an innocuous and non-stressful test.

Two modules of the Structured Clinical Interview for the Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV-TR) Axis I Disorders (SCID-I; First, Spitzer, Gibbon & Williams, 2001) were used to screen for present and past episodes of psychopathology. These modules, Screening Questions and Psychotic Screening, together consisted of 20 screening items such as “In the past 6 months have you ever felt particularly nervous or anxious?” and “Has it ever seemed like people were talking about you or taking special notice of you?” Items allow for follow-up questions to probe the extent and impact of the problem. Four supplementary questions on the history of cancer, psychosis, depression, and family history of mental illness were added to the modules. The SCID-I has been found to have adequate inter-rater reliability, adequate content and construct validity, and excellent clinical utility (Hunsley & Mash, 2008).

The Cortisol Survey was used to assess factors, other than the manipulation, that could have affected cortisol levels. The survey consisted of 6 questions on amount of sleep, Vitamin C and caffeine consumption, and use of contraceptives and cigarettes (Appendix D). Each question had a dichotomous YES-NO answer format with sections for additional information when

required. Each of these factors has been shown to influence cortisol levels (see Appendix C for the evidence base behind each question).

The perceived risk impact (PRI) questionnaire is a 13-item self-report measure of the impact participants think the disorder will have on their future, relationships, and coping abilities. The PRI has been used in previous research but has no psychometric data available (Linscott & Cross, 2009).

### **Psychological measures.**

The Profile of Mood States (POMS; McNair et al., 1992) is a 65-item clinical self-report questionnaire that provides a measure of transient mood states. It consists of a list of adjectives for each of which participants are asked to rate current mood state using a 5-point Likert scale (0 = *not at all* and 4 = *extremely*). The POMS has good psychometric properties. Internal consistency reliability is high, ranging from  $\alpha = .84$  to  $.95$ . The concurrent and predictive validity of the POMS has been demonstrated in various settings (for example, controlled outpatient drug trials and in studies with cancer patients) and has been found to be sensitive to change in these situations. The POMS has also been found to correlate with other scales measuring similar constructs, such as the Hopkins Symptom Distress scale, MMPI-2, and the Beck Depression Scale, demonstrating adequate concurrent validity. The POMS has been normed on different samples, including male and female outpatients, college students, adults, and older people (McNair et al., 1992). The POMS provides scores from 0 to 60 for six subscales (depression-dejection, tension-anxiety, confusion-bewilderment, anger-hostility, fatigue-inertia, and vigour-activity) with higher scores indicating increased mood disturbance.

The Stigma Consciousness Questionnaire (SCQ; Pinel, 1999) is a 10-item self-report measure of the extent to which a person believes having a disorder will result in stigmatisation.

Each item consists of one statement, such as “Stereotypes about disability would not affect me personally”, that participants rate using a 7-point agreement rating scale (0 = *strongly disagree* and 6 = *strongly agree*). The psychometric properties of the SCQ are adequate across all forms with good internal consistencies (range from  $\alpha = 0.64$  to 0.84) and principal axis factor analyses provide good evidence for a single factor model (Pinel, 1999). The SCQ provides one score from 0 to 60 with higher scores indicating greater stigma consciousness (Pinel, 1999).

The Multidimensional Health Locus of Control scale (MHLC; Wallston et al., 1978) is a widely used 18-item self-report measure of perceived control over, and responsibility for, health. Each item consists of one statement, such as “Good health is largely a matter of good fortune”, that participants rate on a 7-point Likert-type scale (0 = *strongly disagree* and 6 = *strongly agree*). The MHLC provides three independent subscale scores each based on six items. These are: Internal Health Locus of Control (IHLC), Chance Health Locus of Control (CHLC) and Powerful Others Externality (PHLC). Test-retest data has been found to be adequate with correlations of .66, .73, and .71 for the three scales respectively (Lefcourt, 1991). The MHLC scale has a large validity evidence base including concurrent (Furnham & Steele, 1993), convergent and discriminant validity (Lefcourt, 1991), and has been used with a wide range of illnesses. Form A was used in the present study with one modification made to the Likert scale; the original scale has only a 6-point Likert-type rating scale. Unpublished data from an earlier study with the modified form A (Linscott, 2006) shows that internal consistency is adequate for each of the three subscales with Cronbach  $\alpha$  values at the high end of previously reported internal consistencies (IHLC:  $\alpha = .61$  to .80, CHLC:  $\alpha = .55$  to .83, PHLC:  $\alpha = .56$  to .75; Lefcourt, 1991).

**Cortisol assay (saliva).**

Salivary cortisol was measured from passive drool samples. To collect passive drool, each participant allowed saliva to accumulate in his or her mouth and then allowed saliva to fall through a short plastic straw (approximately 5cm) into a 5ml sample tube. At least 1 millilitre of saliva was required for each sample. All participants rinsed their mouths with water 10 minutes prior to the start of the testing. Samples were frozen until assay. Canterbury Health Laboratories, Christchurch, undertook assays.

**General Procedure**

Participants were randomly assigned to disorder group. After informed consent was obtained, participants rinsed their mouths with water before completing any measures. They then completed the POMS to obtain a baseline measure of mood.

To ensure that all participants received the key experimental manipulation (information), the researcher then verbally repeated the TAED information contained in the information sheet (Experimental protocol, Appendix B). The researcher informed each participant that TAED has been associated with some health concerns, namely a ten-fold increase in risk for the disorder as per group assignment. The participants were also informed that despite the association of TAED with health concerns, for the present experiment the researchers were interested in the correlations of the deficiency with stress measures and semantic processing abilities.

Demographic data were subsequently recorded and the SCID-I was then administered. The interviewer reviewed each participant's answers immediately after completion of the screening questionnaire to determine whether the exclusion criteria were met. Those who met the criteria discontinued participation at this point and were debriefed. Participants who remained

eligible to participate then completed the cortisol survey and provided a saliva sample for baseline cortisol.

The TAED diagnostic test was then carried out. Participants were informed before the test that the deficiency was only found in 1 out of 15 people. Participants rinsed their mouths in a glucose solution, expelling the solution into a sample cup. A glucose/water solution was used as a mouth rinse (15mls glucose syrup per 500mls water).

The TAED test strip was then placed in the sample by the researcher. Reagent strips for urinalysis were used as TAED test strips. Each participant observed the test strip change colour and was informed that the change indicated that he or she had TAED.

The Pyramids and Palm Trees test was then administered. After 25 minutes, the participant completed the POMS a second time, provided a second saliva sample (post manipulation cortisol) and then completed the HLC and SCQ.

Each participant was fully debriefed as to the fictitious nature of the TAED test and the true purpose of the study (see Appendix B for full script). During debriefing, the participants were informed that the TAED test was fictitious and, consequently, the researcher did not know whether they were at increased risk for the disorder. Each participant was also told that the TAED test was designed specifically so the test strip would change colour in the mouthwash and watched a demonstration of this. The rationale behind the experiment was explained and any questions the participants had were answered at this time.

The success of the deception and each participant's level of belief in the deception were measured with a four-item manipulation validation questionnaire (Appendix D). The PRI was also completed at this time. Participants were also invited to comment on their experience of the study. Completing all questionnaires and tests took approximately 90 minutes.

## Data Analysis

Analyses were conducted using SPSS 13 and Microsoft® Excel. An *a priori* significance level of .05 was set for all analyses. The independent measure was the group assignment (four levels: schizophrenia, cancer, depression, or TAED only [control group]). Cortisol scores were transformed to adjust for non-normality using square-root transformations (Zar, 1999). Skew and kurtosis were used as guidelines for the effects of transformation on the data as was the nonparametric Kolmogorov-Smirnov statistic. Descriptive statistics are reported as transformed data except where otherwise specified.

### Dependent measures

The dependent variables from the POMS were the total mood disturbance scores before and after the manipulation. The total mood disturbance score was calculated by adding the first five subscale scores together (depression-dejection, tension-anxiety, confusion-bewilderment, anger-hostility, fatigue-inertia) and subtracting vigor-activity. Analyses were conducted with a total mood disturbance change score (TMDS). The TMDS was calculated by subtracting the total mood disturbance score at Time 2 from the score at Time 1. Therefore, negative scores indicate deterioration in mood disturbance and positive scores indicate improved mood.

The dependent variables from the saliva samples were the cortisol levels before and after manipulation. Analyses were conducted with a cortisol impact score (CI). The CI was calculated by subtracting the cortisol score at Time 2 from the score at Time 1. Given this, negative CI scores indicate an increase in cortisol from Time 1 to Time 2, whereas positive CI scores indicate decreased cortisol. Outliers were defined as scores  $\pm 3$  SDs from the group means (Grunau et al., 2004; Gunnar, Connors & Isensee, 1989; Ramsay & Lewis, 2003).

The dependent variable from the PRI was the total risk impact score, which was calculated by summing all responses on the questionnaire. Higher scores indicated the individual anticipated the negative impact would be greater after receiving the risk information.

### **Statistical methods**

Stepwise multiple regression was used to identify the most effective set of predictor variables. For the PRI, one-way ANOVA was performed to investigate the differences between groups. Planned contrasts were carried out between schizophrenia and depression, schizophrenia and cancer, and schizophrenia and TAED.

### **Results**

There were no missing data from the POMS. There were seven participants with missing cortisol data, five due to error when the samples were being assayed and two due to insufficient amounts of saliva being provided for assay. These individuals were excluded from the cortisol analyses. The number of outlier scores discarded from the total sample before data transformation was one.

The normality of the CI (cortisol impact score) and TMDS (change in POMS total mood disturbance scores) distributions was tested using the Kolmogorov-Smirnov statistic (K-S statistic) and skew and kurtosis. The distributions are reported in Table 4. A non-skewed distribution is indicated when the skew value is close to zero. A normal distribution is indicated when the kurtosis value is also close to zero, indicating the distribution is not overly peaked (leptokurtic) or flat (platukurtic). The significance of the K-S statistic indicated that the cortisol data distribution was non-normal before and after transformation but there was some improvement as demonstrated by the skew and kurtosis. It was not considered necessary to

transform the TMDS data given the reasonably low skew and kurtosis, although the K-S statistic was significant.

Tables 5 and 6 show the means and standard deviations of the POMS and cortisol levels at Times 1 and 2 for each group, respectively. The cortisol data are presented as raw data. Paired t-tests were conducted for each group and there were no significant differences between Time 1 and 2 for any groups. As can be seen in the Tables, the control group mean decreased slightly over time for both the POMS total scores and cortisol levels. The schizophrenia group means increased for the POMS total scores but decreased for the cortisol levels. Both changes were small. Cancer group means increased slightly for the POMS total scores and decreased slightly for the cortisol levels. The depression group means decreased slightly for both POMS total scores and cortisol levels.

### **First Objective**

#### **Identify impact of risk news of schizophrenia relative to other disorders.**

Table 7 shows the mean and standard deviation of the TMDS for each group. Planned contrasts were carried out between schizophrenia and depression, schizophrenia and cancer, and schizophrenia and control. A one-way between subjects ANOVA was conducted to compare the effect of risk information on the TMDS in all four conditions. There was no significant effect of risk information on the TMDS at the  $p < .05$  level for the four conditions with  $F(3, 156) = 0.90$ ,  $p = .445$ . The overall pattern of the results, although not significant, was the control group with the highest mean, followed by the depression group and the schizophrenia and cancer groups with the lowest means.

Table 4  
*Cortisol and POMS Distribution Statistics*

Measure	Kolmogorov-Smirnov	Skew	Kurtosis
Raw CI data ( $n = 152$ )	2.85*	1.32	12.71
R-T CI data ( $n = 152$ )	1.57*	-0.60	3.98
TMDS data ( $n = 160$ )	1.34*	0.48	6.00

*Note.* POMS = Profile of Mood States, CI = cortisol impact, R-T = root-transformed, TMDS = change in POMS total mood disturbance scores

\* =  $p < 0.05$

Table 5  
*Descriptive Statistics for POMS Total Score at Time 1 and Time 2*

Group	POMS Total Score (Time 1)		POMS Total Score (Time 2)		$t$
	$M$	$SD$	$M$	$SD$	
Control ( $n = 40$ )	10.30	22.05	8.05	18.24	1.18
Schizophrenia ( $n = 40$ )	6.25	14.94	8.15	17.42	-0.97
Cancer ( $n = 39$ )	10.82	21.70	12.62	21.53	-0.63
Depression ( $n = 41$ )	12.24	25.34	11.29	22.59	0.26

*Note.* POMS = Profile of Mood States

\* =  $p < 0.05$

Table 6  
*Descriptive Statistics for Cortisol Levels at Time 1 and Time 2 (Raw Data)*

Group	Cortisol level (Time 1)		Cortisol level (Time 2)		$t$
	$M$	$SD$	$M$	$SD$	
Control ( $n = 38$ )	16.08	6.29	16.00	10.27	0.05
Schizophrenia ( $n = 38$ )	22.75	39.96	20.80	29.14	0.79
Cancer ( $n = 36$ )	17.85	11.37	16.35	9.66	1.44
Depression ( $n = 40$ )	23.40	31.65	21.95	25.20	0.76

*Note.* \* =  $p < 0.05$

Table 7  
*Descriptive Statistics Overall for the TMDS Across Groups (N = 160)*

Group	<i>N</i>	<i>M</i>	<i>SD</i>
Control	40	2.25	12.06
Schizophrenia	40	-1.90	12.38
Cancer	39	-1.79	14.21
Depression	41	0.95	15.96

*Note.* TMDS = change in POMS total mood disturbance scores

Table 8 shows the means and standard deviations of the CI for each group with the transformed data. A one-way between subjects ANOVA was conducted to compare the effect of risk information on the CI in all four conditions. There was no significant effect of risk information on the CI at the  $p < .05$  level for the four conditions,  $F(3, 148) = 0.10, p = .960$ .

## Second Objective

**Identify impact of risk news using subjective and objective measures (POMS and cortisol).**

A Pearson product-moment correlation coefficient was calculated to assess the relationship between the TMDS and the CI. There was a non-significant positive correlation between the two variables,  $r = .017, p = .840$  indicating little correlation between the two measures.

Stepwise multiple regression was used to determine the impact of group assignment on the TMDS by regressing the TMDS onto dummy variables for groups while testing for the relationship of the following potential confound variables: baseline POMS, hours of sleep, hours awake, sex (male), ethnic minority status, a male-minority interaction term, a belief-in-deception score, and a subclinical psychopathology score. Regression results are displayed in Table 9. The

analysis ended with the first step, entry of POMS baseline. The model was a significant predictor of the TMDS ( $p = < .05$ ). Altogether the confound variables listed above shared 17.2% of explained variance,  $R = .415$ ,  $R^2 = .172$ ,  $F(1, 147) = 25.54$ . The only factor that was a significant predictor of the TMDS was the baseline POMS score, with  $\beta = .415$ ,  $t(158) = 5.74$ ,  $p = < .001$ . The analysis showed that the lower participants' self-report scores were at Time 1, the more likely they were to have a greater change in self-report ratings.

Table 8  
*Descriptive Statistics Overall for the CI across Groups (Transformed Data) (n = 152)*

Group	<i>N</i>	<i>M</i>	<i>SD</i>
Control	38	0.06	0.81
Schizophrenia	38	0.10	1.10
Cancer	36	0.16	0.61
Depression	40	0.06	0.96

*Note.* CI = cortisol impact

Table 9  
*Summary of Multiple Regression Analysis for the TMDS – Significant Predictors only (N = 160)*

Step	Variable	B	SE(B)	$\beta$	<i>t</i>	<i>p</i>
1	Baseline POMS score	.268	.047	.415	5.74	< .001

*Note.* TMDS = change in POMS total mood disturbance scores, POMS = Profile of Mood States,  $R^2 = .172$

Table 10

*Summary of Multiple Regression Analysis for the CI – Significant Predictors only (n = 149)*

Step	Variable	B	SE(B)	$\beta$	<i>t</i>	<i>p</i>
Transformed data	Baseline cortisol level	.013	.003	.384	5.06	< .001

*Note.* CI = cortisol impact score,  $R^2 = .147$

Stepwise multiple regression was used to determine the impact of group assignment on the CI by regressing the CI onto dummy variables for groups. The same confound variables were tested for as in the POMS analyses with the exception of POMS baseline and the addition of baseline cortisol and all cortisol questionnaire items. Regression results are displayed in Table 10. The analysis ended with the first step, entry of baseline cortisol level. Altogether the variables mentioned above shared 14.8% of explained variance,  $R = .384$ ,  $R^2 = .147$ ,  $F(1, 148) = 25.57$ . The model was a significant predictor of the CI ( $p = < .05$ ). The analysis showed that baseline cortisol was the only significant predictor of the CI,  $\beta = .013$ ,  $t(148) = 5.06$ ,  $p = < .001$ . This result indicates that participants with lower baseline cortisol levels tended to have a lesser decline in their cortisol levels between Time 1 and Time 2.

### Third Objective

**Determine the relationship of stigma and health locus of control to participants' reactions.**

Stepwise multiple regression was used to determine the relationship of both stigma and health locus of control to participants' reactions. Firstly, regression analysis was used to test if the SCQ total score significantly predicted participants' TMDS. The analysis ended with the first step, entry of SCQ total score. Across all groups, the SCQ total score was found to be a significant predictor of the TMDS, indicating that greater stigma was associated with greater

deterioration in mood,  $\beta = -.417$ ,  $t(157) = 3.32$ ,  $p = .001$ . Regression results are presented in Table 11.

The same analysis was performed for the TMDS and health locus of control with one difference, that is, without the SCQ score and with all three subscales of the MHLC (Internal Health Locus of Control [IHLC], Chance Health Locus of Control [CHLC] and Powerful Others Externality [PHLC]) entered as covariates. None of the subscales was found to be a significant predictor of change in POMS scores ( $p = > .05$ ).

Stepwise multiple regression was conducted to test whether the SCQ total score significantly predicted the CI. Across all groups the SCQ was not found to be a significant predictor of the CI ( $p = > .05$ ).

Finally, regression analysis was then conducted to predict the CI from the three subscales of the MHLC (SCQ not included). The PHLC subscale was found to be a significant predictor of the CI, indicating that the PHLC was associated with less distress as measured by cortisol levels,  $\beta = .071$ ,  $t(148) = 2.10$ ,  $p = .037$ . Regression results are presented in Table 12.

Table 11

*Summary of Multiple Regression Analysis for the TMDS and SCQ – Significant Predictors only (N = 160)*

Step	Variable	B	SE(B)	$\beta$	$t$	$p$
1	SCQ total score	-.417	.126	-.238	-3.32	.001

*Note.* TMDS = change in POMS total mood disturbance scores, SCQ = Stigma Consciousness Questionnaire,  $R^2 = .226$

Table 12

*Summary of Multiple Regression Analysis for the CI and MHLC Subscales – Significant Predictors only (n = 149)*

Step	Variable	B	SE(B)	$\beta$	<i>t</i>	<i>p</i>
1	PHLC	.071	.034	.163	2.10	.037

*Note.* CI = cortisol impact, MHLC = Multidimensional Health Locus of Control, PHLC = Powerful Others Externality subscale,  $R^2 = .115$

**Fourth Objective**

**Identify the anticipated impact of risk news on factors in the participants’ lives.**

Stepwise multiple regression was used to determine the relationship of the PRI items to the distress measures (TMDS and CI). Initially regression analysis was conducted to test whether any of the PRI items significantly predicted the TMDS. The model was a significant predictor of the TMDS across all groups ( $p < .05$ ). Altogether the items of the PRI accounted for 8.8% of explained variance,  $R = .296$ ,  $R^2 = .088$ ,  $F(2, 154) = 7.41$ ,  $p = .006$ . Two questions were found to be significant predictors of deteriorating POMS scores (deteriorating mood), specifically, *How anxious did you feel about your future?*,  $\beta = -2.34$ ,  $t(154) = -3.45$ ,  $p = .001$  and *How likely did you think it would be that you would die from this condition?*,  $\beta = 3.79$ ,  $t(154) = 2.77$ ,  $p = .006$ . Both questions are keyed in the same direction but the first question has a negative association, that is, higher scores on the PRI question (suggesting more general future anxiety) predicted a lower TMDS, indicating an increase in distress. The second question has a positive association indicating that higher scores on the PRI question (suggesting increased future concern about dying) predicted a greater TMDS, indicating reduced distress. Regression results are presented in Table 13.

Table 13

*Summary of Multiple Regression Analysis for the TMDS and PRI – Significant Predictors only (N = 160)*

Step	Variable	B	SE(B)	$\beta$	<i>t</i>	<i>p</i>
1	Anxiety question	-2.34	.680	-.281	-3.45	.001
	Possible death question	3.79	1.37	.226	2.77	.006

*Note.* TMDS = change in POMS total mood disturbance scores, PRI = Perceived risk impact,  $R^2 = .088$ , Anxiety question = How anxious did you feel about your future?, Possible death question = How likely did you think it would be that you would die from this condition?

In order to determine whether the predictive value of these two questions differed between groups, a one-way between subjects ANOVA was performed. One question (*How anxious did you feel about your future?*) was found to be significantly different between groups, with  $F(3, 156) = 6.31$ ,  $p < .001$ . The Least Significant Difference (LSD) post hoc test was conducted to determine which of the groups differed significantly from the others in relation to this question. The LSD test indicated that the control group mean was significantly lower than all other groups. Therefore, participants in the control group indicated that they thought they would experience less anxiety about the future than participants in other groups.

When regression analysis was used to test whether the PRI items significantly predicted the CI, the model was a significant predictor across all groups (of CI) ( $p < .05$ ). The analysis ended with the first step, entry of PRI items. Altogether the items of the PRI accounted for 8.9% of explained variance, with  $R = .298$ ,  $R^2 = .089$ ,  $F(2, 147) = 6.90$ ,  $p = .010$ . Two questions were found to be significant predictors of change, specifically, *How likely did you think it would be that you would die from this condition?*,  $\beta = -.86$ ,  $t(147) = -3.57$ ,  $p < .001$  and *How likely were you to have made different decisions about relationships and children because of this condition?*,

$\beta = .307$ ,  $t(147) = 2.63$ ,  $p = .010$ . Again, these results of these questions are in different directions. The first question suggests that greater concern about the future was associated with a lower CI, indicating greater increase in distress. The second question suggests that greater likelihood of making different decisions in the future was associated with greater CI, indicating reduced distress. Regression results are presented in Table 14.

In order to determine whether the predictive value of these two questions differed between groups, a one-way between subjects ANOVA was performed. One question (*How likely were you to have made different decisions about relationships and children because of this condition?*) was found to be significantly different between groups at the  $p < .05$  level ( $F(3, 156) = 4.805$ ,  $p = .003$ ).

The LSD test indicated that again the control group mean was significantly lower than all other groups. This result illustrates that participants in the control condition thought they would be less likely to make different decisions about relationships and children because of the TAED condition, than other groups.

Table 14

*Summary of Multiple Regression Analysis for the CI and PRI – Significant Predictors only (N = 160)*

Step	Variable	B	SE(B)	$\beta$	$t$	$p$
1	Possible death question	-.858	.240	-.308	-3.57	< .001
	Different decisions question	.307	.117	.227	2.63	.010

*Note.* CI = cortisol impact, PRI = Perceived risk impact,  $R^2 = .089$ , Possible death question = How likely did you think it would be that you would die from this condition?, Different decisions question = How likely were you to have made different decisions about relationships and children because of this condition?

### Discussion

The current practice of screening for schizotypy involves the withholding of information about risk status from participants. This aspect of research does not completely adhere to generally accepted recommendations for good ethical practice. Four key principles have been posited as the basis of good practice - autonomy, beneficence, non-maleficence, and justice (Gillon, 1994). When considering these principles, several issues with schizotypy screening can be identified, including the lack of informed consent, deception, and nondisclosure of results. The rationale for the current screening practice is based on a theory of the aetiology of schizophrenia (Meehl, 1990). This theory surmises that the proportion of people with schizotypy who express the disorder is low. There is also the concern that participants may experience significant harm upon receiving the risk news (Linscott & Cross, 2009). In addition, screening measures can be fallible and researchers wish to avoid false positives (M. Lenzenweger, personal communication, August 8, 2011).

However, the lack of reliable evidence surrounding this issue makes it difficult to determine the full implications of these ethical concerns. One way to inform the debate is to ascertain the impact of risk information on participants. In a hypothetical study of risk Linscott and Cross (2009) asked participants to imagine being at increased risk for medical and psychological disorders, including schizophrenia. It was found that news of risk for schizophrenia was thought to be more distressing than heart disease, arthritis, depression, and diabetes but less distressing than risk for cancer and Alzheimer's disease.

Following on from the Linscott and Cross (2009) research, the present study used a more realistic paradigm to assess the impact of risk information. The aim of the present study was to identify the reactions of non-help seeking individuals to disclosure of personally relevant

information about risk for schizophrenia. The objectives were firstly to identify the impact of news of risk for schizophrenia, relative to other diseases, secondly to quantify reactions using both subjective (self-report) and objective (salivary cortisol levels) measures, thirdly to determine the relationship of stigma and health locus of control to participants' reactions, and fourthly, to investigate the anticipated impact of the risk information on several aspects of participants' lives.

Initially the findings regarding group differences in reactions will be discussed followed by an examination of the results of the specific measures used. The relationship of stigma and health locus of control to the current results will then be considered. Subsequently, remarks on additional findings regarding other measures in the study will be provided. Specific hypotheses are reported in concordance with the discussion of the relevant results, as are particular thoughts for future research. Directions for general future research and the implications of the present study for the ethical debate on screening research will lastly be described. As mentioned earlier in the introduction, there is a scarcity of evidence specifically related to the ethics of the current screening practice of schizotypy. Therefore, this discussion will draw parallels from research on different pathologies.

### **Group Differences**

What were the overall differences between the groups? The findings differ from previous research investigating the impact of risk information, which found that imagining risk for schizophrenia was rated more distressing than several medical disorders and less distressing than cancer (Linscott & Cross, 2009). The results of the present study show that there were no statistically significant differences between the groups in relation to the impact of risk information. It was expected that participants would react in a similar way to previous research (Linscott, unpublished data) and therefore the impact of news of risk for schizophrenia would be

similar to that associated with risk for cancer, greater than that associated with risk for depression, and for the TAED condition. This hypothesis was not supported.

The lack of statistical significance raises two issues that need consideration. Firstly, what is the magnitude of the difference and secondly, is it an issue that is related to the power of the study? In order to answer these questions, the overall pattern of results must be considered. The magnitude of the difference between Time 1 and 2 for both the self-report measure and the cortisol data is not large either across or between the groups (see Tables 5, 6, 7, and 8). For the self-report data, the control group had the greatest improvement in mood, followed by the depression group with a slight improvement in mood, with the schizophrenia and cancer groups showing worsening mood (Table 7). For the cortisol data, the pattern showed the cancer group with the least increase in the stress hormone followed by the schizophrenia group with the depression and control groups showing the largest increase (Table 8).

These results are somewhat similar to the pattern expected, but only for the self-report data. The cortisol data is nearly the exact opposite of what was expected. Therefore, it seems that for the cortisol data, the lack of evidence is not an issue of power and adding more participants would not increase the likelihood of statistical significance in the direction expected. In addition, the sample size was reasonably large although admittedly only comprising undergraduate students. It is important to note again that the above data were not statistically significant and the standard deviations on both measures were very large so it is difficult to draw any strong conclusions.

There are several possible explanations for these results. Firstly, it is necessary to consider whether the hypothesis was mistaken. The hypothesis regarding differences in reactions between groups was based, as mentioned, on the previous research of Linscott and Cross (2009). It may be

that while this previous research was a good estimate of imagined distress, responses to actual risk differ.

One difference between the Linscott and Cross (2009) study and the present research that may account for the different findings is the design of the studies. The present study was a 'between-subjects' design while the previous research was 'within-subjects'. It may be that being asked to imagine being at risk for many disorders increases the significance of the information and participants are deciding for themselves which one may be worse. Being told of risk for one disorder in a real-life situation may mean there are several other processes occurring. For example, cognitive minimisation of the disorder and risk news. These possible processes are discussed in more detail in the distress measures section below.

The context of the experiment needs to be considered when examining the previous results. The participants were university undergraduate students who were all taking undergraduate psychology papers. Therefore, the issues raised earlier regarding deception may be relevant here. That is, psychology students were possibly more likely to expect deception, particularly as the experiment took place in a university psychology building. If the experiment had been conducted in the hospital context or in a medical department, it is feasible that there may have been different findings. As an anecdote to this explanation, one participant said during the experiment that he did not think a psychology department would be running experiments involving risk for cancer. This disbelief was because he perceived cancer to be a medical condition only. In the optional comments written after the experiment, several participants also mentioned this idea. One in particular wrote, "a psyc (sic) student will always remain at least a little sceptical in any type of experiment though so perhaps some civilians could increase accuracy?"

Given the findings of no significant differences between groups, it is likely that one explanation could be that the testing process and impact of receiving a risk diagnosis was equally stressful for all groups. One way to investigate further the effect of receiving a risk diagnosis overall would be to add in a complete control condition. There was a control group who received the TAED information only but it would be interesting to include a group who received no diagnosis, i.e., being told they did not have TAED after completing the test.

Another rationale for the above findings could be that it takes a longer time to process fully receiving risk information than allowed for in the experiment. It may also take some time for an individual to evaluate the consequences the risk information will have on his or her life. Relevant information on processing distressing information can be drawn from studies on grief and bereavement. Research has found that the acute reaction to grief can often be delayed (Lindemann, 1944). Even patients who have had successful treatment for cancer can take some time to adjust psychologically afterwards (Cella & Tross, 1986). However, due to ethical concerns and the requirements of the ethics committee, it was thought best not to allow participants to believe the information for too long a period.

It could also be that the time period for measuring the cortisol levels was not appropriate. The decision to test participants' cortisol levels at the beginning of the study as a baseline and again at approximately 25 to 30 minutes after the manipulation, was based on a recent comprehensive meta-analysis (208 studies) (Dickerson & Kemeny, 2004). The meta-analysis was conducted to determine under which conditions psychological stressors influence cortisol levels and it was found that acute, uncontrollable psychological laboratory stressors triggered substantial cortisol changes. The greatest effect sizes were found within the 21 to 30 minute time period after a stressor (see Dickerson & Kemeny, 2004). However, due to the nature of the

experiment, the requirements of the ethics committee, and financial limitations, it was not possible to run a pilot study and test for the best time to measure cortisol. It is possible that performing more cortisol tests at different time periods, such as at 5-10 minute intervals after the manipulation until the completion of the experiment, would provide a better understanding of the results and the overall cortisol pattern.

A final point worth consideration regarding the group cortisol data is that although the results were not significant, participants in the depression group had the greatest increase in cortisol from Time 1 to Time 2. There has been a large focus on increasing awareness about depression in recent years in New Zealand, particularly in mainstream media such as television advertising. It may be that this increased focus has had an impact on how individuals view the disorder, that is, depression may be seen as more stressful. This could be an interesting area for future research.

### **Distress Measures**

A limitation of the Linscott and Cross (2009) research was that participants' (imagined) distress was collected with measures that were not independently validated. Therefore, in the present study two well-known and validated measures were used to assess participants' reactions to the risk information, a subjective (self-report) and an objective measure (salivary cortisol). The intention behind using these two different types of measures was also to provide a check for possible biased reporting from the self-report measure. A correlation between the change in POMS scores and the change in cortisol levels was not significant. Therefore, it appears that the measures used may either both not be valid measures of stress or modifications need to be made for their use in future studies.

One issue regarding the cortisol measure is that cortisol has been found to fluctuate over the day (Kudielka, Schommer, Hellhammer & Kirschbaum, 2004; van Eekelen, Kerkhof & van Amsterdam, 2003). Participants were all tested within a four hour period of the afternoon to minimise the effects of circadian variation and were asked about other factors that have been found to affect cortisol in the literature (such as caffeine, for example see Lovallo et al., 2005). However, it may be that cortisol decreased over time due to the stressor (risk information) not being prolonged or intense enough and this decrease was stronger than the effect of the stressor (Dickerson & Kemeny, 2004).

There may have also been problems with the selection of the filler task (Pyramids and Palms Trees test [PPT]), which could have affected the accuracy of the distress measures. The PPT was not stressful or particularly challenging and consequently could have engendered boredom or created uncertainty. This factor may have decreased cortisol levels. In addition, if a participant became bored or unsure due to the PPT, his or her self-report scores may have also been affected due to inattention when completing the measure.

The differences in the patterns of the self-report and cortisol data as discussed in the previous section, specifically, the control group with the least increase in mood disturbance for self-report but the largest increase for cortisol, could relate to the information provided. There was not a lot of detail about TAED on the information sheet (see Appendix A) and it could be that participants were unsure of the condition and hence, felt more distressed about it. Before being debriefed, several people commented that they were going to go home and research the condition on the Internet. One study investigating the impact of receiving news of cancer type found that the way the news was communicated and explained was important for the person's outcomes (Randall & Wearn, 2005). For example, receiving sufficient factual information about

the illness could reduce people's fear of the condition. Whether the cancer was curable or not also changed the outcomes. One additional finding was that people wanted the experience of the news to be individualised (Randall & Wearn, 2005). In the present study participants were all told they had TAED and were then either informed of a risk association or not. It may be that the impact of hearing about an unknown disorder is more apparent with objective measures. It is not clear why this result would also not translate to increased self-report scores.

The specific results for both the self-report and cortisol data will now be considered. It was hypothesised that the self-report scores would be greater the second time the measure was administered. Across all groups there was a minute increase from Time 1 to Time 2. However, this was not significant. When analysing the group data, the schizophrenia and cancer groups increased slightly and the control and depression groups decreased slightly. These differences were also not significant (see Table 5). Therefore, this hypothesis was not supported. Regression analysis also showed there was no effect of group on the self-report scores. All measured confounds together accounted for 17.2% of the variance. The strongest and only significant predictor of change on the measure was the baseline self-report score.

It was hypothesised that cortisol levels would likely decrease for all participants given the length of each experimental session but that a lesser decrease would occur for the schizophrenia condition. All groups decreased slightly from Time 1 to Time 2 (see Table 6); none of these was a significant decrease. The group with the least decrease was the control group. However, this was also the group with the lowest level of cortisol overall. The schizophrenia group had the largest decrease in cortisol levels which is in the opposite direction to that hypothesised. Therefore, the above hypothesis is not supported.

Regression analysis showed that there was no effect of group on cortisol levels. All measured confounds together accounted for 14.8% of the variance in the cortisol levels. Similar to the self-report data, the strongest predictor of cortisol change was the baseline cortisol score. When the analysis was re-run with the raw data there were two significant predictors, the baseline cortisol score and time of awakening. This additional finding with the raw data is consistent with previous research, which indicates the influence that time of awakening has on cortisol levels. Salivary cortisol levels are found to increase rapidly in the first hour of awakening (Kudielka & Kirschbaum, 2001; Stalder, Hucklebridge, Evans & Chow, 2008).

Again, there are different possible processes that may underlie these findings. Research into the psychological consequences of predictive genetic testing found that there was little evidence of cognitive or behavioural consequences (Broadstock et al., 2000). The Broadstock and colleagues (2000) study raises questions about the present research, which investigated physical changes and self-reported mood changes. There are possibly other signifiers of distress that were not measured. For example, an interesting aspect not fully included in the current study was the cognitions of participants. Some indication of cognitions was provided with the perceived risk impact questionnaire, discussed further below. A space was provided for comments if participants wanted to leave remarks but this was optional and not guided in any way. One verbal comment received after an experiment indicated that a participant had been thinking about the risk information in a serious manner. She was in the cancer condition and described thinking that she should have worn more sunscreen that day. This comment suggests that she would likely have engaged in behaviour change after hearing the risk information.

Another process could be that of threat minimisation, a form of denial (Croyle & Ditto, 1990). Threat minimisation refers to the act of underemphasising a potential danger to the self, in

this instance, minimising the seriousness of an illness (Croyle & Ditto, 1990). Ditto, Jemmott and Darley (1998) found that participants rated TAED as less threatening and severe when they were given no potential treatment options. Those participants given treatment options about TAED subsequently rated the disorder as the most life-threatening. This finding suggests that participants were minimising the illness. It appears that denial in some form is a relatively common response to risk news and also to a diagnosis. Drozdowicz (2002) found that people who have been diagnosed with schizophrenia are likely to deny being mentally ill when first diagnosed, a proclivity that decreased over time.

It is thought that people's understanding about the prevalence of a disorder can impact on their ideas of the severity of an illness (Jemmott, Ditto & Croyle, 1986). One study specifically using the TAED paradigm found that when TAED was described as a low rather than a high prevalence disorder, the disorder was regarded as more serious. A design factor of the present study that may have reduced the levels of distress is the comment regarding the prevalence of TAED (1 in 15 people, see experimental protocol in Appendix B). Several people mentioned that they thought it was a common deficiency when told this prevalence. It may have been more effective to use a larger number, for example, 1 in 50, as people may have then thought it was more uncommon to be diagnosed with the deficiency. The statement made by the experimenter about the TAED condition indicated that it was a benign condition (Appendix B), which may have also been a contributing factor for decreasing worry or distress.

When considering the self-report outcome measure, it may have been that participants were trying to present a good self-image and did not want to appear upset. This possible response bias may have resulted in lowered second scores. In accordance with this idea, several people wrote that they were not upset by the experiment but the behavioural observations contradicted

these statements. For example, people were observed to blush, begin fidgeting and ask numerous questions about the TAED condition.

### **Relationship of Stigma and Health Locus of Control**

Participants completed the SCQ (Pinel, 1999) and the MHLC (Wallston et al., 1978) after receiving the risk information and completing the filler task. The results of the SCQ will firstly be discussed. The findings for the self-report measure showed across all groups that the SCQ was a significant predictor of change in POMS scores. This finding supports the hypothesis that the SCQ would predict the level of distress experienced. Specifically, participants with lower baseline mood disturbance levels were more likely to react to the manipulation with an increase in mood disturbance. There were no differences between groups. This finding indicates that being conscious of the possibility of being stigmatised has an effect on self-reported distress. The findings for the cortisol data show that the SCQ was not a significant predictor of change in cortisol levels across all groups. Therefore, the hypothesis regarding the SCQ is supported with the self-report data but not with the cortisol data. The finding that stigma is related to self-reported distress is consistent with reports that individuals experience stigma across many different domains in life (for example, Jenkins & Carpenter-Song, 2009 and Zelst, 2009).

The results of the SCQ predicted distress as measured with the self-report questionnaire but not the cortisol samples. This difference may have occurred because having a concern about being stigmatised in the future may not have been a large enough immediate stressor to affect cortisol levels, in particular if the levels were starting to decrease near the end of the experiment when the SCQ was administered. It could also be that stigma does not have as direct an effect in the short term as in the long term, once the full consequences of risk information have been realised. In addition, stigma is a concept that people tend to notice more in specific situations, for

example in a work or dating context (Jenkins & Carpenter-Song, 2009). Therefore, there may be a delayed effect of stigma on the self.

The MHLC has three subscales (Internal Health Locus of Control [IHLC], Chance Health Locus of Control [CHLC], and Powerful Others Externality [PHLC]). For the self-report measure, none of the subscales was found to be significant predictors of change. These findings do not support the hypothesis that those with an internal locus of control would show greater distress reactions than those with an external locus of control.

When considering the MHLC and the cortisol data, one subscale was found to be a significant predictor of change in cortisol levels. Specifically, the PHLC was associated with less change in distress. The hypothesis that an internal locus of control would be related to greater distress reactions is not supported because the IHLC was not significantly associated with cortisol. The result regarding the PHLC is interesting and suggests that people who believe health professionals have control over their health or have an important role in their health care are more likely to have lower levels of change in distress, as measured by their cortisol levels.

The theory behind the MHLC, as mentioned briefly in the introduction, is based on the locus of control concept, which was founded on social learning theory. The premise is that having an internal locus of control relates to beliefs that personal behaviour influences health and vice versa for an external locus of control. Therefore, if health problems are viewed as externally based, the problem could be seen as unchangeable. It appears that participants who have the belief that others have control over their health, feel less distressed, perhaps precisely because the problem is viewed as out of their control. However, it is also possible that this result could be an artefact of the testing situation. The experimenter could have been seen as in control as she was the one telling the participants about the risk. Therefore, the external aspects of participants'

health belief systems may have been activated. It could also be that participants were thinking they would need to talk to a health professional to find out more information, and subsequently rated the questions of this subscale higher.

Referring again to the large cortisol meta-analysis regarding psychological stressors, one interesting finding was that the uncontrollability of a stressor significantly predicted effect sizes and was associated with a greater cortisol response (Dickerson & Kemeny, 2004). It was found that in order for cortisol levels to change, the stressor not only had to be uncontrollable but also had to threaten a motivational domain (Dickerson & Kemeny, 2004). It was thought for the present study that an important motivational domain would be the health domain. Given the overall results, it appears that in the context of receiving risk news, as researched in the present study, the health domain is not as important as was thought. It is possible that the MHLC may be a more useful predictor of future behaviours, such as help-seeking and ability to cope, once a person has received the risk information (Wallston et al., 1978).

### **Findings of the Perceived Risk Impact (PRI) Questionnaire**

Upon receiving the risk information there were two possible cognitive processes participants engaged in. The first process was whether they believed the manipulation and the second process was whether they thought about the implications of the manipulation. That is, whether participants thought they were likely to be at increased risk for the disorder and then thought about the impact this risk or the disorder would have on their lives. The PRI was intended to provide a measure of the possible future impact of the risk information. It was expected that participants who were informed about risk news of schizophrenia, cancer, or depression would anticipate the news to have a greater impact on their lives than the control condition.

For the PRI measure, participants were asked to think back to how they felt when they received the risk news. They were then asked to imagine how they thought this information would have affected their lives subsequent to receiving the information. There were several interesting findings from the PRI, however, two qualifications need to be made when considering these data. The PRI was a post hoc measure; participants completed it at the very end of the study following debriefing. In addition, the validity of the PRI has not been previously tested.

In relation to the self-report data, two questions were found to be significant predictors of change across all groups, specifically, *How anxious did you feel about your future?* and *How likely did you think it would be that you would die from this condition?* When further analyses were conducted, the control group was found to be significantly lower than other groups on the question *How anxious did you feel about your future?* This outcome suggests that the control group (TAED) thought they would be significantly less concerned than other groups about their future, supporting the hypothesis that participants in established disorder conditions would consider the risk news to have a higher impact on their lives. This result appears to speak to the validity of the study. In other words, it may be that an established and more well-known illness results in more anxiety than an unknown, benign enzyme deficiency.

For the cortisol data two questions were also found to be significant predictors of change across all groups, specifically, *How likely did you think it would be that you would die from this condition?* and *How likely were you to have made different decisions about relationships and children because of this condition?* Further analysis of group differences again found the control group to be significantly lower on the second question, supporting the above hypothesis. This result suggests that the control group thought they would be less likely to change the decisions

they would make in the future regarding their children and relationships than participants in other conditions.

Data from the PRI suggest that when participants are asked to imagine how they may feel in the future, the results are as expected for some areas. That is, the control group was less distressed than the other groups when considering future decision making and future anxiety. These results are consistent with the previously discussed findings of reduced levels of self-reported distress in the control condition but contrast somewhat with the results of the cortisol data, in which the control condition had an increase in distress. It may be that distress about TAED was greater upon receiving the risk news but the perceived significance of the deficiency lowered when contemplating the impact this news would have on potential future outcomes. There were however some contradictory findings from the PRI. Perceived potential for survival was associated with reduced mood disturbance but a greater increase in cortisol levels. It is not clear why this factor would have an effect on cortisol rather than self-report data. It may be that again there was a response bias and people did not want to appear as upset as they felt. It is evident however that further research is necessary to determine why there are differences between people's thoughts about future behaviours and their cortisol levels.

### **Future Directions**

Several specific changes that could be made to improve the present study for future research have been outlined throughout the discussion. There are also several broad areas that would be interesting to investigate further. Firstly, whether people wish or do not wish to be informed of their risk-status post screening is a crucial area of research for the schizotypy area. Research on screening for other pathologies suggests that people will often state they do want to know but if provided with the chance to find out, will not take the opportunity (Corcoran et al.,

2005; Croyle & Lerman, 1995). It has also been found that people take different pathways to arrive at the actual screening process (Marteau, 1995). For example, some people may be searching for answers or results because they have noticed changes within themselves. Therefore these individuals would want to know their results and may feel relieved upon receiving them.

Given that some people do experience more distress than others when receiving risk news, it will be important to research further methods of elucidating who is likely to be more distressed. Another possible avenue is investigating techniques to mediate this distress. It is possible that having another person present when the test results are presented may alleviate the distress in some way if the person is a support person. Conversely, having an unknown person present may impact negatively on receiving risk information if the individual receiving the risk news has a concern about being stigmatised. Previous research using the TAED paradigm found that social influence (in the form of a same-sex confederate) reduced individuals' self-reported concern about the diagnosis (Croyle & Ditto, 1995). Interestingly, participants' intentions to take action to reduce the risk were not affected.

One other possible area for future research was indicated by comments from several participants during and after the study. Several people described wanting to find out further information after the experiment. It could be interesting to examine how they would search for this information and whether their intent matched their actions.

The long term consequences of this study were not investigated. A thorough debriefing was provided to minimise participant concern and distress over the fictitious test results. However, it is possible that some participants may have still been worried when they returned home. Reactions over time differ from immediate reactions as people find out new information

about a diagnosis (Lazarus & Folkman, 1984) and it may be similar for risk information. It would be of interest to follow-up how people felt and what they were thinking some time after the study.

### **Implications**

Research focused on screening for risk is an expanding area and more information is being gathered about a variety of aspects in this process (e.g., Cyhlarova & Claridge, 2005; van Os & Delespaul, 2003). It is likely that future screening will include a wider range of people than are presently involved in screening studies, moving to those with fewer signs of risk. Currently screening is extending to general population samples of children and is likely to extend to screening based on genotypes (Linscott & Cross, 2009; Riecher-Rossler et al., 2006). As screening tests become more specific and predictive it becomes more important to examine the ethical issues surrounding the current practice. The social value of this study lies in investigating one aspect of these ethical issues and in challenging the current practice of screening studies for risk of schizophrenia. The study also helps to progress the research available on screening for schizophrenia and contributes to the debate surrounding this area. Replication in different populations will further inform the debate.

It is important to note that the present research focus was on individuals' reactions to news of a benign enzyme deficiency that was purported to be associated with an increase in risk. Therefore, direct conclusions and implications cannot be drawn regarding screening research. This news of risk also cannot be compared to news of a disorder diagnosis.

As Marteau (1995) outlines, it is important to have research that can help explain how people respond to screening. The present research contributes to this understanding by providing details of how non-help seeking individuals react to risk information. It is also important to have an understanding of how people react to news of risk to determine the practicalities and use of

early screening. Schizophrenia is a debilitating disorder with a relatively late onset and the benefits of early screening may not be so substantial if the individual loses the symptom-free period of their life to concern about the disorder (Corcoran et al., 2005). In relation to screening measures, it is argued that they must be tested rigorously before being implemented in order to remove the chance of harm (O'Toole, 2000). O'Toole states that for a screening measure to be found appropriate for low prevalence disorders such as schizophrenia, large populations are needed to demonstrate adequately high sensitivity and specificity.

Although there were few significant findings, it cannot be claimed that telling people they are at increased risk for a disorder has no effect and is not detrimental. The findings of nonsignificant differences in distress reactions across groups could be interpreted as providing evidence to continue the current practice of schizotypy screening as it is. These results could also be interpreted as providing a reason to tell participants about their risk status given that the majority of people do not appear to become distressed, in particular because the information is about an increased risk only, not a diagnosis. The process for telling participants would need to be carefully considered and include sufficient factual information about the condition as well as provide avenues for participants to seek further help or information if required.

What are the ethical issues if people do not appear to experience significant distress (as measured in the present study by self-report and cortisol)? The issues of informed consent, nondisclosure, and deception are still present. To avoid these ethical problems, providing participants with knowledge about the purpose of screening would allow for informed consent and remove the need for deception. The concern that participants may experience distress upon receiving risk news is perhaps not well-founded. Therefore, it may be better to inform participants of the results and avoid concerns regarding nondisclosure. In one anecdotal study

with help-seeking adolescents who were receiving information regarding their prodromal status for schizophrenia, 20% were reportedly able to recognise and agree with the information to some degree and a further 40% were willing to join an early intervention study although they were unconvinced of the risk information (McGlashan, 2001). It is important to note that some individuals do experience distress upon receiving risk news. In order to ensure the least possible distress occurs, future research is necessary to investigate and develop more specialised measures that can be used to assess any distress before or during the screening process.

The possible costs of telling participants their risk results have been outlined throughout this work (for example, possible discrimination for participants and the impact on researchers financially and emotionally, Fernandez et al., 2003). However, there are also gains that could be made by passing on risk information. Disclosing information about risk status may provide participants with the option of implementing preventative measures for those factors that have been linked to schizophrenia. For example, reducing the use of illicit substances such as cannabis (Moore et al., 2007) or engaging in behaviour change to reduce the likelihood of experiencing stressful situations (Corcoran, Gallitano, Leitman & Malaspina, 2001). People may also become aware of any prodromal symptoms earlier and seek treatment sooner, reducing the duration of untreated psychosis (Yung & McGorry, 1997).

The findings relating to stigma consciousness and the association with self-reported distress have important implications. It is likely that individuals who have a greater stigma consciousness will require more support when receiving risk news. It may be useful to administer the SCQ before screening for risk to determine which individuals may experience greater distress upon testing. Stigma, even perceived stigma only, can have a pervasive effect and negative consequences in many areas of life (Chandra et al., 2003; Jenkins & Carpenter-Song,

2009; Zelst, 2009). For instance, the course of a physical illness can worsen with perceived stigma and often an individual will not seek treatment due to the fear of stigmatisation (Link & Phelan, 2006). Zelst (2009) views stigma as occurring even before an individual has been diagnosed with schizophrenia, thought to be due to possible behavioural features associated with schizotypy. She also argues that stigma could be a contributing factor in the onset of the disorder because it is a significant stressor in people's lives as well as a factor relating to poorer outcomes.

### **Conclusion**

The present study has provided information on how non-help seeking individuals react to news of increased liability for schizophrenia. Low levels of distress were found across both self-report and objective measures for all disorders and participants did not appear more distressed when informed of risk for schizophrenia compared to other disorders. It was also found that the fear of being stigmatised predicted participants' self-reported distress. Although there were few significant findings, the research has implications for informing the ethical debate regarding schizotypy screening research. Replication of the present research with different populations and further research into other aspects of the screening process is necessary to ascertain more clearly how individuals react to risk information. Ultimately, the burden of making considered, ethical decisions lays with researchers who must decide whether the social value of their research outweighs the lack of informed consent, the use of deception, and nondisclosure of results.

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## Appendix A

*Note.* The information sheet was altered for each group; the 10-fold increase in risk was changed to the appropriate condition (schizophrenia, cancer, depression, or no risk for the control condition [TAED only]).



*Te Whare Wānanga o Ōtāgo*

### THIOAMINE ACETYLASE ENZYME DEFICIENCY AND STRESS INFORMATION SHEET FOR PARTICIPANTS

04/04/2012

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

#### **What is the Aim of the Project?**

The aim is to determine the relation of thioamine acetylase enzyme deficiency (TAED) to measures of stress and cognition. TAED is a benign condition but is linked with a ten-fold increase in risk for schizophrenia. We are interested in the relationship between TAED and stress and semantic memory. This project is being undertaken as part of the requirements for a Master of Science thesis.

#### **What Type of Participants are being sought?**

We are seeking undergraduate students in Psychology. People who have a history of mental health problems or cancer and people who have been diagnosed with a psychosis or have someone in their immediate or extended family with a psychosis will not be able to participate in the project.

#### **What will Participants be Asked to Do?**

Should you agree to take part in this project, you will be asked to wash the inside of your mouth with a solution and spit this into a specimen jar. We will then test this solution with a TAED test-strip that gives an immediate result if you have TAED. You will also be asked to complete a demographics questionnaire, a test of semantic processing, a measure of mood state, give two saliva samples from which we will measure cortisol, and complete a stigma consciousness and health locus of control questionnaire. Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

**Can Participants Change their Mind and Withdraw from the Project?**

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

**What Data or Information will be Collected and What Use will be Made of it?**

We will record the TAED test result, your responses to the questionnaires, and levels of cortisol in your saliva. The responses you give will be collated with other participants' results and analysed to look at overall patterns in the data. This data may be used for presentations or publications. All of your answers will be kept confidential and you will not be identified in the research project or any publication of the research as the personal information you provide will be kept separate from the data.

The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) your anonymity will be preserved. You are most welcome to request a copy of the results of the project should you wish.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

**What if Participants have any Questions?**

If you have any questions about our project, either now or in the future, please feel free to contact either:

Roni Alder,  
Research Student,  
Department of Psychology

Tel. 479 5681

E-mail: [aldro598@student.otago.ac.nz](mailto:aldro598@student.otago.ac.nz)

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This study has been approved by the University of Otago Human Ethics Committee.

If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

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*Te Whare Wānanga o Ōtāgo*

**THIOAMINE ACETYLASE ENZYME DEFICIENCY AND STRESS  
CONSENT FORM FOR PARTICIPANTS**

04/04/2012

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for ten years, after which they will be destroyed;
4. The procedures used are not physically harmful and do not cause physical discomfort.
5. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but my anonymity will be preserved.

I agree to take part in this project.

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Signature of participant

---

Date

This study has been approved by the University of Otago Human Ethics Committee.

If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

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*Te Whare Wānanga o Otāgo*

## THIOAMINE ACETYLASE ENZYME DEFICIENCY AND STRESS DEBRIEFING FORM FOR ALL PARTICIPANTS

04/04/2012

Thank you for contributing to this project. This project is concerned with the field of clinical psychology (area = other).

### **Purpose**

The purpose of this project is to determine the acute psychological impact of information about risk for schizophrenia (and several control diseases) using a paradigm that makes the risk information personally relevant only during participation in the study. The results of the study will inform debate on the application of the principle of informed consent in studies of risk for schizophrenia.

### **Overview**

In this study, we used the thioamine acetylase enzyme deficiency (TAED) paradigm to cause participants to believe that they were at increased risk for developing schizophrenia, cancer, or depression. In this paradigm, participants are told that TAED is benign but associated with an increased chance for developing schizophrenia, cancer, or depression. Participants are diagnosed with TAED using a simple mouthwash procedure: Participants rinse their mouths with a sugar solution, expelling the solution into a cup. Participants are told that a special TAED test strip will turn blue if they have this condition. The test strip is a conventional test for sugar in liquids and turns blue because of the sugar in the rinse solution. All participants are led to believe they have TAED. However, TAED does not exist. It is a make-believe condition and, as such, has no relationship with schizophrenia, cancer, or depression.

Before and after the test, participants will complete a brief measure of distress and provide saliva samples from which cortisol is measured. A full debriefing which involves explanation of the study aims and a demonstration of the mouthwash changing the test strip colour will be conducted at the end of the session.

### **Hypotheses**

We are testing several hypotheses. One hypothesis is news of risk for schizophrenia creates acute psychological reactions that are more severe than that generated by news of risk for depression or the presence of benign disorder.

### **Design**

We are using a between-subjects design to test this hypothesis. There is one independent variable in this study—groups differ according to the disorder—and two dependent measures (cortisol reaction, mood reaction).

**Deception**

We used deception to cause participants to believe they had TAED and were at risk for schizophrenia, cancer, or depression. However, there is no such thing as thioamine acetylase enzyme deficiency or TAED. That is, TAED is a make-believe condition. It does not exist.

We misled you when we said TAED was linked to schizophrenia, cancer, or depression. Also, we do not know what the risk is that you will develop schizophrenia or any of the other disorders we told people about.

Our misleading of participants is necessary because it allowed us to safely create the belief that individuals are at risk for schizophrenia, and to compare this to risk for other disorders. If people taking part knew what our real intentions were, or if we reported genuine risk, participants may have reacted differently or suffered long-lasting harm.

If you want to read about the use of the thioamine acetylase enzyme deficiency deception paradigm in research, we encourage you to look up one or both of the following papers:

Ditto, P. H., & Croyle, R.T. (1995). Understanding the impact of risk factor test results: Insights from a basic research paradigm. In R. T. Croyle (Ed.), *Psychosocial effects of screening for disease prevention and detection* (pp.144-184). New York: Oxford University Press.

Hicken, B., & Tucker, D. (2002). Impact of genetic risk feedback: perceived risk and motivation for health protective behaviours. *Psychology, Health and Medicine*, 7(1), 25-36.

If you wish to Google the TAED paradigm it is usually known as the TAA paradigm.

**Questions**

You are welcome to contact us at any time with questions about this study. Our contact details are:

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This study has been approved by the University of Otago Human Ethics Committee.

If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (ph 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

**Appendix B**  
**Experimental Protocol**

**SAY:**                   **Thanks for coming along. Here is an information sheet and consent form. Please read these carefully before deciding whether or not to participate and sign here if you want to take part.**

**ADMINISTER:**       *INFORMATION SHEET AND CONSENT FORM*

**SAY:**                   **Before we go any further, I'll get you to complete this questionnaire that is a measure of mood state. This is a list of words that describe feelings people have. Please read each one carefully. Then fill in the answer that best describes how you are feeling right now.**

**ADMINISTER:**       POMS

**SAY:**                   **Just to let you know, I'll be reading mostly off this sheet to standardise the procedure. Also, to make sure you understand the procedure, we are trying to find out about the relationship between thioamine acetylase enzyme deficiency (TAED) and measures of stress and semantic memory. TAED is a benign condition**

**IF . . . THEN:**       [NC] . . . . CONTINUE BELOW  
                               [SZ] . . . . *but its linked with a ten-fold increase in risk for schizophrenia*  
                               [CC] . . . . *but its linked with a ten-fold increase in risk for cancer*  
                               [DP] . . . . *but its linked with a ten-fold increase in risk for depression*

**SAY:**                   **It does not have any symptoms and most people who have it don't even know they have it. So, in a few moments we are going to test you for it by dipping one of these TAED test strip into a mouth rinse I will get from you. Then if you are one of those with TAED, we will carry on and do some other tests. Is that okay?**

**The study is quite straightforward. I am going to get you to complete a couple of the measures twice because that way the measures are more stable.**

**SAY:**                   **First we will collect some general information. I'll get you to fill out this demographics questionnaire. If you have any questions feel free to ask me.**

**ADMINISTER:**       *DEMOGRAPHICS QUESTIONNAIRE*

- SAY:** Now I need to ask you some screening questions, everything you say is confidential and any data collected won't be linked to your identity.
- ADMINISTER AND SCORE:** SCID
- IF PARTICIPANT EXCLUDED SAY:** Thank-you for your time. Sorry, we can't let you do the rest of the study. We'll tell you what it is about so you can still get the course credit. (*Go to modified debriefing*)
- IF PARTICIPANT INCLUDED SAY:** We need to get a saliva sample from you now to test for cortisol. You will need to rinse your mouth with water then swallow it. Then allow saliva to pool in your mouth. Then let the saliva fall through a straw into this tube. Try to get it about a third full. Do you have any questions?  
(*Put gloves on*)
- COLLECT:** TIME 1 SALIVA
- SAY:** Now we'll test for TAED. Here is the TAED test strip. If you have TAED, it will turn brown after 30 seconds. If you don't have TAED, it will stay this colour. It's not very likely to change, because only 1 out of 15 people has the deficiency.
- INSTRUCTIONS:** Rinse your mouth with this mouth rinse for about 5 seconds and then spit in this cup. We'll dip the test strip in it.
- ADMINISTER:** TAED DIAGNOSTIC TEST
- SAY:** Because the test takes about 1 min to read, I'll get you to do a short survey to screen for factors that might influence your cortisol levels while we're waiting.
- ADMINISTER:** CORTISOL SURVEY
- SAY:** Ah, okay, that's interesting. That means you have TAED. Because you are one of the people who have TAED we'd like to see how this result is related to stress and semantic memory. Do you have any questions/is that all right with you?  
We'll do this memory test next.
- ADMINISTER:** PYRAMIDS AND PALM TREES
- TEST INSTRUCTIONS:** We'll do a practice item first.  
Here are three items. You have to decide which one of these two at the bottom goes with the one on top. Is it this one or this one?  
(point to pictures)
- SAMPLE ITEM 1:** (1 word/2 pictures)

Correct response: **That’s right, they go together because a waistcoat and a bow tie are both worn by men.**

Incorrect response: **No, the bow tie goes with the waistcoat because they are both worn by men.**

IF INCORRECT GO TO SAMPLE ITEM 2

*SAMPLE ITEM 2:* **Now try this one. Which of these two items goes with the one at the top? (point to pictures)**

Correct response: **That’s right. They go together because you pour from a bottle into a glass.**

Incorrect response: **No, it’s this one. They go together because you find both a clown and a lion at a circus, not a giraffe.**

*1 WORD AND 2 PICTURES:*

**Now let’s do the testing items.**

**Let’s try this one. Which of these two pictures goes with the word up the top? (say for items 1 and 2, all following items “Now try this one”)**

*2 WORDS AND 1 PICTURE:*

**Now we’ll try the same thing, but with 2 words. Which of these two words goes with the picture up the top?**

*SAY:*

**Now we’ll get you to complete the same two measures as before. This is the mood state measure again.**

*ADMINISTER:*

POMS

*SAY:*

**We also need another saliva sample.**

*COLLECT:*

TIME 2 SALIVA

*SAY:*

**There is one final short questionnaires, it’ s a health attitude questionnaire. There is a list of statements, please rate how much you agree or disagree with them.**

*ADMINISTER:*

HEALTH LOCUS OF CONTROL QUESTIONNAIRE AND STIGMA CONSCIOUSNESS QUESTIONNAIRE (together on one sheet)

**Debriefing Protocol for included participants**

- SAY:** That is the end of the study. Now, I need to go over some information with you to tell you about what we have been doing.
- This is quite important because in order for the study to work I had to mislead you about some things.
- First, there is no such thing as thioamine acetylase enzyme deficiency or TAED. That is, TAED is a make-believe condition. It does not exist.
- I made you believe you had TAED by having you rinse your mouth in this sugar solution and then dipping a test strip like this in the solution. The thing is, this test strip is designed to test for the presence of sugar in liquids. Watch this.
- DEMONSTRATE:** TAED TEST SOLUTION TURNS DIPPER BROWN
- SAY:** The second thing I have been misleading you about is the real purpose of the study.
- We are trying to find out how people react to news that they may be at increased risk of developing schizophrenia, compared to how people react to news about increased risk for other disorders. We did this by telling some participants that TAED is linked to a 10-fold increase in risk for schizophrenia. People in other groups were told different things. You were in the group that was told . . .
- Other groups: Because TAED does not exist, we misled you when we said TAED was linked to [disorder]. Also, we do not know what the risk is that you will develop [disorder] or any of the other disorders we told people about.
- Control group: You were in the group that was told TAED was not linked to anything. Other participants were told TAED was linked to a disorder such as cancer, but they were misled because TAED does not exist.
- We are interested in this question about schizophrenia because people who take part in risk research often are not told that the researchers are looking into risk. One of the reasons people are not told is that researchers are concerned people may become upset if they find out that they are at risk. However, there is no evidence that this is the case.
- ASK:** Do you have any questions so far?
- SAY:** Our misleading of participants is necessary because it allowed us to safely create the belief that individuals are at risk for schizophrenia, and to compare this to risk for other disorders. If people taking part

**knew what our real intentions were, or if we reported genuine risk, participants may have reacted differently or suffered long-lasting harm.**

**Our findings will contribute to debate about giving information to volunteers in schizophrenia risk studies.**

*SAY:* **Here is a debriefing sheet with the same information on it.**

*ADMINISTER:* DEBRIEFING SHEET

*SAY:* **Could you answer these questions about what you thought of the study?**

*ADMINISTER:* MANIPULATION VALIDATION QUESTIONNAIRE

*SAY:* **Thank-you for your time. Please don't talk to any other students who might do the study as that will affect the results.**

**Debriefing Protocol for excluded participants**

**SAY:** Participants were told they had an enzyme deficiency called thioamine acetylase enzyme deficiency or TAED. They were made to believe they had this deficiency by rinsing their mouths with a sugar solution and then dipping a test strip in the solution. The test strip is designed to test for the presence of sugar in liquids.

The purpose of the study was to try to find out how people react to news that they may be at increased risk of developing schizophrenia, compared to how people react to news about increased risk for other disorders. We did this by telling some participants that TAED is linked to a 10-fold increase in risk for schizophrenia. People in other groups were told different things.

Because TAED does not exist, participants were misled when they were told TAED was linked to a disorder.

We are interested in this question about schizophrenia because people who take part in risk research often are not told that the researchers are looking into risk. One of the reasons people are not told is that researchers are concerned people may become upset if they find out that they are at risk. However, there is no evidence that this is the case.

Our misleading of participants is necessary because it allows us to safely create the belief that individuals are at risk for schizophrenia, and to compare this to risk for other disorders. If people taking part knew what our real intentions were, or if we reported genuine risk, participants may have reacted differently or suffered long-lasting harm.

Our findings will contribute to debate about giving information to volunteers in schizophrenia risk studies.

**ASK:** Do you have any questions?

**ADMINISTER:** DEBRIEFING SHEET

**SAY:** Thank-you for your time. Please don't talk to any other students who might do the study as that will affect the results.

### Appendix C

The following information covers the evidence base for each question in the cortisol survey.

1. How many hours sleep did you get last night? *And* 2. What time did you get up this morning?

Research suggests that short-term partial sleep deprivation can lead to an increase in cortisol (Leproult, Copinschi, Buxton & Van Cauter, 1997). Studies have also found that salivary cortisol levels increase rapidly in the first hour of awakening (Kudielka & Kirschbaum, 2003; Stalder, Hucklebridge, Evans & Chow, 2008). All participants were tested in the afternoon (between 12pm and 4pm) but the second question was included to control for any participants who had woken shortly before the experiment.

3 (a). Have you eaten any food containing Vitamin C today? e.g., oranges, grapefruit, kiwifruit, broccoli, capsicum, spinach. *And* 3 (b). If yes, how much?

One study has previously also used a cortisol factor survey that included questions regarding diet (Hausmann, Vleck & Farrar, 2007).

4 (a). Have you consumed any caffeine today? e.g., black, tea, coffee, energy drinks.

*And* 4 (b). If yes, how much?

There is much research investigating the effects of caffeine on cortisol levels and it has been found that dietary levels of caffeine increase cortisol secretion (Lovallo, Al'Absi, Blick, Whitsett & Wilson, 1996; Lovallo et al., 2005). One study has also examined the effects of caffeine when combined with stress and it was found that cortisol levels were further increased when both variables were present (Lovallo, Farag, Vincent, Thomas & Wilson, 2006).

5. Do you take an oral contraceptive?

Research has shown that progesterone (a hormone found in most commonly prescribed oral contraceptives) is positively correlated with salivary cortisol (Wirth, Meier, Fredrickson & Schultheiss, 2006).

6 (a). Do you normally smoke cigarettes? *And* 6 (b). If yes, how many have you smoked today?

Research into the effect smoking cigarettes has on cortisol levels has found that smoking increases salivary cortisol (Badrick, Kirschbaum & Kumari, 2007; Wilkins et al., 1982).

## Appendix D General Demographics Questionnaire (Short Form)

### INSTRUCTIONS

Please work through this questionnaire at your own pace. If you have any questions, however small you think these may be, please feel speak to the person who gave this form to you to complete.

### You and Your Circumstances

The following questions ask about demographics, that is, who you are and the circumstances you live in.

1. When were you born?      day (e.g., 15)      month (e.g., Jun)      year (e.g., 1966)

--	--	--	--	--	--	--	--

2. Which country were you born in?

(Tick the circle which applies to you.)

- New Zealand
- Australia
- England
- Scotland
- The Netherlands
- Cook Islands
- Samoa
- Fiji
- Other. Please print the present name of the country: \_\_\_\_\_

→ If not born in New Zealand, when did you first arrive in New Zealand?  
Give year and month if known.

month (e.g., Aug)	year (e.g., 1971)

3. Are you . . .       female?       male?      (Tick one circle.)

4. Which ethnic group do you belong to?

(Tick the circle or circles which apply to you.)

- New Zealand European
- Maori
- Samoan
- Cook Island Maori
- Tongan
- Niuean
- Chinese
- Indian
- Other. Please state: \_\_\_\_\_

5. Are you descended from a Maori (that is, did you have a Maori birth parent, grandparent or great-grandparent, etc)?

Yes  No  Don't know

→ Do you know the name(s) of your iwi (tribe or tribes)?

Yes  No

→ Give the name and home area, rohe or region of your iwi.

\_\_\_\_\_ Iwi and Rohe (iwi area)

6. Which language is your native language?

(Tick one circle.)

English  Maori  Samoan  New Zealand Sign Language  Other language(s). Please state: \_\_\_\_\_

7. In which other language(s) could you have a conversation about a lot of everyday things?

(Tick as many circles as you need to answer this question.)

English  Maori  Samoan  New Zealand Sign Language  Other language(s). Please state: \_\_\_\_\_

8. Which psychology papers have you taken previously or are you currently enrolled in?

(Tick as many circles as you need to answer this question.)

	Current	Previously
PSYC111	<input type="radio"/>	<input type="radio"/>
PSYC112	<input type="radio"/>	<input type="radio"/>
PSYC201	<input type="radio"/>	<input type="radio"/>
PSYC202	<input type="radio"/>	<input type="radio"/>
PSYC203	<input type="radio"/>	<input type="radio"/>
PSYC204	<input type="radio"/>	<input type="radio"/>
1 or more 300-level	<input type="radio"/>	<input type="radio"/>
Others (please list): _____		



**Health Questionnaire**

**Please circle the number that corresponds to how strongly you agree or disagree with the following statements.**

	<b>Strongly disagree</b>		<b>Neither agree nor disagree</b>				<b>Strongly agree</b>	
	0	1	2	3	4	5	6	
1. If I get sick, it's my own behaviour which determines how soon I get well again	0	1	2	3	4	5	6	
2. I am in control of my health	0	1	2	3	4	5	6	
3. When I get sick I am to blame	0	1	2	3	4	5	6	
4. The main thing which affects my health is what I myself do	0	1	2	3	4	5	6	
5. If I take care of myself, I can avoid illness	0	1	2	3	4	5	6	
6. If I take the right actions, I can stay healthy	0	1	2	3	4	5	6	
7. Having regular contact with my physician is the best way for me to avoid illness	0	1	2	3	4	5	6	
8. Whenever I don't feel well, I should consult a medically trained professional	0	1	2	3	4	5	6	
9. My family has a lot to do with my becoming sick or staying healthy	0	1	2	3	4	5	6	
10. Health professionals control my health	0	1	2	3	4	5	6	
11. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, and friends) have been taking good care of me	0	1	2	3	4	5	6	
12. Regarding my health, I can only do what my doctor tells me to do	0	1	2	3	4	5	6	
13. No matter what I do, if I am going to get sick, I will get sick	0	1	2	3	4	5	6	
14. Most things that affect my health happen to me by accident	0	1	2	3	4	5	6	
15. Luck plays a big part in determining how soon I will recover from an illness	0	1	2	3	4	5	6	
16. My good health is largely a matter of good fortune	0	1	2	3	4	5	6	
17. No matter what I do, I'm likely to get sick	0	1	2	3	4	5	6	
18. If it is meant to be, I will stay healthy	0	1	2	3	4	5	6	

*Note.* The first page of the Health questionnaire is the Multidimensional Health Locus of Control Scale and the second page is the Stigma Consciousness Questionnaire.

Imagine that you had a serious physical or mental disability.  
How much do you think you would agree or disagree with each of the following statements?

Circle the number that indicates how much you agree or disagree with the statement.

<b>If I had a serious physical or mental disability . . .</b>	<b>Strongly Disagree</b>			<b>Neither Agree nor Disagree</b>			<b>Strongly Agree</b>
. . . stereotypes about disability would not affect me personally.	0	1	2	3	4	5	6
. . . I would never worry that my behaviours will be viewed as stereotypical of my disability.	0	1	2	3	4	5	6
. . . I would feel like healthy people interpret all my behaviours in terms of the fact that I am disabled.	0	1	2	3	4	5	6
. . . most healthy people do not judge people with disabilities on the basis of their disability.	0	1	2	3	4	5	6
. . . my having a disability would not influence how healthy people interact with me.	0	1	2	3	4	5	6
. . . I would almost never think about my disability when I interact with healthy people.	0	1	2	3	4	5	6
. . . my having a disability would not influence how people interact with me.	0	1	2	3	4	5	6
Most healthy people have a lot more negative thoughts about disabled people than they actually express.	0	1	2	3	4	5	6
I often think that healthy people are unfairly accused of discriminating against those with disabilities.	0	1	2	3	4	5	6
Most healthy people have a problem viewing those with disability as equals.	0	1	2	3	4	5	6

**Manipulation Validation Questionnaire**

1. Did you believe TAED was a real condition? YES NO
2. How would you say that you reacted to the news that you had TAED?

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3. Did you notice that I said TAED was . . .  
 . . . benign? YES NO  
 . . . associated with increased risk for [*disorder*]? YES NO

4. How would you say that you reacted to this part of what I said?

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I would like to ask you several specific questions about this and get you to respond by giving me a rating on a 0 [zero] to 6 scale, where zero = not at all, 3 = moderately, and 6 = extremely. When you were thinking about your risk for [*disorder*] . . .

How distressed did you feel?	0	1	2	3	4	5	6
How optimistic were you about your ability to cope with this?	0	1	2	3	4	5	6
How likely were you to make different lifestyle choices because of this?	0	1	2	3	4	5	6
How anxious did you feel about your future?	0	1	2	3	4	5	6
How sympathetic did you think others would be to your situation?	0	1	2	3	4	5	6
How likely did you think it would be that you would die from this condition?	0	1	2	3	4	5	6
How supportive did you believe your family would be in the future?	0	1	2	3	4	5	6
How helpless did you feel about your situation?	0	1	2	3	4	5	6
How positive were you about your future?	0	1	2	3	4	5	6
How distressed would you have been one week after hearing this news?	0	1	2	3	4	5	6
How distressed would you have been six months after hearing this news?	0	1	2	3	4	5	6
How likely was it that you would have been beaten by this condition?	0	1	2	3	4	5	6
How likely were you to have made different decisions about relationships and children because of this condition?	0	1	2	3	4	5	6

Do you have any comments on your experience of this study or any feedback you would like to give?

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