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Assessment of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal people using the CAARMS

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Certificate of Originality

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma of the University or other institute of higher learning, except where due acknowledgement is made in the text.

I also declare that the intellectual content of this thesis is the product of my own work, even though I may have received assistance on the style, presentation and expression of this work.

Signature B. Hamilton

Student's Name Blake Hamilton

Date 27th March 2008

Acknowledgements

"Ask not what disease the person has, but rather what person the disease has."
William Osler

Womba: Mad or not thinking right
Garrah: not thinking right
Nurigah: not thinking right
Wingara: Thinking right
- Words to describe thinking from traditional Aboriginal languages.

As with any work of this nature the name embossed upon the spine belies a host of people without whom this research would not have been possible.

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A note on terminology

Throughout this thesis the term 'Aboriginal people' is used to signify all Australian Aboriginal and Torres Strait Islander peoples. Aboriginal people, and where required Aboriginal person or Aboriginal, is preferred to Aboriginal and Torres Strait Islander People, or the common abbreviation ATSI. This is in recognition that Aboriginal people are the traditional landholders in NSW, where this thesis was researched and where the majority of participants in this research come from. Similarly, the term Aboriginal people is preferred in this work to more recent terms such as 'Indigenous people' in recognition of the distinct culture and identity of Aboriginal and Torres Strait Islander people. The term 'Indigenous people' is used worldwide to signify the first inhabitants of a country. This thesis uses 'Aboriginal people' to refer to a specific culture and group of people. The use of 'Aboriginal people' is in keeping with the terminology preferred and used by the Aboriginal people who advised upon, and participated in this research. Aboriginal people is also consistent with recommendations within current Aboriginal terminology guidelines (New South Wales Department of Health, 2004).

Abstract

The purpose of this research study is to investigate the validity of the use of an instrument designed to detect early psychosis, in a sample of Aboriginal people.

Psychotic illness is a common distressing and disabling condition associated with significant personal and societal cost. Research has demonstrated disadvantaged people are at higher risk for psychosis and have worse outcomes from illness. Current treatments for psychosis have failed to reduce a significant proportion of the illness burden borne by sufferers.

The Early Psychosis (EP) paradigm has demonstrated a reduction of illness burden is possible. The early psychosis approach has highlighted the importance of reducing the duration of untreated Psychosis (DUP) as critical to illness reduction. EP research has also identified socio-economic disadvantage as being of primary importance in identifying those who are most at-risk for psychosis.

Aboriginal people are the most disadvantaged sub-population in Australia across all socio-economic indicators with higher rates of mental illnesses including psychosis. Factors contributing to Aboriginal people's poorer mental health appear related to disadvantage, socio-political history, and hidden disadvantage such as racism. In particular, Aboriginal culture may contain unique elements that may appear as psychotic-like symptoms, causing difficulties in accurate assessment, differential diagnosis, and treatment. Little research effort has been directed toward understanding or investigating the emergence of psychosis in Aboriginal people. A leading cause and compounding factor has been the lack of psychosis assessment tools validated for use with this population.

EP researchers have developed The Comprehensive Assessment of At-Risk Mental States for Psychosis (CAARMS) to identify those at-risk. It is not currently known if this instrument is valid for use with young Aboriginal people. This study

sought to provide preliminary data on the validity of the CAARMS for use with young Aboriginal people.

This study used a cross-sectional 2x2 factorial design to compare the scores of participants between 18 and 25 years of age (n = 81, 80.3% male) on the CAARMS and Brief Psychiatric Rating Scale (BPRS). The study consisted of four sub-samples, Aboriginal people with psychotic illness, Aboriginal healthy controls, non-Aboriginal people with psychotic illness and non-Aboriginal healthy controls. Participants were drawn from NSW Health EP services, NSW Prisons, and the Aboriginal and non-Aboriginal community.

The results of this study found Aboriginal participants scored significantly higher on both the CAARMS and BPRS than non-Aboriginal participants. The CAARMS and BPRS differentiated between those participants with psychotic illness and healthy controls. Participants suffering psychotic illness scored significantly higher on both measures than healthy controls.

The results obtained in this study have significant implications for the assessment of young Aboriginal people at-risk for psychosis using available instruments. It is concluded that there is a risk of increased Type-1 errors for the CAARMS in its current form if used with young Aboriginal people.

Preamble

Chapter 1 Psychosis

This chapter discusses the concept of psychosis, the taxonomy and symptoms associated with psychotic illness. The prevalence, disability, and cost associated with psychotic illness are reviewed and it is argued that standard treatments have been unable to reduce a significant proportion of illness burden. The early psychosis paradigm is reviewed and it is shown that this paradigm has demonstrated a reduction in illness burden is possible. The concepts of the psychotic prodrome and the duration of untreated psychosis, noted as critical in reducing illness burden, are reviewed. The evidence from the early detection paradigm within early psychosis is reviewed and the link to disadvantage noted. The chapter concludes by arguing that disadvantage is an identifiable and important factor in identifying those at highest risk of psychotic illness.

Chapter 2 Aboriginal disadvantage and mental health

This chapter reviews the accumulated evidence that Aboriginal people are the most disadvantaged community in Australia. It is argued that Aboriginal health and hidden disadvantages form a large component of overall Aboriginal disadvantage and that mental health in turn forms a significant and overlooked proportion of these components. The available statistics on Aboriginal people's mental health and literature surrounding aspects of Aboriginal mental health are reviewed. Unique elements from Aboriginal culture intersecting with psychiatric symptoms, particularly psychosis, are discussed. It is argued via a conceptual model that Aboriginal people are at higher risk for psychosis and supporting evidence is presented. The literature on psychosis amongst Aboriginal people is reviewed. The chapter ends with an argument that a lack of clinical research evidence about measuring psychosis in Aboriginal people is directly linked to an overall lack of knowledge about psychosis amongst Aboriginal people.

Chapter 3 Measurement of psychosis in Aboriginal people

This chapter reviews the theory and research of measuring psychosis and early psychosis, and recent developments in the concept and measurement of at-risk mental states for psychosis. The measurement of psychosis in Aboriginal people is reviewed and the little research evidence outlining aspects of psychosis in Aboriginal people is highligted. The lack of evidence surrounding the application of measurement of at-risk mental states for psychosis in Aboriginal people is discussed. An argument is made for the importance of researching the detection of at-risk mental states in psychosis in young Aboriginal people. The chapter ends with a summary of the first three chapters and the stating of the research aims and hypothesis.

Chapter 4 Method

This chapter outlines the method used to test the hypothesis generated in this study. The chapter begins by describing the participants in this study and where participants were drawn from. Composition of the four groups of participants and aspects of groups are discussed. The measures used in the study are described and the procedure to gather data outlined. This chapter ends by discussing the design of the study and the statistical analyses used to interpret the results.

Chapter 5 Results

This chapter lists the analysed statistical data generated by the study. Data gathered on the whole samples and the data comparing groups is presented. The results obtained on the demographics of the participants, drug and alcohol use, mental health, and medical record data is presented and discussed. The chapter ends with the discussion of qualitative data gathered from the pilot study and two case-studies of included participants is discussed.

Chapter 6 Discussion

This chapter discusses the results obtained in the study and presented in chapter five. The chapter begins by discussing the results for the use of the CAARMS and the BPRS with young Aboriginal people. Other data gathered and qualitative data is discussed. Limitations to the sample and methodology of the study are outlined and discussed. The implications of the results to the broader context of Aboriginal mental health assessment and knowledge of Aboriginal mental health are presented. The chapter ends by presenting a conclusion to the study and the results obtained.

Chapter 1
Psychosis

1.1 Introduction

Psychotic disorders represent serious mental illnesses that impose a substantial burden on individuals, families and carers, and are associated with significant health care costs (Carr, Neil, Halpin, Holmes, & Lewin, 2003; Gureje, Herrman, Harvey, Morgan, & Jablensky, 2002). The global life-time prevalence rates for the most common psychotic disorder, schizophrenia, is estimated to be in the range of 0.50-1.72% (Jablensky et al., 1992) with a world-wide median incidence of 15.2 cases per 100,000 per year (McGrath, 2005). Recent data indicates that both sexes are not equally affected with men having a higher incidence (male to female risk ratio = 1.4) (McGrath, 2005). Psychotic disorders have a predominant onset in adolescence, although the modal age for males appears to be earlier (18-25 years) as compared to females (25-35 years) (Goldstein & Lewine, 2000). Early onset of illness is associated with greater severity and poorer prognosis (Carr, Lewin, Neil, Halpin, & Holmes, 2004; McGlashan, 1998).

Economic costs of psychosis are significant with the annual average cost for an individual Australian sufferer estimated at $46,200 (Carr et al, 2003). This amount includes: $27,500 in lost productivity; $13,800 in inpatient mental health care; and $4,900 in other mental health and community service costs (Carr et al, 2003). The total estimated cost of psychosis is $1.45 billion to the government and $2.25 billion to society, a total cost of psychosis per annum to Australia of $3.7 billion (0.59% of GDP). This cost is estimated to be 2.6% of the combined health and community services budget (Carr et al, 2003).

Knowledge of the precise aetiology of psychosis remains elusive, although there is consensus of a multi-factorial origin in which a polygenetic-determined biological vulnerability interacts with a range of environmental risk factors (Crow,

2007; Levinson, 2005; Neale & Oltmanns, 1980). Both the genetic and environmental factors are summarised by the stress-diathesis model of aetiology (Zubin & Spring, 1977) in which it is proposed that psychosis is mediated by a threshold of environmental stressors interacting with a biological predisposition. Stressors contributing to the risk of psychosis may be broadly divided into biological and psycho-social. Biological factors associated with psychosis include intra-uterine events such as birth complications (Cannon, Jones, & Murray, 2002), pre-natal viral exposure (Mednick, Machon, Huttenon, & Bonnett, 1988) or peri-natal hypoxia (Cannon, Jones, & Murray, 2002), and low birth-weight (Smith et al., 2001). Psycho-social factors include socio-economic disadvantage (Bebbington et al., 1996; Croudace, Kayne, Jones, & Harrison, 2000) and high levels of daily stress (Bebbington et al., 2004; Macdonald, Pica, McDonald, Hayes, & Baglioni, 1998).

Aboriginal people represent a sub-set of the Australian population who are characterised by significant health, developmental, and socio-economic disadvantage and stresses (Steering Committee for the Review of Government Service Provision, 2005). Currently, the Aboriginal population, including Aboriginal and Torres Strait Islander people, represent approximately 2.5% of the total Australian population (Australian Bureau of Statistics, 2004). Just under 30% of the total Aboriginal population reside in New South Wales and 26% in Queensland. There are demonstrated socio-economic and health disadvantages suffered by many members of the Aboriginal community (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Steering Committee for the Review of Government Service Provision, 2005). Given the role of external stresses as precipitants in vulnerable individuals suggested by the stress-diathesis model of psychosis (Zubin & Spring, 1977), it is reasonable to anticipate high rates of psychosis may be found in this population. In the context of limited access to mental health services (Hunter, 1995; Swan & Raphael, 1995), it may also be argued that a proportion of Aboriginal people with symptoms or disorders may remain unidentified. Additionally, those presenting

with a range of psychiatric symptoms or disorders may be misdiagnosed due to cultural differences. Substance abuse in particular furthers the likelihood of misdiagnosis in the context of cultural differences. Accurate and timely detection is reliant upon the availability of reliable and culturally valid assessment measures. The purpose of this thesis is to evaluate the utility of a mainstream diagnostic instrument in detecting early at-risk states of mental illness in young Aboriginal people. The aim of this thesis is to provide preliminary data on validity of the Comprehensive Assessment of At-Risk Mental States (CAARMS: Yung et al., 2003) for use with young Aboriginal people.

1.2 Psychosis: The concept

The term 'psychosis' is of Greek origin: *'Psyche' & 'osis' (disease or abnormality)* and refers to loss of contact with external reality characterised by impaired perceptions and thought processes (Beer, 1995; Grivas, 2000). Despite its common use, psychosis remains difficult to satisfactorily define given the difficulty in precisely delineating the boundary between psychosis as a set of symptoms and psychosis as a psychotic disorder (syndrome). Psychosis as symptoms may be considered a set of unusual mental experiences experienced by an individual: a mental state, while in contrast, psychotic disorder refers to the spectrum of symptoms and signs meeting criteria for a defined syndrome persisting over time. The importance of this distinction lies in the recognition that symptoms of psychosis, whilst a necessary precursor to psychotic illness, do not signify psychotic illness by their presence alone. Illness is considered to be a threshold of: the number of psychotic symptoms; the intensity and duration of symptoms; and sufficient dysfunction (Rosenman, Korten, Medway, & Evans, 2003). Similar difficulties arise when considering the threshold where an individual's mental state reaches criteria for psychosis. Some authors have argued that psychotic experiences lie on a continuum with normal experience (Jackson & Fulford, 1997; Johns & van Os, 2001; Scott, Chant, Andrews, & McGrath, 2006), but with no definitive threshold where an individual transitions

from a non-psychotic to a psychotic mental state. This is problematic for current diagnostic systems, where psychosis represents a weigh-point not considered wellness, nor in the absence of specifiers, illness. As such, current diagnostic systems have been developed favouring diagnosis for psychotic illness, rather than the diagnosis of psychosis (Peralta & Cuesta, 2003; Rosenman, Korten, Medway, & Evans, 2003; Van Os et al., 1999). The signs and symptoms of psychosis form the basis of current diagnostic criteria.

1.3 Taxonomy

The two systems most widely used in the diagnosis of psychotic illness are the International Classification of Diseases Tenth Edition (ICD-10) (World Health Organization, 1994) and the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition -Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). Both systems recognise psychosis as a hallmark feature of several disorders. The DSM-IV-TR groups psychotic disorders under schizophrenia and other psychotic disorders (American Psychiatric Association, 2000). The DSM-IV-TR diagnostic criteria for schizophrenia describes the necessary attributes required for the diagnosis of psychotic illness:

> "Schizophrenia
>
> A. *Characteristic symptoms:* Two (or more) of the following, each present for a significant portion of time during a one-month period (or less if successfully treated):
>
> (1) delusions
>
> (2) hallucinations
>
> (3) disorganized speech (e.g., frequent derailment or incoherence)
>
> (4) grossly disorganized or catatonic behaviour
>
> (5) negative symptoms, i.e., affective flattening, alogia, or avolition
>
> Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the

person's behavior or thoughts, or two or more voices conversing with each other.

B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).

C. *Duration:* Continuous signs of the disturbance persist for at least six months. This six-month period must include at least one-month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. *Schizoaffective and mood disorder exclusion:* Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have occurred during active-phase symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. *Substance/general medical condition exclusion:* The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. *Relationship to a pervasive developmental disorder:* If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions

or hallucinations are also present for at least a month (or less if successfully treated)." (American Psychiatric Association, 2000, p. 312)

DSM-IV-TR also recognises psychotic disorders that are primarily concerned with mood (Schizoaffective Disorder), substance use (Substance-Induced Psychotic Disorder), and those too brief to meet the criteria for schizophrenia (Brief Psychotic Disorder and Schizophreniform Disorder). Additionally DSM-IV-TR recognises three personality disorders sharing psychotic, or psychotic-like symptoms: Paranoid Personality Disorder, Schizoid Personality Disorder, and Schizotypal Personality Disorder.

The ICD-10 (World Health Organization, 1994) system has broadly equivalent groupings of disorders. Whilst there are noted differences between the DSM-IV-TR and ICD-10 systems in the diagnosis of psychotic illness (Jager, Bottlender, Strauss, & Moller, 2004; Jakobsen et al., 2005; Peralta & Cuesta, 2003), many authors have argued that the two systems are broadly concordant (Jager, Bottlender, Strauss, & Moller, 2004; Jakobsen et al., 2005; Pillmann, Haring, Balzuweit, Bloink, & Marneros, 2002). In particular, the ICD and DSM systems converge diagnostically for chronic psychotic illnesses such as schizophrenia. Centrally important in the current diagnostic criteria is the presence or absence of types of psychotic symptoms.

1.4 Symptoms

Historically there has been much debate about what psychotic symptoms are, and how they should be grouped (Cohen, 2003). Echoes of this debate can be seen in current taxonomic distinctions between a categorical and dimensional approach. There is continuing debate (Grube, Bilder, & Goldman, 1998; Lenzenweger, 1999; Nakaya, Suwa, & Ohmori, 1999) over how many groups of psychotic symptoms co-occur, or rather, should be grouped together. At the most fundamental, psychotic symptoms are divided into two groups (Baldwin et al.,

2005; Scully, 2001), one characterised by positive and the other negative symptoms.

Positive symptoms and signs are conceived of as additional or beyond what may be considered the range of cultural experience and behaviour. Positive symptoms are distortions in: thought content (delusions); perception (hallucinations); language and thought processes (disorganised speech); and self-monitoring of behaviour (grossly disorganised or catatonic behaviour) (American Psychiatric Association, 2000). Auditory hallucinations in the form of voices are the commonest psychotic symptom and are regarded as a hallmark symptom of psychosis. Positive symptoms may be further subdivided into two distinct dimensions; a psychotic dimension (delusions and hallucinations) and a disorganisation dimension (disorganised speech and behaviour) (American Psychiatric Association, 2000).

In contrast, negative symptoms are defined as "...those patient characteristics that appear missing from the presentation" (Scully, 2001, p. 59). This may involve affective flattening, apathy, social withdrawal, and poverty of thought and content of speech. Affective flattening is considered a common negative symptom and is characterised by an immobile and unresponsive face with poor eye contact and reduced body language (American Psychiatric Association, 2000). Negative symptoms have been noted as important in establishing more reliable differential diagnoses for syndromes such as schizophrenia (Andreasen, 1982a) and are associated with chronic course and poorer prognosis (Andreasen, 1982a).

However, factor analytic studies of schizophrenia have shown a positive-negative solution to symptom sets to be inadequate (Nakaya, Suwa, & Ohmori, 1999). A three-factor solution that includes disorganised symptoms (Grube, Bilder, & Goldman, 1998) has been suggested to better account for the range of common symptoms. Meta-analyses have confirmed that disorganisation warrants a distinct symptom set (Lenzenweger, 1999; Peralta & Cuesta, 2001).

Disorganisation symptoms are qualitatively different in nature to delusions and hallucinations and are manifested as a disruption to cognitive processes rather than an extension of experience observed in positive symptoms. Disorganisation is observed in the broad categories of speech, behaviour, and movement, where speech is a proxy for all cognitive processes and where severely disrupted; signifies formal thought disorder. Disorganisation ranges from childlike silliness in interaction with others to unpredictable agitation and includes: difficulties organising activities of daily living; dressing in an unusual manner; inappropriate sexual behaviour; and unpredictable and non-triggered agitation. Movement may also be interrupted, resulting in catatonic motor behaviours such as stupor, rigidity, negativism, posturing, and excitement (American Psychiatric Association, 2000).

Whilst the three factor solution has been accepted by some (Grube, Bilder, & Goldman, 1998), other authors (de Leon, Wilson, & Simpson, 1991; Ebel, Gross, Klosterkotter, & Huber, 1989; Huber, 1983; Huber & Gross, 1989) have argued for a fourth symptom group; basic symptoms hypothesised to be close to the somatic substrate of psychotic illness (Huber, 1983; Huber & Gross, 1989). Huber and Gross (1989) argue that typical psychotic phenomena are formed and modified by secondary working-up processes and that basic symptoms are the primary and necessary symptoms of psychotic illnesses such as schizophrenia. Thus the disruptions observed as positive, negative, and disorganised symptoms are secondary disturbances caused by disturbances to more basic brain structures and processes. Basic symptoms are general non-specific symptoms regarded as a failure of efficiency. Basic symptoms manifest as neuro-cognitive changes affecting energy, drive, attention, motor problems, and disturbances to bodily sensation (Huber & Gross, 1989). These symptoms have been linked to fundamental impairments in information processing and thought to be important in the recognition of the primary disturbance of psychotic syndromes, including

impairments in information processing, and as necessary pathology for the development of positive, negative and disorganised symptoms (Huber, 1983).

Current diagnostic systems do not recognise basic symptoms as a separate set. This is consistent with the diagnosis of psychotic illness over psychosis. There is emerging evidence (Klosterkotter, Hellmich, Steinmeyer, & Schultze-Lutter, 2001; Ruhrmann, Schultze-Lutter, & Klosterkotter, 2003) that these symptoms may be of prime importance in recognising the transition to psychosis and as predictors of disability and cost.

1.5 Prevalence, disability, cost of psychosis

Psychotic illness is associated with high levels of distress, disability and cost (Carr et al, 2004), and these combined with the prevalence of psychotic illness, mark it as a significant public health concern. Prevalence varies between 0.50-1.72% (Jablensky et al., 1992) with an average of 1.1%, although considerable variation by region has been found (Bresnahan, Menezes, Varma, & Susser, 2003).

Australian data (Jablensky et al., 2000) has reported a point prevalence for all psychotic disorders in urban Australia over a measured period of one month of 4.7 per 1,000 people. This drops to 3.7 people per 1,000 when affective psychoses are excluded. In line with schizophrenia prevalence, the rates of psychosis differ across the sampled geographical areas (range 2.8-5.1 per 1,000), with the highest rates being identified in urban area and the lowest in semi-rural. These rates are comparable with prevalence rates for schizophrenia and related disorders from North American and European studies (Jablensky et al., 2000).

It is noteworthy that these Australian rates were measured only for individuals presenting for treatment. Thus the possibility remains other untreated cases were

not included and therefore the above estimates are likely to be conservative. A treatment gap in psychotic disorders identified in comparable countries (Kohn, Saxena, Levav, & Saraceno, 2004) suggests there are an additional 15-35% of sufferers with illness in need of treatment. Such data suggests the rate of 4.7 per 1,000 derived in the low prevalence disorders study (Jablensky et al., 2000) may be artificially low. Based on this data, an adjusted prevalence rate is likely to be in the range of 5.4-6.4 per 1000 for a single month, marking psychotic illness as more prevalent than reported.

Prevalence, however, is not the only reason why psychotic spectrum illness is a major public health burden. Despite relatively low prevalence against other mental illnesses, the burden of psychosis is found in the high levels of distress and disability experienced the majority of sufferers (Gureje, Herrman, Harvey, Morgan, & Jablensky, 2002). Distress is caused by the nature of the symptoms themselves, for example paranoia, unpleasant hallucinations, delusions, and negative emotional states. Disability associated with psychotic illness renders sufferers less able to interact with family and friends, work, or fulfil social and occupational roles. A recent review (Wiersma, 2006) demonstrated that one of the greatest unmet needs of people with severe mental illness is psychological distress, and that psychotic disorders are associated with greater unmet need.

Dysfunction and disability in chronic psychotic illness is a burden borne by both individuals and the community. Dysfunction may be to: interpersonal relations; work or education; or self-care (American Psychiatric Association, 2000). Disability may be via direct action of symptoms interfering with function, or from changes to role function associated chronic course and relapse. Psychotic illness is associated with a breadth of disability, and a large proportion of patients have difficulties with self-care including cooking, cleaning, and general interest in the world around (Gureje, Herrman, Harvey, Morgan, & Jablensky, 2002; Waghorn, Chant, White, & Whiteford, 2004).

The combination of distress, dysfunction, and disability represent an individual's quality of life (QOL)(Chopra, Couper, & Herrman, 2004). It is therefore not surprising that psychotic illness is associated with a pervasive and much lower overall QOL than for many other psychiatric disorders (Chopra, Couper, & Herrman, 2004; Waghorn, Chant, White, & Whiteford, 2004; Wiersma, 2006).

Along with the personal costs, psychotic illness represents a significant cost to Australian society of around 2.6% of the combined health and community services budget (Carr, Neil, Halpin, Holmes, & Lewin, 2003). Important in any attempt to reduce illness cost are the predictors of chronic illness and attendant disability. Failure to complete high-school education and the chronicity of illness course, have been identified as the best predictors of overall illness cost (Carr, Lewin, Neil, Halpin, & Holmes, 2004). Other predictors of increased cost identified are age-at-onset, male gender, and overall disability. Schizophrenia costs are higher than for other psychotic illnesses reflecting the higher levels of disability and chronicity associated with this illness.

Thus psychotic illness represents a reduced QOL, disability, and significant cost for sufferers and society. Reducing illness burden is of significant advantage to individual sufferers and society. Available treatments for psychotic illness are yet to significantly reduce the overall illness-burden.

1.6 Treatment

Treatments for psychotic illness have substantially improved, particularly over the past 30 years (Scully, 2001), but no treatment can be said to cure the illness. Current pharmacotherapy treatments have less side effects than previously, (Ban, 2004; Scully, 2001) and psychosocial interventions (Haddock, Morrison, Hopkins, Lewis, & Tarrier, 1998; Jackson et al., 2001) have demonstrated effectiveness in assisting patients to cope with illness by reducing symptoms and

secondary disability. However, despite improvements to treatments, these are still inadequate to significantly reduce illness burden for many sufferers.

Research suggests that mental health services in Australia using standard treatments are able to reduce around 13% of the aggregated burden attributable to schizophrenia (Andrews, Sanderson, Corry, & Lapsley, 2000). Burden reduction rises to 29% if best practice guidelines are followed. However 71-87% of the disability caused directly by the illness is currently borne by the patient even in the presence of adequate treatments.

A supplementary approach to standard treatment for psychotic illness is required if current illness burden is to be reduced. The paradigm of treating sub-threshold illness earlier, as utilised in other chronic diseases (Loeb & Catalona, 2007), has been shown to reduce illness burden (McGorry, 1999). Disability and dysfunction from illness is difficult to reduce when disease becomes chronic. However these are easier to limit or reduce when illness is in early stages as shown by studies of Intervention into heart disease, diabetes, and several forms of cancer. This model utilising earlier detection, and earlier interventions into pathology to reduce symptoms has also been shown to be capable in many cases of preventing the transition to chronic illness (Loeb & Catalona, 2007; Smith, 2007).

By the early 1990's such an approach was being considered and investigated for use in mental health (Bell, 1992; McGorry et al., 1990). This is still considered somewhat radical within psychiatry which has traditionally treated disease only once it reached a diagnostic threshold of severity (McGorry, 1999).

A paradigm shift has occurred within mental health over the last 15 years to embrace an early intervention framework (Birchwood & Macmillan, 1993; Falloon, 1992) aimed specifically at reducing illness burden. This framework has also allowed exploration of the possibility of preventing psychotic illness altogether. This paradigm shift in treating psychotic illness and the movement

this shift has generated have been encapsulated under the banner of early psychosis.

1.7 Early psychosis

Early Psychosis (EP) and First Episode Psychosis (FEP) are the commonly used terms representing the investigation and treatment of the early stages of psychotic illness.

The definition of EP is hampered by the ambiguity of the terms "psychosis" and "early". The Australian Clinical Guidelines for Early Psychosis (National Early Psychosis Project, 1998) recognise this difficulty:

> "While there is no single authoritative definition of 'early psychosis', it clearly has an onset focus. It includes the period described as the prodrome and is also considered to include the critical period up to five years from entry into treatment for the first episode" (National Early Psychosis Project, 1998).

In this regard, EP is the clinical practice and research effort directed towards the detection of early course, or phase in the course, of illness particularly in the period before and directly after a first episode of psychosis. A conceptual framework for EP can be viewed as providing a platform for the identification and intervention into psychotic illness early in its course. The aim is to reduce illness and thereby prevent secondary disability and where possible transition to chronic illness. Early Psychosis is based upon the heuristic that intervening early in the course of psychotic illness can reduce or possibly prevent illness burden and thereby improve outcome.

Although the concept of earlier treatment of psychotic illness is not new (McGorry, 1999), broader acceptance of the establishment of EP programs has been gained only in the last 10 or so years. There continues to be debate over the utility of the EP approach (Pelosi & Birchwood, 2003), with criticisms directed

to the lack of high quality confirmatory evidence for better outcomes (McGorry, 1999) and the significant increase in intervention effort required and offset by relatively modest gains (Jackson et al., 2001; McGorry et al., 2002).

Despite this criticism, the amassed evidence from this approach is encouraging. Australian researchers were amongst the first to demonstrate a reduction in psychotic illness burden through early intervention (McGorry, Edwards, & Mihalopoulos, 1996), with subsequent research worldwide demonstrating improvements in outcome, at the 12-month follow-up point (McGlashan, 1996; Wyatt, 1995), and that intervention in the early phases of illness reduces iatrogenic damage and improves recovery (McGorry, 1999).

The essential elements identified for successful intervention into early stages of psychotic illness are included in the Australian Clinical Guidelines for Early Psychosis (National Early Psychosis Project, 1998). These guidelines suggest that best practice includes an individually tailored combination of: psychopharmacological interventions; psychological interventions; intensive case management; family involvement; psycho-education; and group programs. Several studies have highlighted a reduction in illness burden via this approach in an Australian context. The effectiveness of this approach adopted by specialised early psychosis services (McGorry, Edwards, & Mihalopoulos, 1996), novel early detection services (Yung, McGorry, McFarlane, & Patton, 1995) and enhanced cognitive treatments for early psychosis (Jackson et al., 2001) has been supported by randomised controlled trials (Craig et al., 2004; McGorry et al., 2002; Thorup et al., 2005).

Research utilising the early intervention approach has highlighted the length of the period of psychotic symptomatology experienced before diagnosis and treatment occur (Loebel et al., 1992; McGorry, 1994) as a factor important to outcome. This period has become known as the psychotic prodrome

(McGlashan, 1998; McGorry, 1994; Miller, McGlashan, Rosen, Cadenhead, Ventura et al., 2003).

1.8 Psychotic prodrome

'Prodrome' is defined by the Australian Clinical Guidelines for Early Psychosis as "...the earliest form of psychotic disorder, or an at-risk mental state" (National Early Psychosis Project, 1998, p. 11). The guidelines acknowledge there is no single authoritative definition for prodrome, noting it can be considered as a retrospective concept signifying the earliest changes to an individual's mental state.

Whilst the concept of a psychotic prodrome is not new (McGorry, 1999) its importance has been highlighted by studies demonstrating that individuals have a mean prodromal period of two years before making the transition to psychosis, at least in schizophrenia (Loebel et al., 1992).

Theorists and researchers have thus argued that significant illness burden could be prevented by intervening in the early stages of threshold illness (McGlashan, 1996; McGorry, Edwards, & Mihalopoulos, 1996; Mrazek & Haggerty, 1994).

Whilst this approach has now gained widespread acceptance (McGlashan, 2003), there remains the significant difficulty of identifying those who are at incipient risk of psychosis and subsequent psychotic illness.

Researchers (Yung, 2003) credit Falloon (1992) with the first study attempting to identify pre-psychotic or prodromal individuals by training general practitioners to recognise prodromal signs outlined in the DSM-III-R (American Psychiatric Association, 1987). Identified cases were given early intervention procedures including psycho-education, comprehensive stress management, and neuroleptic medication. Whilst methodological limitations and a high rate of false positives

were acknowledged (Falloon, 1992), the limited results nevertheless indicated that early identification and treatment, might be possible. This research also suggested that early identification may improve outcome and reduce illness burden.

Building on this early work, several authors (Birchwood & Macmillan, 1993; Kane, Krystal, & Correll, 2003; McGlashan, 1998; McGorry, Edwards, & Mihalopoulos, 1996; McGorry & Singh, 1995; Yung et al., 1996; Yung, McGorry, McFarlane, & Patton, 1995) have argued for a necessary reduction in psychotic prodrome as crucial to better outcomes. The above research has indicated that intervention in the prodrome, provides the best chance for improved outcome. This process is analogous to other forms of chronic illnesses, whereby the early detection reduces the risk of chronic illness. The critical period hypothesis suggests that intervention in the prodrome allows the possible reversal of illness. After this period the illness may only be stabilised (Birchwood & Macmillan, 1993). Prodrome research (Loebel et al., 1992; McGorry, Edwards, & Mihalopoulos, 1996) has yielded a recognition that subsequent to the prodome; individuals often enter a period of prolonged time where threshold psychosis occurs, but is yet to be diagnosed or treated. The length of the period immediately subsequent to the prodrome and before diagnosis and first treatment, has been recognised as important in reducing overall illness burden (McGorry, 1999), and is termed the duration of untreated psychosis.

1.9 Duration of untreated psychosis

The Duration of Untreated Psychosis (DUP) has become recognised as an important factor in predicting outcome. The DUP is defined by Catts (2001, p25) as "...the length of time between onset of the first ever psychotic symptoms and when the diagnosis of possible or definite psychotic disorder was first made by a mental health service provider." This definition raises questions of where the critical period begins and where this is placed in relation to threshold diagnostic

criteria. Other definitions regard DUP as the period during which the individual has a psychosis meeting diagnostic criteria but that has not yet been diagnosed or treated (McGorry, 1994; Wyatt, 1995). In this sense, some regard the prodome and DUP as equivalent whilst others interpret DUP to be undiagnosed threshold illness. Studies have shown that the DUP is longer than previously thought (Johnstone et al., 1992; Jones et al., 1993; Loebel et al., 1992; Wyatt, 1991). Individuals not uncommonly suffer with threshold psychosis for a year or even longer before the first treatment (McGorry, 1999). These findings are important; individuals may experience a delay of up to two years before the first treatment when the prodome is added to the DUP. McGorry (1999) has argued that prolonged delays in treatment may reduce capacity for psycho-social recovery during the developmental periods of adolescence and early adulthood. He also argues that delays the commencement of antipsychotic medication may reduce the effectiveness of these treatments when eventually administered. In this sense a longer DUP may reduce outcome by impairing developmental progress, or the ability to catch up to peers, and by increasing neuropathology. Increased neuropathology may have an additional effect on illness by reducing the effectiveness of subsequent anti-psychotic medication.

Despite the noted relationship between DUP and outcome (Johnstone et al., 1992; Jones et al., 1993; Loebel et al., 1992; Wyatt, 1995), McGorry (1999) highlights that there is not yet high-grade confirmatory evidence such as randomised controlled trials to confirm improved outcome via reducing DUP. In the absence of such evidence it remains possible that a third factor is mediating both treatment delay and poor outcome. Some have suggested that factors such as a predominance of negative symptoms or persecutory delusions (McGorry, 1999), associated with poorer prognosis, may play a part in accounting for the variation in response to EP treatments.

Recent evidence from two meta-analyses (Marshall et al., 2005; as cited in McGorry, Killackey, & Yung, 2007; Perkins, Gu, Boteva, & Lieberman, 2005) has

further supported the robustness of the EP paradigm in reducing illness burden by reducing DUP. Studies such as these have to some extent assuaged the criticisms alluded to by McGorry (1999) and ensured the acceptance of the EP approach as having demonstrated effectiveness (McGorry, Killackey, & Yung, 2007).

1.10 Early detection

The possibility of reducing illness burden for an individual at-risk of incipient psychosis therefore rests on early detection of pre-cursor illness. EP by its very nature is considered to be early detection when considered in the context of traditional interventions for psychotic illness (McGorry, 1999), However the term early detection is used here to signify EP research concerned with detecting and assessing individuals at the very earliest signs of illness. As can be seen above, EP as a treatment approach involves a range of individuals, from those who are experiencing prodromal symptoms to those who have experienced their first psychotic episode. Early detection however, in this sense, is aimed at identifying individuals who have the earliest or first emergent signs and symptoms of a possible psychosis. This is can best be represented by Figure 1 below.

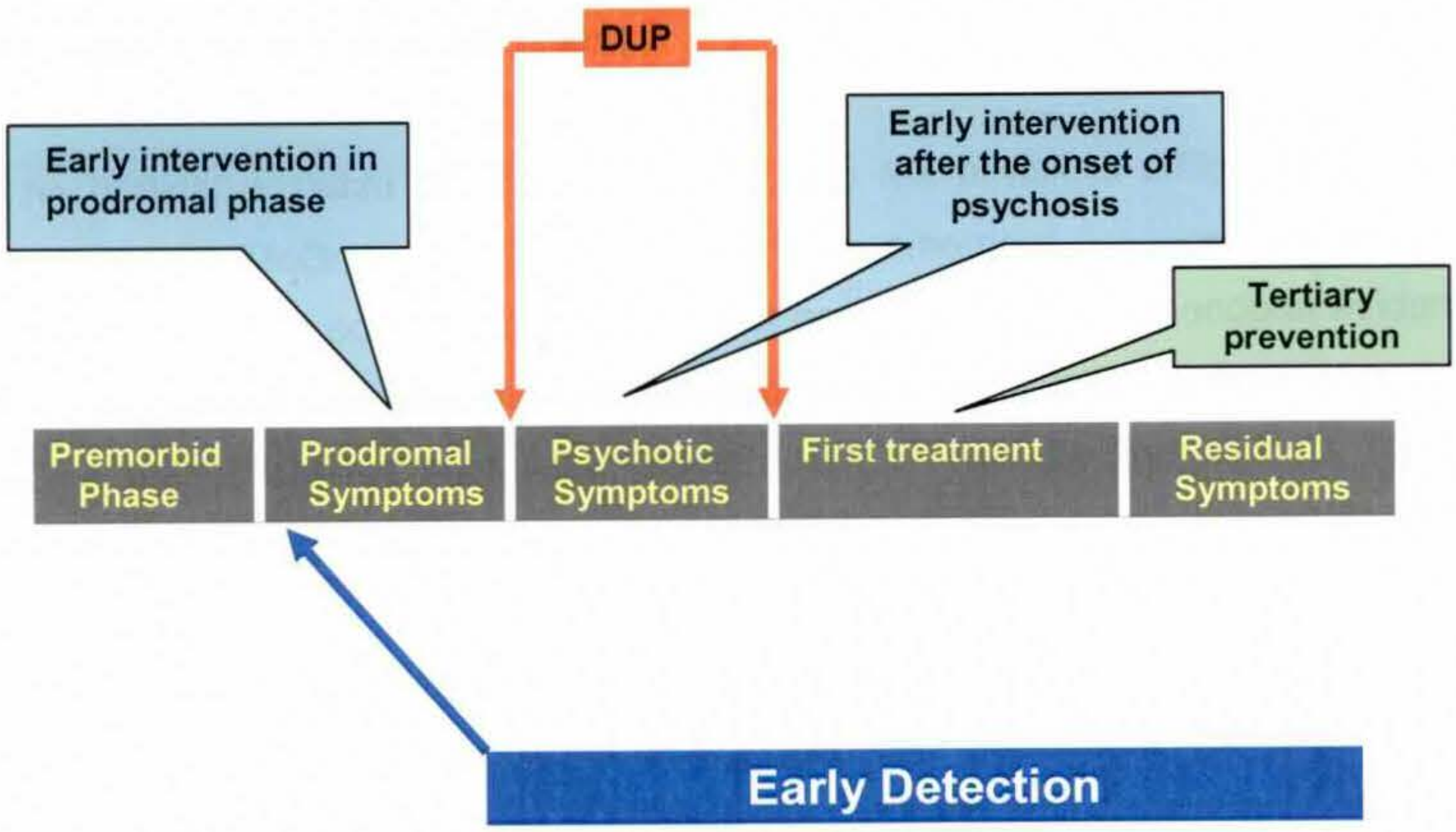

Figure 1. Topography of the first episode of psychosis.

Early detection research is derived from the finding (McGorry, Edwards, & Mihalopoulos, 1996) that improving the treatment outcome of psychotic illness is dependent upon reducing the length of the DUP. In order to successfully reduce illness burden or make prevention possible, individuals must be detected at the earliest possible point of pathology, where the first symptoms emerge. In this sense the focus in this area of the EP paradigm is identifying the earliest detectable signs of possible illness.

The earliest possible detection of those who are at-risk is difficult for several reasons. As McGorry (1999) has pointed out, emergent psychotic pathology is diffuse and often covers a broad range of psychopathology. Anecdotal evidence has suggested that patient relatives and carers often feel there is something going on but are not sure what (SANE, 1996). Thus the first difficulty for this approach is delineating possible psychosis from other emerging mental illnesses. Falloon (1992), in what has become accepted as the first study into detecting pre-schizophrenia, identified the necessarily high rate of false positives (Type I errors) in attempting to detect individuals who will make the transition to psychosis. Other researchers (McGorry, Yung, & Phillips, 2003; Yung, McGorry, McFarlane, & Patton, 1995; Yung, Phillips, Yuen, & McGorry, 2004) have utilised and extended Bell's (1992) methods of multiple gate screening and a close-in approach to reduce false positives to good effect. This approach identified the period of highest incidence (16-25 years) and systematically began identifying those who were most at risk. Included amongst these ultra-high risk individuals (McGorry, Yung, & Phillips, 2003; Yung, Phillips, Yuen, & McGorry, 2004) are those: with a first degree relative and a functional decline; those with sub-threshold symptoms; and those who have brief limited intermittent psychotic symptoms.

There is a further difficulty of developing systematic standardised methods of detection able to objectively measure the risk of transition to psychosis. In order

to detect those at-risk of psychosis new methods beyond established diagnostic criteria were needed by EP researchers and clinicians. Traditional methods based on categorical diagnostic systems proved too insensitive to the range of sub-threshold symptoms and changes to mental state. In designing new and more sensitive methods, EP researchers (Yung, Phillips, Yuen, & McGorry, 2004; Yung et al., 2003) broadened the range of psychopathology assessed and included the concept of basic symptoms. These symptoms first proposed by Huber (Huber, 1983; Huber & Gross, 1989) include disruptions to speech, memory, attention, and concentration and are thought to be important pre-cursor symptoms to psychosis (de Leon, Wilson, & Simpson, 1991; Ebel, Gross, Klosterkotter, & Huber, 1989; Huber, 1983).

Recent research (McGorry et al., 2002) has demonstrated improvement in not only identifying at-risk individuals but also in intervening to improve outcome. McGorry (McGorry, Killackey, & Yung, 2007) has argued there is now reliable evidence for the EP paradigm in terms of reducing illness burden for individuals detected early.

Thus EP research has highlighted many of the processes and predictors of transition to psychosis (Carr, Lewin, Neil, Halpin, & Holmes, 2004; Cornblatt & Auther, 2005; Hulbert, Jackson, & McGorry, 1996; Klosterkotter, Hellmich, Steinmeyer, & Schultze-Lutter, 2001; Yung, Phillips, Yuen, & McGorry, 2004). These include individuals with a direct genetic link (Crow, 2007; Levinson, 2005), those who have identifiable psychological variables (Hulbert, Jackson, & McGorry, 1996; Krstev, Jackson, & Maude, 1999), and those using significant amounts of drugs and alcohol (Patterson, Holman, English, Hulse, & Unwin, 1999).

However, EP has not provided significant new aetiological insights. In the absence of confirmed aetiologies, EP has adopted the the stress-diathesis model of aetiology proposed for schizophrenia (National Early Psychosis Project, 1998;

Zubin & Spring, 1977). This model proposes that psychosis occurs as a result of environmental stress mediated upon a biological predisposition. Whilst research interest remains high into the genetics of psychotic illness and schizophrenia in particular (Catts, Fox, Ward, & McConaghy, 2000; Crow, 2007; Levinson, 2005), the role of the environment in the precipitation of psychotic illness has also received much attention (Bebbington et al., 1996; Bebbington et al., 2004; Croudace, Kayne, Jones, & Harrison, 2000).

Many of the identified environmental factors can be grouped together under the term disadvantage. EP has contributed to research in this area by highlighting environmental factors present at the beginning of illness rather than as a result of illness. EP research has demonstrated the role of type of disadvantage in increasing the risk of psychotic illness (Baldwin et al., 2005; Garety & Rigg, 2001). Further supporting this link between psychosis and disadvantage is the finding that individuals in the general community with the highest reported incidence of psychotic-like experiences are those from the lowest socio-economic levels (Scott, Chant, Andrews, & McGrath, 2006).

1.11 Disadvantage

Australian research has supported the link between disadvantage and psychosis (Carr, Lewin, Neil, Halpin, & Holmes, 2004; Jablensky et al., 2000; Scott, Chant, Andrews, & McGrath, 2006) with overall level of disadvantage perhaps the best non-specific predictor of risk for psychotic illness (Croudace, Kayne, Jones, & Harrison, 2000). Moreover, risk is increased with childhood adversity (Bebbington et al., 2004) and the amount of disadvantage experienced (Wicks, Hjern, Gunnell, Lewis, & Dalman, 2005).

Multiple sources of disadvantage may increase risk in a cumulative fashion via and mediate specific factors known to place individuals at increased risk for psychosis. Examples of this are to be found in the link between poor infant

health, such as low birth weight (Bersani et al., 2007; Cannon, Jones, & Murray, 2002; Smith et al., 2001), child victimisation, and psychotic illness (Bebbington et al., 2004; Wicks, Hjern, Gunnell, Lewis, & Dalman, 2005).

Thus disadvantage is an important risk factor to be considered in the detection of individuals who are at highest risk for psychosis. With the identified highest incidence for psychosis in 16-25 year olds; individuals in this age range with high rates of childhood adversity and disadvantage are possibly most at risk (Bebbington et al., 2004; Wicks, Hjern, Gunnell, Lewis, & Dalman, 2005). In order to reduce illness burden significantly amongst the largest number of individuals, detection and intervention should be focused upon the most disadvantaged young people.

In Australia young people are an identified group who are at increased risk for mental disorders. Statistics have shown those aged 18-24 years have the highest prevalence rates for mental disorders at 27%, much higher than any other age group (Australian Bureau of Statistics, 2006). Risk increases further where there are factors of disadvantage such as: poorer health; lower levels of education; low income; reduced wealth; and poorer housing.

Amongst disadvantaged people at-risk for mental disorders including psychotic illness there are groups recognised as being at increased risk by the severity of their disadvantage. One of the most disadvantaged are the Australian Aboriginal people (Steering Committee for the Review of Government Service Provision, 2005). Furthermore, Aboriginal people have been shown, consistent with the above to have higher rates of psychosis than the general population (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Australian Institute of Health and Welfare, 2005; Jablensky et al., 2000). Therefore young Aboriginal people aged 16 -25 years have amongst the highest risk for psychosis due to age-prevalence rates and disadvantage.

The following chapter will discuss the pre-determinates of psychosis amongst Aboriginal people and the current lack of data about psychosis in this community.

Chapter 2
Aboriginal Disadvantage and Mental Health

2.1 Aboriginal demographics

Aboriginal people currently comprise around 2.4% of the Australian population (in mid 2005), an estimated resident population of 492,700 (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). Sixty-nine percent of Aboriginal people live outside of cities and one-quarter of Aboriginal people live in remote areas. Just over half live in New South Wales and Queensland (Australian Bureau of Statistics, 2004). The Aboriginal population is much younger than the broader Australian population with a median age of 20.5 years compared to 36.1 years. Of the current Aboriginal population, 40% are under 15 years of age. Furthermore, the Aboriginal population is growing faster than the broader population with an increase of 15.4% from 1996 to 2001 (Australian Bureau of Statistics, 2004). The 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSIS) (Australian Bureau of Statistics, 2004) revealed that just over half of Aboriginal people identified with a clan, tribal, or language group, with almost 70% aged over 15 years having attended a cultural event in the past 12 months. This cultural attachment index remains unchanged from the 1994 NASTSIS (Australian Bureau of Statistics, 1995), although there has been a decline from 29% to 22% of people living in homelands or traditional country.

2.2 Aboriginal disadvantage

Knowledge and concern about Aboriginal disadvantage is relatively recent. A telling indicator of the past consideration of Aboriginal people can be found in anthropology: "Most people who think at all of the Aborigines are concerned not so much with understanding their social, religious, and mental life, as with gaining information about their classification and place of origin." (Elkin, 1964). Yet, if recent past consideration was marked by ignorance and indifference, the

past forty or so years has been witness to significant change. Accumulating evidence has demonstrated Aboriginal people are in a condition of general plight (Australian Bureau of Statistics, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; National Aboriginal Community Controlled Health Organisation & Oxfam, 2007). Perhaps the most significant problem facing the Aboriginal community today is pervasive disadvantage across a range of socio-economic indicators. The magnitude and efforts to reduce this are perceived as a problem for the government and the broader society (Abbot, 2006; Jopson, 2003; Moore, 2006).

Disadvantage in a social equality context is perhaps best reflected by the indicators used to measure it: life expectancy at birth; rates of disability; education; employment rates; home ownership; income; and health (Steering Committee for the Review of Government Service Provision, 2005). Disadvantage is where an individual has significantly lower levels of one or more of these indicators. Disadvantage is cumulative in its effects. An individual's ability for improvement on any single indicator is reduced by the presence of each additional indicator. Indicators are proximate measures of individual potential; possessing less of the attributes measured by such indicators reduces likelihood of reaching individual potential in life.

Aboriginal people remain the most disadvantaged group in Australia since colonisation (Steering Committee for the Review of Government Service Provision, 2005).

That they *remain* the most disadvantaged group highlights a history of disadvantage that is cumulative. Whilst many groups in Australian society face similar types and even extents of disadvantage to Aboriginal people, what is significant is the pervasiveness of disadvantage, extending to all spheres of life.

2.3 The factors of Aboriginal disadvantage

The reduction of Aboriginal disadvantage is now high on the Australian national policy agenda, and the attempt to measure and subsequently improve the plight of Aboriginal people has given rise to a series of reports (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2003, 2005; Australian Institute of Health and Welfare, 2005). Such reports measure perceived root causes of disadvantage (Steering Committee for the Review of Government Service Provision, 2005). Aboriginal people as a whole have poorer outcomes on all the measured factors of disadvantage than the broader non-Aboriginal community. The factors included in most reports include: health, education and employment; income and wealth; housing; disability; alcohol and drugs; and violence and crime (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2003, 2005; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; National Aboriginal Community Controlled Health Organisation & Oxfam, 2007; Urbis Keys Young, 2001). These findings have been echoed by studies surveying Aboriginal people directly about their circumstances (Australian Bureau of Statistics, 1995, 2004).

The hallmark indicator of Aboriginal disadvantage, and one often viewed as fundamental (Steering Committee for the Review of Government Service Provision, 2005), is life expectancy at birth. Currently Aboriginal people, on average, have a life expectancy of 17.2 years less than that of other Australians. For Aboriginal men this represents an age at death of 59 years (vs. 77 years for non-Aboriginal men), and for Aboriginal women an age of 65 years (vs. 82 years for non-Aboriginal women). Comparable life expectancy figures for indigenous communities in other countries, such as the USA, Canada, and New Zealand are 7-7.5 years lower than the respective non-indigenous populations (National Aboriginal Community Controlled Health Organisation & Oxfam, 2007). Life expectancy is viewed as being fundamental as it is influenced by all other

indicators beyond just physical health. As such, life expectancy is reduced by the presence of disadvantage in other indicators. Therefore overcrowding of households, poorer education, lower employment rates, and disability all contribute to reducing life expectancy in addition to poor physical health. However, of all the factors of disadvantage associated with Aboriginal people, none have had the attention as those associated with health.

2.4 Aboriginal health

Health is a factor of disadvantage where the disparity between Aboriginal and non-Aboriginal people has been perhaps the largest. Poor physical health is a fundamental factor in Aboriginal disadvantage; impacting negatively upon all other factors. Where physical health is poor the stressors suggested by the stress diathesis model of mental illness (Zubin & Spring, 1977) as necessary for illness are likely to be increased.

Aboriginal people have the worst health of any group in Australia and worse health than comparable groups such as New Zealand's Maori people, American Indians and Canadian First Nation People The United Nations now lists life expectancy of Aboriginal people as lower than underdeveloped nations such as Bangladesh and Nigeria (United Nations, 2003). Some claim new methods for estimating life expectancy make comparison with previous figures impossible (Steering Committee for the Review of Government Service Provision, 2005). However, it is likely that life expectancy for Aboriginal people has not improved and is possibly slightly worse than 10 years ago.

At the centre of health problems that reduce Aboriginal life expectancy is that of chronic health problems. Included amongst these are: neoplasms (tumours); ischaemic heart disease (angina and heart attack); chronic obstructive pulmonary disease (COPD, lung and respiratory disease); cerebrovascular disease (strokes); and diabetes. The Close the Gap report lists the mortality rates

comparing Aboriginal people and non-Aboriginal people and reports the relative risk to Aboriginal people for these conditions. The relative risks are 1.3 times for neoplasms, 1.9 times for heart disease, 2.1 times for stroke, 2.5 times for COPD and an extraordinary 9.8 times for diabetes (National Aboriginal Community Controlled Health Organisation & Oxfam, 2007). The reported rates illustrate the importance of chronic poor health as a contributing factor to the reducing life expectancy. Many of these conditions are directly attributable to lifestyle factors and as such diet, smoking, and lack of exercise. Highlighted again is how other factors of disadvantage contribute to an overall reduction in health status. Here, poor education, low-income and lack of wealth converge to reduce the health of Aboriginal people. The relative risk of other health conditions is also significantly increased. Aboriginal people have 2.1 times the risk for pneumonia and influenza and experience significantly increased rates of other communicable diseases including respiratory and gastro-intestinal infection.

Health problems for Aboriginal people start in infancy or childhood and infant mortality is amongst the highest for any indigenous culture at 14.3 per 1,000 births (National Aboriginal Community Controlled Health Organisation & Oxfam, 2007), with state-based estimates at around 11.9 deaths per 1,000 live births. Both figures are still well above the 5 per 1,000 for non-Aboriginal people (Steering Committee for the Review of Government Service Provision, 2005). In reporting these rates it is acknowledged that they may be an underestimate. The higher rate of deaths has been attributed to congenital disorders, sudden infant death syndrome, respiratory and cardiovascular disorders, and accidents (Australian Bureau of Statistics, 1996).

For live births, more than twice the babies born to Aboriginal mothers were low to extremely low birth weight than those born to non-Aboriginal mothers (Steering Committee for the Review of Government Service Provision, 2005). Low birth weight is a predictor of future chronic health conditions and low birth weight in

Aboriginal babies has been attributed to foetal growth retardation or premature birth (Sayers & Powers, 1997).

Aboriginal children beyond infancy have significantly worse health than their broader community counterparts, including poorer nutrition, lower immunisation, and high rates of infectious disease (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). The Western Australian Aboriginal Child Health Survey (WAACHS) (Zubrick et al., 2004), a landmark study into the health of Aboriginal children in Western Australia revealed that, in addition to the above, Aboriginal children higher rates of disability, including higher rates of children without normal vision or hearing, respiratory problems including Asthma, and recurring infections as such ear or chest infections.

The health problems, encountered early in life, reduce overall health and predispose Aboriginal people to further health problems later in life. Amongst these are mental health problems, in particular psychosis. There is evidence that problems with in-utero development, low birth-weight, and poor infant health increase risk for psychotic illnesses such as schizophrenia (Bersani et al., 2007; Cannon, Jones, & Murray, 2002; Mednick, Machon, Huttenon, & Bonnett, 1988). Thus poor infant health and development may be the first environmental stress increasing risk for this group in a stress-diathesis model (Zubin & Spring, 1977).

Other reports such as the Health and Welfare of Australia's Aboriginal and Torres Strait Islander peoples (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005) have published the hospitalisation rates for Aboriginal people. Overall Aboriginal people are hospitalised at about twice the rate of non-Aboriginal people proportionate for population data (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). These figures support the chronic health data above. All but four principal diagnostic categories for hospitalisation have between 1.5-12.0 times the expected

admission rates for Aboriginal people. Diabetes, with 12 times the admission rates for care and 9.8 times the risk compared to non-Aboriginal people is perhaps the most significant chronic health problem facing the Aboriginal community as a whole.

The above data, drawn from hospitalisation rates and mortality statistics, is not the only way to gauge Aboriginal health. The National Aboriginal and Torres Strait Islander Social Survey (Australian Bureau of Statistics, 2004) asked a number of subjective health related questions. These included self-assessed health status and indicated that only 44% of Aboriginal people rate their health as excellent or very good, whilst 23% rate their health as fair or poor (Australian Bureau of Statistics, 2004). The NATSIS notes the difficulty in comparing Aboriginal and non-Aboriginal people on self-assessed health status due to the age difference in the populations; the Aboriginal population being significantly younger on average. Older age is necessarily linked with poorer health. However, adjusting for age differences, 35% of Aboriginal people over 18 years report their health as excellent or very good compared to 59% of non-Aboriginal people. Aboriginal people are twice as likely to report their health as fair or poor (33% versus 16%) (Australian Bureau of Statistics, 2004).

Of the many factors that affect the health of Aboriginal people, few have received more attention or notoriety than drug and alcohol use. Data from several sources (Australian Bureau of Statistics, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Steering Committee for the Review of Government Service Provision, 2005) have demonstrated high use of drugs and alcohol amongst Aboriginal people. Just over half of the Aboriginal population 15 years or over smoke cigarettes, and whilst fewer Aboriginal people use alcohol than non-Aboriginal people, alcohol is used to more harmful levels by those people who do drink, with 1 in 6 Aboriginal people over 15 years reporting risky alcohol consumption. Whilst there is poorer quality objective data on illicit drug use, available subjective data from surveying Aboriginal people (Australian

Bureau of Statistics, 2004) demonstrated high usage of illicit substances with extremely high rates of marijuana and amphetamine use amongst young Aboriginal men compared to the non-Aboriginal population. High rates of alcohol and illicit substance use are a risk factor for mental health problems and may be linked, in part, to hidden disadvantage.

2.5 Hidden disadvantage

Disadvantage can also be derived from non-specific factors such as racism, marginalisation, and the despair of membership of a severely disadvantaged community. Several authors (Eckerman et al., 2006; Franklin & White, 1991; Hunter, 1993) have noted the impact of racism, both individual and institutionalised, on the health of Aboriginal people. This serves to undermine individual self-worth and self-esteem, and devalue the shared characteristics that combine to create Aboriginal culture and community. Racism may have indirect impacts such as reducing health and likelihood to further education, and increasing drug use. It may be more direct in the form of violence, or reduced opportunities for employment, advancement or recognition. Being an Aboriginal person is to endure a barrage of negative media reports serving to remind that being Aboriginal is to be severely disadvantaged (Abbot, 2006; Franklin & White, 1991; Jopson, 2003; Metherell & Peatling, 2006; Moore, 2006). Beyond the direct and indirect impacts of racism, the impact of such messages upon Aboriginal people's self-concept and self-esteem is hard to imagine, and even more difficult to measure. Some hint of the seriousness of the impact of the above can be found in a recent strategic document that outlines "... the desire not to attract further negative sentiment towards the Aboriginal and Torres Strait Islander communities through reporting higher incidences of mental health problems..." (National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004, p. 50). The intent here appears two-pronged. Firstly, it is presumably an attempt to avert increased negative views of Aboriginal people (as perhaps more likely to be mentally ill), by the non-

Aboriginal community. Secondly, in line with the above, such a move is perhaps intended to reduce the negative impacts of data outlining Aboriginal disadvantage upon the Aboriginal community. It is a serious consideration. Not only has Aboriginal disadvantage served to promote a negative message about Aboriginal people to all Australians, the way these data have been disseminated has found no more impact than within the Aboriginal community itself. The impact of negative messages about Aboriginal people and the subsequent effects on Aboriginal people is now recognised as a form of disadvantage in itself by the Aboriginal community (Mindframe Media and Mental Health Project, 2004; Swan & Raphael, 1995). This disadvantage is perceived as furthering negative stereotypes of Aboriginal people.

These hidden factors of disadvantage, racism and self-esteem, may be thought of as factors that impact upon and form a part of mental health. The mental health of Aboriginal people is another, until recently, hidden factor of disadvantage. Whilst racism, marginalisation, and membership of the most disadvantaged community are all external factors or processes, the true impact of these is felt by the individual, or community, internally and psychologically. The psychological impacts of racism and marginalisation may constitute mental health problems in themselves or serve to contribute, with other indicators of disadvantage to overt mental illness in the Aboriginal community.

2.6 Aboriginal mental health

Mental health is now recognised as an area of significant disadvantage in the Aboriginal community (Hunter, 2008). However, mental health is an area of disadvantage that has not traditionally been recognised amongst other media and government headline indicators. Where factors such as poverty, education, and physical health, have long been measured as primary indicators, mental health has not necessarily been viewed as fundamental to disadvantage (Hunter & Tsey, 2003; Reser, 1991; Steering Committee for the Review of Government

Service Provision, 2005) The reasons for this are complex. Mental health fits broadly under the banner of overall health, yet also accounts for a proportion of disability. Beyond this, mental health is a likely component of other headline indicators. For example, the rates of mental illness amongst prisoners are around 74% for any psychiatric disorder in a 12 month period in NSW prisons (Butler & Allnutt, 2003). When tabulated with the over-representation of Aboriginal inmates, these findings suggest mental illness may play a part in a significant proportion of Aboriginal crime and incarceration.

An illustration of the reciprocal relationship between mental health and other indicators is yielded by tabulating the overlap between mental health and other indicators. For example, in 2003-04, Aboriginal people were admitted to Australian hospitals for mental disorders due to a psychoactive substance at 3.85 times the rate of other Australians (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). In the same period it was reported that substance use disorder was by far the most common psychiatric diagnosis amongst NSW inmates (Butler & Allnutt, 2003), where 30.1% of inmates were Aboriginal. Whilst the data here is not conclusive or specific, it is suggestive of a relationship. It is likely that the spectrum of mental health problems increase the risk for drug use and crime, which may, in turn, exacerbate mental illness. In this way mental health problems are related to components of disadvantage and may increase the likelihood of disadvantage in other factors.

Mental health as an indicator of disadvantage is complicated by difficulties in distinguishing for reporting purposes, between mental illness (diagnosed illness) and mental health problems (such as distress and sub-threshold mental illness). Mental health problems are amorphous and range from poor self-esteem (Swan & Raphael, 1995) to symptoms just below the threshold for psychiatric diagnosis. Problems not meeting criteria for inclusion in illness data nevertheless contribute to disadvantage and raise the risk for further disadvantage.

In this vein, high levels of stress are a well recognised problem amongst the Aboriginal community (Australian Bureau of Statistics, 2004; Hunter, 1995; Swan & Raphael, 1995). Ordinarily, whilst high levels of stress may be considered as contributing to mental health problems, stress itself is not a diagnosable mental illness. Response to tress may be considered a mental illness only if specific stringent criteria are met (American Psychiatric Association, 2000). The stress from accumulated disadvantage is unlikely to meet these criteria. As such, the rates of mental illness associated with stress related conditions are likely to be an underestimate if diagnostic criteria are used as the determinant of illness. The same may be true of self-esteem, trauma, and grief; all of which are common if not endemic in the Aboriginal community (Swan & Raphael, 1995).

Further complicating mental health as a primary indicator of Aboriginal disadvantage is the difficulty of mental health's dual role in the cause and effect of disadvantage. Whilst this is not unique to mental health, it appears far less recognised and acknowledged than the relationship between other factors such as education and income, or drug use and crime.

Those with mental health problems are less likely to attain higher standards of education, receive high incomes, or enjoy good physical health (Drukker, Gunther, & van Os, 2007; Hunter, 2007). Yet, exposure to other factors of disadvantage including poverty, violence, drug and alcohol misuse, and stress, places individuals at greatly increased risk for mental illness and mental health problems. In the absence of confirmatory empirical evidence it is likely that where mental health problems are not a direct cause for aspects of disadvantage they are an associated cause and possibly an effect.

In considering the above possibility, the links between disadvantage and mental health problems in Aboriginal people are consistently borne out in the available data. Emergent data from the last 10 years has demonstrated just how much worse the mental health of Aboriginal people as a community is compared to

other Australians (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Brown, 2001; Hunter, 2007; Roxbee & Wallace, 2003).

2.7 The state of Aboriginal people's mental health

In 2008 there remains a lack of available data to understand the epidemiology of psychiatric illness amongst Aboriginal people (Haswell-Elkins, Sebasio, Hunter, & Mar, 2008). As such, the state of Aboriginal people's mental health is at best speculative. Improved recognition of Aboriginal status in data recording (Australian Bureau of Statistics, 1999, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2003, 2005) and greater interest in gauging Aboriginal peoples' mental health (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Australian Health Ministers, 1998; Australian Institute of Health and Welfare, 2006a; Urbis Keys Young, 2001) has resulted in better statistics on the state of Aboriginal mental health. However, the available statistics are neither adequate nor comprehensive. Whilst there is much improvement on the essentially very little data that had been collected and made available by the 1990's (Hunter, 2002; Reser, 1991; Swan & Raphael, 1995), national mental health data collected even in the last 10 years (Australian Bureau of Statistics, 1999) have failed to include an Aboriginal component (Hunter, 2002). This has occurred on a background of increasing evidence that Aboriginal mental health incidence rates are higher than non-Aboriginal rates. The database for Aboriginal mental heath was called woefully inadequate as recently as 2002 (Hunter, 2002), and despite improvements, the information available is still insufficient to accurately gauge the incidence and prevalence of major psychiatric disorders amongst Aboriginal people.

As such, any discussion of Aboriginal mental health based on the available data is limited by the inadequacies of current data collection and published figures are likely to be conservative estimates.

This situation is highlighted in the evaluation of the Aboriginal and Torres Strait Islander Emotional and Social Well Being Action Plan (Urbis Keys Young, 2001), the Commonwealth Government's first comprehensive Aboriginal mental health policy initiative. The consultancy report revealed that in the period from 1996-2001 little progress had been made by state governments in collecting data on Aboriginal mental health.

Despite these shortcomings, there is supplementary data available from a range of sources. These include hospital statistics, health surveys, and scientific research. This data is not comprehensive or reliable enough to yield prevalence rates for specific disorders in-particular psychotic illness. However, the available data illustrates how in line with other forms of disadvantage, Aboriginal people have poorer mental health. The reliability of the available data is questionable due to the noted poor recording of Aboriginal status by health services (Urbis Keys Young, 2001) and the questionable validity of diagnoses for mental illnesses applied to Aboriginal people by non-Aboriginal clinicians (Johnston et al., 1991; Reser, 1991).

Despite these cautions perhaps the most reliable data is that of Australian hospital statistics used by The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples report (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005).

Hospital separation data demonstrates that Aboriginal people are admitted to hospital for all mental and behavioural disorders at 1.5 times the rate of non-Aboriginal people (Australian Institute of Health and Welfare, 2005). Other national hospital morbidity data (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005) list a rate for all mental and behavioural disorders of 1.5 times for Aboriginal women and 2.1 times for Aboriginal men. This yields a considerably higher rate for all Aboriginal people of 1.8 times the

admissions of non-Aboriginal people. This report further divides the data into diagnostic categories as listed in Table 1 below.

Table 1

Rate of hospitalisations for mental and behavioural disorders: Indigenous persons 2003-04 (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005)

ICD- 10 Diagnostic category	Males	Females	Total
Mental disorders due to a psychoactive substance	4.4	3.3	3.85
Mood and neurotic disorders	1.0	1.1	1.05
Schizophrenia, schizotypal and delusional disorders	2.3	2.5	2.40
Organic mental disorders	1.8	1.9	1.85
All other mental disorders	0.8	0.6	0.70
Total	**2.1**	**1.5**	**1.8**

Of note are the significantly higher admission rates for schizophrenia and related illnesses and disorders due to a psychoactive substance. The rate of 3.85 times the non-Aboriginal admissions for mental disorders due to psychoactive substances is difficult to interpret. It is perhaps not surprising in light of the well publicised and researched inflated rates of drug and alcohol use in the Aboriginal community (Jopson, 2003; Patterson, Holman, English, Hulse, & Unwin, 1999).

However, categorical data such as these do not yield specifics of individual presentations. In light of difficulties noted in diagnosing Aboriginal people by mental health clinicians (Haswell-Elkins, Sebasio, Hunter, & Mar, 2008; Reser, 1991; Swan & Raphael, 1995; Wettinger, 1997), it remains possible that both the 2.4 times rate of admissions for schizophrenia and spectrum disorders and the 3.85 time rate for psychoactive substance admissions are inaccurate. The high rates of substance use in the Aboriginal community and the environmental stresses placed on Aboriginal people by increased disadvantage increase risk for psychotic illness. These factors combined with noted diagnostic difficulties

suggest that a proportion of the almost four times admission rate for psychoactive substance use in this community may currently or eventually belong in the higher schizophrenia and related disorders admission data.

These figures, inflated as they are in many diagnostic categories, require caution when being interpreted. Several sources (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Australian Institute of Health and Welfare, 2006b) suggest the likely under-recording of Aboriginal status nation-wide. Whilst the recording of Aboriginal status has improved (Australian Institute of Health and Welfare, 2005, 2006a) there is evidence to suggest that this is still not recorded to a satisfactory level (Urbis Keys Young, 2001). Beyond under-recording is the possibility of misdiagnosis or non-diagnosis via cultural differences skewing the available data. Cultural differences influencing diagnosis may act to award diagnoses to individuals where this is not warranted (false positives), or under-diagnose individuals who do indeed warrant diagnosis (false negatives). Whilst it is likely that there is a mixture of these cases in connection with Aboriginal mental health diagnoses, some have suggested that there is a bias in favour of under-diagnosing Aboriginal people due to cultural differences (Burdekin, 1993; Johnston et al., 1991; Swan & Raphael, 1995). In the absence of data confirming numbers of undiagnosed but true cases, the rates of illness should perhaps be regarded as conservative estimates.

Hospital admission data, when examined alone, raises questions of the role of access to services. It has been widely acknowledged that Aboriginal people have reduced access to mental health services, and are less likely to access existing health services (Hunter, 2007; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; Swan & Raphael, 1995). Inflated admission rates may reflect more acute illness, in-part driven by lack of primary mental health services. However, existing rates of illness must be considered in conjunction with the likely under-recording of Aboriginal status. If status is under-recorded then the current recorded rates may

well be conservative estimates of the true rates. For each Aboriginal admission to hospital for a mental illness, there are likely to be many more Aboriginal people, warranting intervention or perhaps even admission. These cases may simply be receiving no treatment at all despite exceeding threshold symptomatology for treatment. This remains speculative in the absence of supporting data. For Aboriginal people admitted to hospital for mental illness there is currently no published data on whether illness burden is reduced significantly, or on the rates of re-admission. There does not yet exist an adequate system for producing national psychiatric length of stay data for all psychiatric patients, and certainly there is not one detailing Aboriginal psychiatric patients alone. With the documented reduced access to mental health services (Hunter, 2007; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; Swan & Raphael, 1995) it is likely that many Aboriginal people receive treatment via crisis intervention in hospital only when illness becomes very severe. This is mediated by little or inadequate follow up in the community (National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004). This situation is particularly bad in rural and remote communities where there are reduced mental health services (Hunter, 2007).

Hunter (2002) has criticised the National Survey of Mental Health and Wellbeing (Australian Bureau of Statistics, 1999) for lacking an Aboriginal component, despite the mounting evidence of increased rates of mental illness. Yet the 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS, Australian Bureau of Statistics, 2004), specifically designed to gauge well-being amongst the Aboriginal community, also failed to address mental health problems at all. More surprisingly perhaps is the intention for the NATSISS to include a mental health component which was not fulfilled. Previously the Australian Bureau of Statistics and the Australian Institute of Health and Welfare, in advertising the yet to be completed 2002 NATSISS, advertised a mental health component to the survey. This comprised the administration to respondents of

the two widely used psychiatric measures, the SF-36 (Ware & Sherbourne, 1992) and the K-10 (Kessler et al., 2002). The reason given by ABS and AIHW for the non-inclusion of this of data was concern about the validity of these instruments for use in the Aboriginal community. Thus it can be seen that the gap in Aboriginal mental health data collection, rather than narrowing, is seemingly widening due to a lack of knowledge about how to subjectively, and perhaps objectively, measure aspects of Aboriginal mental health.

2.8 Aspects of Aboriginal mental health

Beyond the possible causes of increased mental health problems in the Aboriginal community and the lack of available data, it is imperative to note the differences in how Aboriginal people perceive and experience their own mental health. All literature concerning Aboriginal mental health, particularly that written by Aboriginal people, notes a different approach to mental health from the western European derived approach of the broader Australian community (Reser, 1991; Swan & Raphael, 1995; Vicary & Westerman, 2004; Westerman, 2004). This primary distinction rests upon the notion that in Aboriginal culture mental health is considered within a broader, holistic sense of health and well-being. Swan and Raphael (1995) have conveyed that health itself is a broader concept in Aboriginal community:

> "Health does not just mean the physical well-being of the individual but refers to the social, emotional and cultural well-being of the whole community. This is a whole of life view and includes the cyclical concept of life-death-life. Health care services should strive to achieve the state where every individual can achieve their full potential as human beings and thus bring about the total well-being of their communities."
> "This is an evolving definition." (Swan & Raphael, 1995)

Health is more narrowly perceived in the broader community as pertaining to mainly the physical and possibly the psychological. But Aboriginal people may

consider health as being compromised when such things as culture or community is interrupted or community members are unhealthy. This notion reflects the collectivist nature of Aboriginal society where, in particular, family and community, are much less distinguished from self. Also noted by these authors is an accepted definition of a mental health problem: "A mental health problem is a disruption of the interactions between the individual and the environment producing a diminished state of mental health" (N.S.W. Aboriginal Mental Health Report p.7, cited in Swan & Raphael, 1995). Highlighted in this definition is the importance of mental health as a problem with interactions with the environment which, perhaps more so for Aboriginal people than other groups, is associated with family, community and culture.

Aboriginal people have struggled for some time to communicate the notion that, unlike the predominant community approach, it makes little sense to speak of mental health as a separate entity or an abstract in the Aboriginal community (Vicary & Westerman, 2004; Westerman, 1997a). Here, what might be thought of as a mental health problem, or mental health symptoms, may be attributed to entirely other aspects of health and well-being. These things, such as cultural well-being are often not viewed as being associated with health by those from the broader Australian culture.

2.9 Aboriginal culture and psychiatric symptoms

Aboriginal people are more likely to attribute what might be thought of as mental health or psychiatric symptoms to such things as having acted against their culture (Reser, 1991; Vicary & Westerman, 2004; Westerman, 1997a) or spirits being angry with them. This is also true also for attribution of psychological difficulties in others, where signs and symptoms are attributed to having done the wrong thing culturally, or having wronged a relative. Westerman (1997a) points out that Aboriginal people are much less likely to think of the behaviour of an individual that may constitute mental illness in the broader community, as a

process or illness. Here these behaviours are more likely to be attributed to personality. Western Australian researchers have suggested that when you ask many Aboriginal people about the behaviour of an individual displaying identifiable signs and symptoms the answer will be the characteristic "That's just the way he is" (Vicary & Westerman, 2004). Their qualitative study on depression in Perth and the Kimberley highlighted that almost three in four Aboriginal respondents did not perceive depression as a state that could be addressed by treatment (Vicary & Westerman, 2004). This finding raises questions about how Aboriginal people, or a proportion of Aboriginal people, perceive what are viewed as psychiatric symptoms by the broader community. It suggests that more work need be done to assess what type of behaviour or symptoms are necessary before an Aboriginal person or their carer would consider abnormal to the point of possible illness. It speaks of an approach in the Aboriginal community that is less likely to label behaviours as abnormal and more likely to normalise or accept different or extreme behaviour.

The attribution of what might be thought of as mental distress, mental health problems, or illness does not however stop with the individual. Several authors (Bianchi, Cawte, & Kiloh, 1970; Reser, 1991; Vicary & Westerman, 2004) have documented that where Aboriginal people encounter distress or psychiatric symptoms, these may be attributed to a process or event outside of the person. There is no clear documentation outlining under which circumstances attributions shift from personality to external events. However it is likely that these will vary with the cultural group, recent events, and possibly the individual making the attribution or suffering the possible symptoms. Traditional Aboriginal culture is based upon traditions and spirituality that is by nature superstitious (Elkin, 1964) and which embraces a much less rigid distinction between the living and the dead, and between human, animal, and natural environment spirits. To this end Elkin (1964) has argued that traditional Aboriginal culture is best described as animistic and as such belief in sorcery and evil spirits are common. This relates to mental health whereby potential mental health symptoms may be attributed to

evil spirits, sorcery, or ancestors being angry. So strong is the belief in culture that it is not uncommon for Aboriginal people whom are suffering in some way (for example mentally) and where there is not another apparent reason, to believe they have offended their culture, had a curse put on them, or that the ancestors are angry with them (Reid & Trompf, 1991; Vicary & Westerman, 2004; Westerman, 2003). Other authors (Bianchi, Cawte, & Kiloh, 1970; Brown, 2001) have noted the powerful beliefs many Aboriginal people have around sorcerers and healers and how the power of these people is thought to be supernatural and can be used for good or evil. In this regard, what may be thought of as psychiatric symptoms in the traditional western sense can ensue when an Aboriginal person believes that they have been the target of a cultural event such as having the bone pointed at them or having been 'sung' (been the victim of a singing curse). So strong are these beliefs amongst some groups of Aboriginal people that several authors (Brown, 2001; Westerman, 2004) have argued that, where the belief of cause of illness is cultural, to deny a cultural cure (for example being offered a smoking ceremony or access to a healer) is to risk the continuation of the symptoms in the face of other treatments.

Even armed with knowledge of possible attributions, difficulties remain. A continual difficulty in discussing symptoms in Aboriginal mental health lies in the poor literature and data collection on established differences in type of symptoms and phenomenology of mental illness in the Aboriginal community. Much early data was collected in the 1960's and 1970's by ethno-psychiatrists who travelled to traditional communities in an attempt to gauge the cultural and mental health aspects of Aboriginal people relevant to psychiatry (Bianchi, Cawte, & Kiloh, 1970; Cawte, 1964; Jones, 1972; Kahn, Henry, & Cawte, 1976; Kiloh, 1975). These researchers proceeded initially upon an assumption that Aboriginal people had lower rates of mental illness than the broader community and in many cases were interested in the possible effects on mental health of retaining traditional culture or rapidly adopting or adapting to the broader western European culture (Bianchi, Cawte, & Kiloh, 1970; Cawte, 1964). These investigations highlighted

the lack of knowledge about the relationship between traditional culture and psychiatric symptoms. What became clear to these researchers, and remains important today, is that psychiatric diagnosis in the western sense is very difficult in the absence of sound cultural knowledge and experience. However they did note in their observations that both retention of traditional culture, and acquisition of western cultural patterns is not a significant causal factor in mental illness (Bianchi, Cawte, & Kiloh, 1970). Where the cultural distinction is important is in the assessment of symptoms where mental illness is suspected.

There is surprisingly little published on cultural phenomena that may be mistaken as psychiatric symptoms and symptoms that appear as culture. This is despite the very real danger of misdiagnosis and dire consequences as outlined in Royal Commissions (Burdekin, 1993; Johnston et al., 1991). The transcultural, or ethno-psychiatrists were amongst the first to call for a better understanding of Aboriginal culture before mental illness can be assessed or treated by non-Aboriginal people. Despite the passing of several decades there has been little unified or published progress on the difficulties of assessing or treating mental illness in Aboriginal people from a western psychiatric viewpoint.

One possible reason for this is the diversity of Aboriginal culture, whereby the experiences and phenomena of one group of Aboriginal people will be very different to another. Elkin (1964) in his anthropological study of Aboriginal people over 25 years, details much of the range of customs, beliefs, and mythology that differ across groups of Aboriginal people in many regions. Highlighted in this work are both the subtle and dramatic differences in mythology, spirituality, custom, and language that exist in groups who are geographically proximate. For example, neighbouring tribes of Aboriginal people may have different rules for the number and assigning of totems (based on membership to clans and the tribe's dreaming), or for what totems can be adopted (animals, features of the environment, or processes of nature such as weather) (Elkin, 1964).

Despite the diversity of Aboriginal culture, some identifiable cultural differences commonly appearing as symptoms to non-Aboriginal people have been documented (Bianchi, Cawte, & Kiloh, 1970; Brown, 2001; Reser, 1991). The most commonly noted of these are those associated with mythology and spirituality and may be mistaken for psychotic phenomena. These include thought content, and in particular beliefs. Aboriginal people may believe in possession, passivity phenomena, spells, or curses that can cause death (Sheldon, 2001). For example, early research in this field (Bianchi, Cawte, & Kiloh, 1970) with the Aboriginal people of Mornington Island in the Gulf of Carpentaria described such beliefs. This research demonstrated differences in the rates of belief in *malgri* and *puri-puri* between different Aboriginal ethnic groups on the island. Malgri is a traditional possession syndrome characterised by abdominal pain, distension, headache and drowsiness and is thought to occur after a breach of territorial rules. Puri-puri is a belief in sorcery involving poison and the likely experiences after such sorcery. Three different ethnic Aboriginal groups on the island believed, to different extents, in the capacity of both malgri and puri-puri to hurt people (Bianchi, Cawte, & Kiloh, 1970).

In comparison to non-Aboriginal culture, these may be perceived as illusory thinking, loose associations, or even delusions. Cultural experiences can be so transporting as to appear very similar to hallmark symptoms of psychotic disorders. It is accepted within cultural limits that hearing the voice of one's ancestors or even seeing spirits or family members is within the normal range of experience. It is possible that these experiences co-occur with psychiatric symptoms. However, it is important to note that not only are these experiences accepted within the community in which they occur as normal, but they are often viewed as healthy or indicative of a healthy spirituality.

Other authors (Sheldon, 2001; Vicary & Westerman, 2004) have outlined that Aboriginal people experience or perhaps express different mood states to that of the broader population. From the 'That's Just the Way he is' study, Vicary and

Westerman (2004) found that almost three out four Aboriginal people did not perceive depression as a state that could be addressed by treatment. A critical finding from this study was that the Aboriginal people surveyed reported that their view of mental illness shifted from characterological to pathological when the illness became visible, for example crying in public, or high risk behaviour (Vicary & Westerman, 2004). These findings raise many questions about how Aboriginal people perceive the difference between visible signs of psychiatric illness and internally experienced symptoms. It also raises questions about how Aboriginal people communicate internal moods and feelings and whether the display of certain emotions (crying for example) is viewed as abnormal. There is some distance to go before these issues are fully understood by non-Aboriginal people, and the possibility remains that the issues are complicated by regional and local differences in Aboriginal communities.

The difficulty in discerning culture from symptomatology is made more complex via the possibility of a reverse paradigm. Many culturally normal experiences may appear to others as psychiatric symptoms. However, what may be psychiatric (or physical) symptoms can also occur due to a belief in a cultural process. The attribution may not be such in Aboriginal communities, but there are numerous documented cases of Aboriginal people who have fallen ill (physically and psychologically) due to believing they have been cursed or affected by evil spirits or sorcery (Bianchi, Cawte, & Kiloh, 1970; Reser, 1991; Swan & Raphael, 1995; Vicary & Westerman, 2004). Thus it can be difficult to discern mental illness from cultural beliefs. Mental illness may cross-over with cultural beliefs, where beliefs are a focus of symptoms. Similarly cultural beliefs may invoke behaviours, distress, and even physical symptoms, akin to mental illness.

Aboriginal people are often said to receive messages from the land or features of the landscape (Brown, 2001).The land or 'my country' is a lexicon for a range of beliefs and experiences that may seem like symptoms to those not familiar with local culture. The land, or one's particular home region, is so central to many

Aboriginal people that some have argued for new disorders based on separation from it (Westerman, 2003). Such disorders validated within the Aboriginal community are often termed 'longing for country' or 'crying for, or, being sick for country' (Westerman, 2003). These disorders with complex symptomatology have in common the psychological distress borne of being separated from one's local region. However such syndromes are yet to be validated by agreement amongst those involved in Aboriginal mental health or the broader psychiatric community. Importantly, studies such as these raise the issue of culture-bound syndromes that represent the possibility of psychiatric illness unique to Aboriginal people. Amongst these are the phenomena of 'malgri' and 'puri-puri' described earlier (Bianchi, Cawte, & Kiloh, 1970). Important to note is that these authors did not view these phenomena as psychiatric in nature, despite their effects on the islander's physical and psychological health. The notion of any of the above experiences being psychiatric in nature is western European. As such, despite apparent distress and dysfunction, Aboriginal culture may view these experiences as entirely within the norm of cultural experience. Illustrated here is the complexity of what constitutes psychiatric illness amongst those who hold traditional beliefs.

Early research (Bianchi, Cawte, & Kiloh, 1970; Cawte, 1964; Kahn, Henry, & Cawte, 1976; Kiloh, 1975) concluded that it was not culture itself that provided an aetiological explanation for psychiatric illness amongst Aboriginal people. However, early Aboriginal mental health research has suggested disadvantage and social determinants that promote ill-health better account for observed symptoms than cultural beliefs and practices. To this end, Bianchi and colleagues (Bianchi, Cawte, & Kiloh, 1970) explored this relationship by correlating psychiatric symptoms with cultural identity. They compared the retention of traditional beliefs or adaptation to western culture with psychiatric symptoms. The findings suggest that mental health problems are better accounted for by social and interpersonal difficulties than cultural activities, interests, or aspirations (Bianchi, Cawte, & Kiloh, 1970).

It is unfortunate that in the time that has passed since this earlier research, little progress has been made in classifying the salient aspects of Aboriginal culture that may overlap with psychiatric illness. However, the constant theme from this research has remained that of the disadvantage, or the social determinants that impact upon the mental health of Aboriginal people (Australian Bureau of Statistics, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Tsey, Whiteside, Deemal, & Gibson, 2003). The findings from this early research may have inadvertently shifted the focus from phenomenology and the role of culture in symptoms to the social determinants of mental health. Despite the calls of these researchers for a better understanding of Aboriginal culture in order to better understand Aboriginal psychiatric illness (Bianchi, Cawte, & Kiloh, 1970; Cawte, 1964; Jones & Horne, 1972), social determinants come to the fore. The evidence from the lack of literature in Aboriginal psychiatric phenomenology suggests this may be the case. It may be that this has arisen due to the recognised relationship between social determinants, mental health, and the past experience in the Aboriginal community.

2.10 Aboriginal mental health and socio-political history

The past experiences of the Aboriginal community are another important difference between Aboriginal and non-Aboriginal mental health and one which continues to be highlighted in the mental health literature (Hunter, 1993, 1995; Swan & Raphael, 1995). Other factors beyond cultural differences make the mental health of Aboriginal people unique to that of the broader community. These factors associated with the socio-political history of Aboriginal people are important to acknowledge. They not only affect the mental health of individual Aboriginal people, but have had lasting negative impacts on the Aboriginal community. These factors are not associated with mental health alone but are an important factor in overall disadvantage to which mental health may be seen as a contributor.

The experiences Aboriginal people have been subjected to in the history of Australia since European colonisation cannot, and should not, be ignored in any examination of the current problems facing the Aboriginal community. Hunter (1993) outlines the way past Western Australian and Federal Governments dealt with Aboriginal affairs, including police entering Aboriginal communities and rounding up lepers and those suspected of mental illness. Other authors (Eckerman et al., 2006; Swan & Raphael, 1995; Westerman, 1997b) have outlined how past treatment of Aboriginal people has created the health and social problems so well documented today. Eckerman and colleagues (Eckerman et al., 2006) provide convincing arguments for how the abuses of the past and the differences in culture have lead to a dire situation today where Aboriginal people have much poorer living conditions and health, and much higher disadvantage than the non-Aboriginal community.

Almost every report on Aboriginal mental health, including the influential Ways Forward report (Swan & Raphael, 1995) has made reference to the increased rates of mental illness being directly linked to past abuses, and contributing to current disadvantage. It is important to consider dispossession from traditional lands, genocide, reduced human rights, and the stolen generations. Only in doing so can one gain an understanding of the suffering of Aboriginal people. This suffering is manifest in the extraordinarily high rates of trauma, grief, and loss (Swan & Raphael, 1995). Many have come to view the Aboriginal community as a traumatised people (Swan & Raphael, 1995). Past trauma and the concept of inter-generational trauma (National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004) has raised the idea that past suffering is being experienced by young Aboriginal people today as a direct result of the suffering of parents and older relatives.

Given the past, and current experiences faced by Aboriginal people it is perhaps not surprising that there are increased rates of mental illness in this community.

Many have argued (Eckerman et al., 2006; Hunter, 1993, 1995; Swan & Raphael, 1995) that past hurt has directly influenced current suffering and promoted disadvantage in the Aboriginal community. This has in turn increased the risk of mental health problems. Some have even gone so far as to argue that given these fertile conditions it is surprising the rates are not higher (Eckerman et al., 2006; Swan & Raphael, 1995).

The historical abuses of Aboriginal people have provided circumstances that have led to higher rates of mental illness. This history of Aboriginal people has led to a raft of illnesses that may be expected under such conditions. Those illnesses found in higher rates include depression, trauma, anxiety, and drug and alcohol abuse (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). However, illnesses that are not always thought of as being linked to identifiable historical social and political processes are a feature of the increased rates of mental illness in this community as well. One such illness is psychosis (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005).

2.11 Psychosis amongst Aboriginal people

There is an absence of comprehensive or conclusive data about the rates of psychosis in Aboriginal people. The available data demonstrate that rates of psychosis are higher in the Aboriginal population than the broader Australian population (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Jablensky et al., 2000). Perhaps the most reliable of this data is that of hospital separation data. Data from 2005 (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005) demonstrate that overall Aboriginal people were hospitalised at 1.5 times the rate of non-Aboriginal Australians for all mental disorders. The same data gives the rate of hospital admissions for ICD-10 schizophrenia, schizotypal, and delusional disorders amongst Aboriginal people as 2.4 times the rate (2.3 for males and 2.5 for

females) than for non-Aboriginal people. This data must be carefully interpreted, as it provides evidence of increased admissions, but not necessarily increased cases. This rate may reflect that Aboriginal people with schizophrenia and associated disorders require more admissions due to poor access to suitable community treatment resulting in increased relapses and more acute episodes. Several authors have suggested there is inadequate community treatment for Aboriginal people with mental illness (Hunter, 1995; National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; Roxbee & Wallace, 2003; Swan & Raphael, 1995). If this is the case, the admission rate, whilst not inaccurate, may be thought of as inflated due to structural problems rather than increased incidence of illness. Given the nature of chronic psychotic illness, including increased care, and more admissions, this is likely to be the case for Aboriginal people, who are acknowledged to have poorer community mental health care.

Other data have recorded that Aboriginal people are hospitalised at an average of 3.85 times (4.4 for men and 3.3 for women) the non-Aboriginal rate for disorders due to a psycho-active substance (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005). It is likely that a proportion of these admissions are for psychotic disorders or what will eventually be diagnosed as psychotic disorders. Interpreting this data is problematic however, as it does not yield the proportion for whom psychosis was present at admission, or for whom psychotic symptoms were present before admission, or after the effects of the substance had subsided.

Diagnosis of schizophrenia and associated disorders in Aboriginal people also presents problems for the accuracy of the published hospital admission rate. All diagnosis faces the problems of false positives (false cases, Type-I errors) and false negatives (undetected true cases, Type-II errors). Cultural differences between non-Aboriginal clinicians and Aboriginal patients in the diagnosis psychotic disorders increases the possibility of these errors. Non-Aboriginal

clinicians have been criticised for having inadequate cultural knowledge to accurately assess and diagnose Aboriginal people for mental illness (Johnston et al., 1991; Swan & Raphael, 1995; Westerman, 1997a). Whilst the possibility remains that the hospital admission rate has been inflated by false positives, research suggests that the likelihood is for false negatives in Aboriginal diagnosis (Burdekin, 1993; Johnston et al., 1991). Western Australian researchers (Mowry, Lennon, & De Felice, 1994) in a rare paper focussing on schizophrenia amongst Aboriginal people found, by retrospective case note analysis, that non-Aboriginal psychiatrists were less likely to diagnose schizophrenia in Aboriginal people than in non-Aboriginal people presenting with similar symptoms. If this finding is indicative of current diagnostic practices, it is likely that the admission rate of 2.4 times is artificially low.

A perhaps more robust way of determining the rate of psychosis is that of measured point-prevalence as used in the study on low prevalence disorders (Jablensky et al., 2000). This study attempted for the first time in Australia to estimate a one-month point prevalence of psychotic disorders across Australia. Included in the methodology was the recording of Aboriginal or Torres Strait Islander status. The findings gave a one-month point prevalence of psychosis in Australia of 4.7 per 1000 people (Jablensky et al., 2000). The study recorded 3.7% of the sample as being Aboriginal. This was contrasted with the (then) expected rate of 2.1% of the sample being Aboriginal in-line with the (then) population data for Aboriginal people. From this study, the point-prevalence of psychosis in Aboriginal people was 1.8 times higher than expected. In light of the hospital admission data this may not be surprising. Jablensky and colleagues' (Jablensky et al., 2000) study eliminated some of the problems of the admission data, including the chance of multiple admissions of the same patient. However, the methodology was not designed to estimate a point-prevalence of psychosis in Aboriginal people; resulting is some difficulty in interpreting the 1.8 times point prevalence finding. The paper yields little discussion of the Aboriginal rate beyond noting it. Identification of Aboriginal patients was from Aboriginal status

identification in medical records introducing the possibility of under-identification well documented in several reports (National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; Urbis Keys Young, 2001).

Published data suggests little doubt that Aboriginal people experience higher rates of psychosis than the previously assumed equal non-Aboriginal rate of recently shown as 4.7 per 1000. The most accurate estimate thus far for the Aboriginal community can be derived from this study and is 8.5 per 1000. Jablensky and colleagues (2000) argue the exact point-prevalence for the broader community is likely to be in the range of 4-7 per 1,000. Applying this methodology to the Aboriginal data, the exact point-prevalence is likely to be in the range of 7.2-12.6 per 1,000, if the collected data is representative of Aboriginal people with psychosis. Perhaps more important than the actual numerical rate, is the finding that psychosis in Aboriginal people is significantly higher.

There is as yet no published data attesting to why Aboriginal people suffer higher rates of psychosis. Aboriginal people have higher rates of almost all illness linked to disadvantage, including mental illness. It has been shown that higher rates of psychotic illness are found amongst those who are most disadvantaged (Drukker, Krabbendam, Driessen, & van Os, 2006; Garety & Rigg, 2001). However, there is not yet a specific mechanism, internal or external, identified to account for higher rates of psychosis in Aboriginal people. There is no evidence that there is a higher genetic risk for psychosis or other mental illness amongst Aboriginal people. Similarly, there is nothing to suggest that being Aboriginal in terms of culture or beliefs contributes to higher rates of psychosis or other mental illness (Bianchi, Cawte, & Kiloh, 1970; Reser, 1991). In the absence of a specific biological or psychological model accounting for the increased rates of psychosis amongst Aboriginal people, the available data must be utilised. The plentiful data on disadvantage in the Aboriginal community (Australian Bureau of Statistics,

2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Eckerman et al., 2006) suggests a risk-factor model may at present be the best way to account for the higher recorded rates of psychosis. A conceptual model illustrated in Figure 1 below suggests that each individual risk associated with psychosis may be thought of as contributing a separate proportionate risk to the advent of the illness. These factors are additive and together contribute to increasing any individual's risk for psychosis. The factors in this model are those which are associated with increased risk for psychosis for all individuals (Bebbington et al., 2004; Karlsen, Nazroo, McKenzie, Bhui, & Weich, 2005; King, Laplante, & Joober, 2005; Krstev, Jackson, & Maude, 1999; McDonald & Murray, 2000; Vauth & Nyberg, 2007; Verdoux, 2004; Wicks, Hjern, Gunnell, Lewis, & Dalman, 2005) and are also those that have been associated

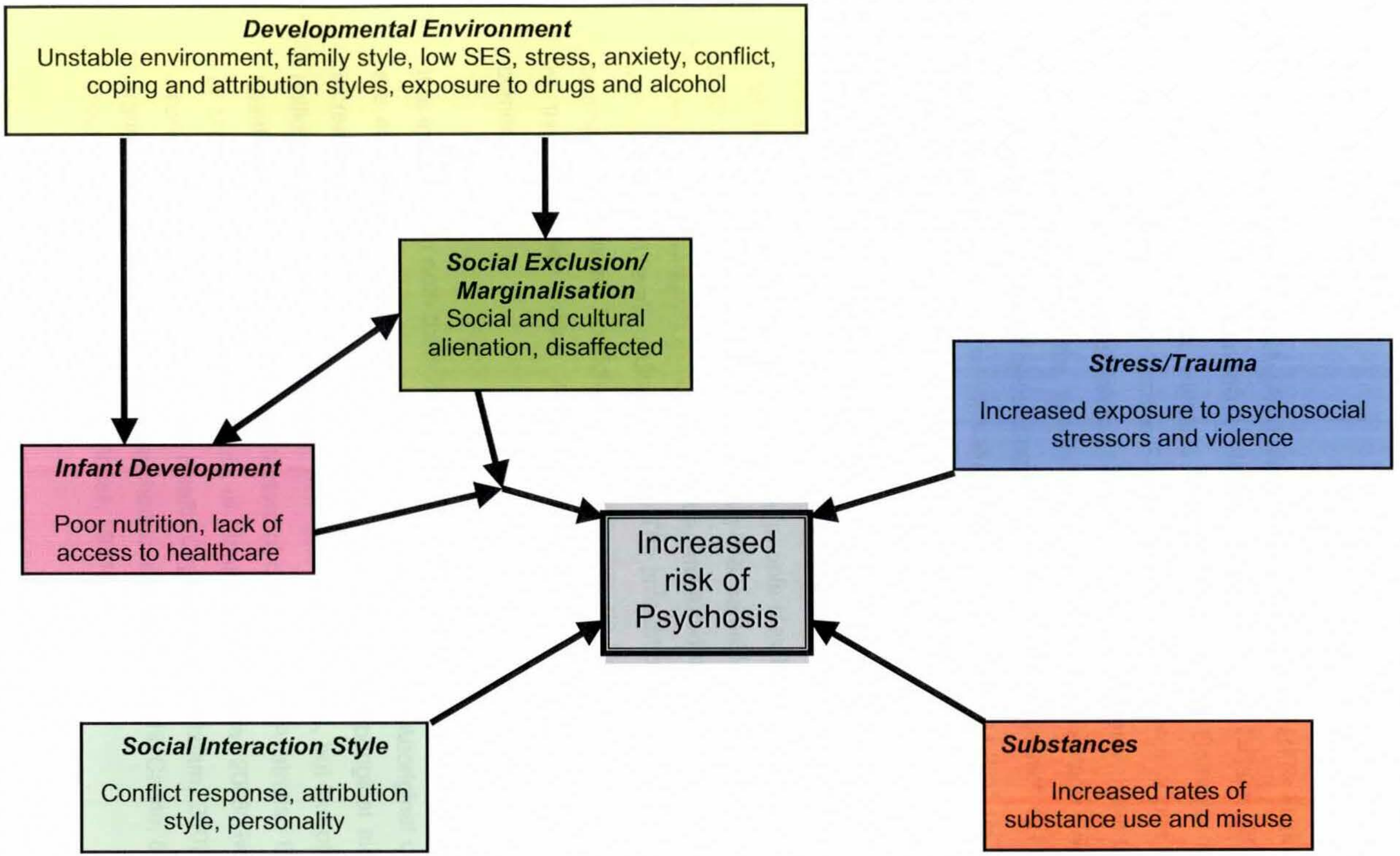

Figure 2 Conceptual model of increased risk for psychosis amongst Aboriginal people

with the Aboriginal community (Australian Bureau of Statistics, 2004; National Aboriginal Community Controlled Health Organisation & Oxfam, 2007; Patterson, Holman, English, Hulse, & Unwin, 1999; Steering Committee for the Review of Government Service Provision, 2005). In this way, a possible explanation for the increased rates of psychosis in the Aboriginal community is the increased rates of the factors associated with disadvantage. Whilst there is currently no way of calculating the proportionate risk for each of these factors, it is likely that the increased risk for Aboriginal people can be explained by the higher rates of several factors of disadvantage. It is important to note that it may well be that the risk for any individual with these factors is similar. However, the amount of, and severity of, these factors in the relatively small Aboriginal population may be driving the rates higher than the broader community. In this way Aboriginal people may have the same risk for psychosis as other Australians who have the same level of disadvantage. However, non-Aboriginal individuals will be measured in a much larger group with lower overall levels of disadvantage. The amount of disadvantage across several factors in the Aboriginal community may be the critical characteristic of this population which inflates figures above those of the broader community.

It is important to note there is no evidence to suggest that Aboriginal people are at a greater genetic risk for psychotic illness, nor that Aboriginal culture increases risk for psychosis or psychotic illness. Being Aboriginal alone is unlikely to be a specific aetiological risk factor for psychosis, but like physical health is likely to be mediated by factors of disadvantage (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; National Aboriginal Community Controlled Health Organisation & Oxfam, 2007) This argument is supported by ethno-psychiatric research (Bianchi, Cawte, & Kiloh, 1970; Hunter, 1995; Kiloh, 1975; Reser, 1991).

There are higher rates of almost all mental illness admissions in the Aboriginal community (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Australian Institute of Health and Welfare, 2005).

However, what might account for psychotic illness being the second highest mental illness rate, at 2.4 times the non-Aboriginal rate?

If one employs the diathesis-stress model, originally proposed by Zubin and Spring (1977) to account for the multiple causes of schizophrenia, three factors are needed for a transition to psychotic illness: biological predisposition, environmental factors, and specific psychological factors. There is nothing thus far to suggest that Aboriginal people compared to non-Aboriginal people have an increased inherent biological or differential genetic predisposition. Similarly there are no identified shared specific psychological factors (such as personality or coping style) to predispose to psychotic illness. Thus in applying this model to increased rates of Aboriginal psychotic illness the environment and individual psychological factors remain.

There is good evidence for the role of the environment in eliciting psychotic illness in those who are already at-risk from biological and psychological factors (Drukker, Krabbendam, Driessen, & van Os, 2006). The diathesis-stress model (Zubin & Spring, 1977) argues that the right combination of environmental factors will elicit psychosis in individuals from any culture with biological and psychological predispositions. Environmental factors such as increased levels of stress, trauma, and exposure to drugs and alcohol have been shown to be associated with the onset of psychosis (Neale & Oltmanns, 1980; Patterson, Holman, English, Hulse, & Unwin, 1999).

High levels of stress, trauma, and exposure to psycho-active drugs have been noted in the Aboriginal community (Australian Bureau of Statistics, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Swan & Raphael, 1995) from a young age (Blair, Zubrick, & Cox, 2005). Thus the inherent biological risk for psychosis may be the same as for non-Aboriginal community, but the necessary environmental factors are present in a sufficient quantity to inflate the rates of illness.

However, environmental risk factors alone are unlikely to be specific enough to account for transition to psychosis over other psychological pathology given

the diverse and shared nature of disadvantage. In the absence of shared specific psychological risk factors amongst Aboriginal people, it may be that individual personality markers, on a background of sufficient specific environmental factors, delineate the transition to psychosis over other pathology.

Whilst there is no conclusive evidence as to the psychological factors that predispose individuals to psychosis, there is evidence that pre-morbid personality is important (Hulbert, Jackson, & McGorry, 1996; Krstev, Jackson, & Maude, 1999; McGorry, Bell, Dudgeon, & Jackson, 1998). The pre-existence of personality disorders or withdrawn or detached personality style has been identified to increase risk (Hulbert, Jackson, & McGorry, 1996). Perhaps of more relevance to the Aboriginal community is the discussion by these authors (Hulbert, Jackson, & McGorry, 1996) that trauma may alter an individual's personality, promoting maladaptive personality traits, and making psychosis more likely. The high rates of stress and trauma in the Aboriginal community (Australian Bureau of Statistics, 2004; Swan & Raphael, 1995) may be a crucial factor in explaining the increased rates. Moreover, specific environmental disadvantage coupled with the above personality markers suggests a model for those Aboriginal people who are the greatest risk for psychosis and psychotic illness.

Highlighted above is how little is known about the reasons why Aboriginal people may be currently experiencing higher than expected rates of psychotic illness. Contributing to the lack of evidence of why Aboriginal people are at increased risk for psychosis is a lack of knowledge of how Aboriginal people experience psychosis.

2.12 Psychotic symptoms and cultural phenomena

Specific research on psychotic illness in Aboriginal people is limited. There is one published study of diagnosis of schizophrenia in Aboriginal people (Mowry, Lennon, & De Felice, 1994). This study used a retrospective case-

note analysis to compare diagnosis between a matched sample of Aboriginal and non-Aboriginal psychiatric patients. Findings suggest that significant differences existed in the diagnosis of Aboriginal patients with less likelihood of these patients being noted as having bizarre delusions, social deterioration, illness duration, or organic exclusion. The researchers acknowledge the inherent methodological difficulties with retrospective design but conclude that fewer Aboriginal patients received a comprehensive medical assessment and symptoms were interpreted differently based on culture (Mowry, Lennon, & De Felice, 1994). This paper raises important issues of Aboriginal people being less likely to share information on the history of illness. However, central to the issues of diagnosis of psychosis in Aboriginal people is the cultural differences that possibly overlap with psychiatric symptoms. Mowry and colleagues (1994) note that bizarre delusions pose a difficulty to diagnose for clinicians of the same culture as patients; unsurprisingly the difficulty increases where the cultures differ. Much of the available literature on psychosis in Aboriginal people alludes to cultural experiences that might be mistaken for psychotic symptoms.

Several authors (Bianchi, Cawte, & Kiloh, 1970; Brown, 2001; Mowry, Lennon, & De Felice, 1994; Parker & Milroy, 2003; Reser, 1991) have outlined phenomena experienced by Aboriginal people that may appear as psychotic symptoms. These include: belief in sorcery and curses; receiving messages from the land; visitations from spirits, passivity phenomena; distortions in time, magical thinking; hearing voices of relatives or ancestors; and having visions. These phenomena may be either an accepted cultural experience or a symptom of psychosis. The suggestion by several authors (Bianchi, Cawte, & Kiloh, 1970; Brown, 2001) is that the above represent common yet not uniform experiences of Aboriginal people. This increases the difficulty of delineating the cultural from the psychiatric where pathology is suspected. Additional difficulties exist in remote contexts (Hunter, 1993, 1995; Sheldon, 2001) and via differences in culture between proximal Aboriginal communities (Bianchi, Cawte, & Kiloh, 1970; Elkin, 1964). Brown (2001) has considered that visions and knowledge of magical powers is attributed to special Aboriginal elders and healers and that these phenomena are beyond our

present understanding. It remains possible that genuine psychiatric symptoms may be interpreted within a community as being special religious or spiritual powers or gifts. The converse is perhaps far more likely, where Aboriginal people accepted within their own communities as healers or spiritual figures are potentially viewed as symptomatic by psychiatric services. These issues are central to the catalogued problems between Aboriginal communities, non-Aboriginal governments, and psychiatric services (Burdekin, 1993; Hunter, 1993; Johnston et al., 1991; Westerman, 1997b) and there exists no definitive guide for the non-Aboriginal mental health clinician as to how to delineate culture from symptom. Some authors have suggested that this can only be successfully done in conjunction with members of the patient's community who possess adequate cultural knowledge (Kahn, Henry, & Cawte, 1976; Westerman, 1997a, 2004).

Perhaps it is the very differences between Aboriginal community clinicians and their non-Aboriginal counterparts that has resulted in little published upon how Aboriginal people themselves delineate between culture and psychiatric symptoms. Anecdotally a broad rubric employed by some involved with Aboriginal mental health is that of the implications following from the experienced phenomena. Where the phenomena promote an improvement in mood or positive action, then the experience is judged as likely to be cultural. Where the opposite is true then pathology is suspected. For example, an Aboriginal man may hear the voices of his ancestors telling him to spend more time with his children. This is positive and not out of step with broad cultural beliefs. Were the voices urging him to harm others the experience is likely to be viewed as pathological and perhaps symptomatic. This paradigm is not absolute and is complicated by the Aboriginal concept of mental health as well as attributions of illness. Clearly, the above raises yet more questions about the borders between Aboriginal cultural experiences and psychiatry. In particular questions exist of where particular cultural experiences begin to overlap with known psychotic symptoms.

A very real impediment to answering the question of why Aboriginal people experience higher rates of psychosis is the lack of a body of empirical

knowledge about psychosis in Aboriginal people. The lack of quality data on psychosis in Aboriginal people outlined above speaks to how restricted this field is. This lack of data has a pervasive effect. Firstly, it renders the data already collected on rates less interpretable. Questions abound surrounding how reliable current diagnoses are. Secondly, there exists little platform upon which to conduct research investigating phenomenology. In order to answer any of the questions above, and for research into Aboriginal psychosis to proceed, basic research is still needed.

2.13 Assessment issues in psychosis amongst Aboriginal people

The platform upon which basic research may proceed is that of increased knowledge of suitable assessment techniques. It has been noted that Aboriginal people are concerned that current psychiatric and diagnostic tools are inappropriate (Urbis Keys Young, 2001). Whilst this is not limited to assessment for psychosis, it is perhaps here that the risk of inappropriate assessment techniques is highest. The questions highlighted above of the accuracy of current collected data and potential differences in phenomenology await answers, which will be afforded only when there is sufficient evidence of how best to assess psychosis in Aboriginal people. These assertions are in concordance with the NH&MRC research road map for improving Aboriginal health (The Aboriginal and Torres Strait Islander Research Agenda Working Group, 2003), aiming to increase research with demonstrable outcomes. Suitable assessment methods for psychosis in Aboriginal people will allow for a reduction in false positives and false negatives, making the prevalence of psychotic illness amongst Aboriginal community clearer. Where suitable assessment methods can be identified such methods will allow exploration of the boundaries between the cultural experiences of Aboriginal people and pathological psychotic phenomena. It is therefore of paramount importance to identify suitable assessment methods for diagnosing psychosis amongst Aboriginal people. This is imperative if progress is to be made in reflecting more accurate prevalence rates and increasing knowledge of the phenomenology Aboriginal psychosis. Where progress has been made in

these endeavours worldwide (Cooper et al., 1972; World Health Organization, 1973) the method identified for this work has been the use of valid and reliable assessment tools. Assessment tools for psychosis allow for either accurate diagnosis of psychosis, or measurement of symptoms.

Chapter 3
Measurement of Psychosis in Aboriginal People

3.1 Measurement of psychosis

Measurement of psychosis is difficult for a number of reasons. The nature of psychosis does not allow for direct observation or measurement of symptoms (Neale & Oltmanns, 1980, p. 19). Enquiry into psychotic symptoms relies on measurement via subjective observation of external signs of illness, and subjective self-report of internally experienced symptoms. As both the signs and symptoms of psychosis are phenomenological in nature, objective measurement is necessarily limited. Where measurement is imposed upon signs and symptoms, further difficulties arise in selecting aspects of experience to measure. Amongst possible symptom dimensions to be measured are severity, intensity, frequency, duration, and disability. Such dimensions are relative, presenting difficulties for establishing baselines for measurement.

Current diagnostic systems such as the DSM-IV-TR (American Psychiatric Association, 2000) and the ICD-10 (World Health Organization, 1994) forestall the above difficulties via the use of a categorical approach to signs and symptoms; simply rating them as present or absent. These systems are intended primarily for use in diagnosing psychotic illness rather than for the measurement of psychotic mental states. Diagnoses are applicable where there is a threshold of present symptoms, with specific psychotic disorders diagnosed via the types of symptoms appearing together.

Several authors (Rosenman, Korten, Medway, & Evans, 2003; Van Os et al., 1999) have criticised this approach noting that it does not consider the dimensions of symptom severity, intensity, duration, or associated disability, thought important in the quantification of illness. A categorical approach does not provide for measurement of any aspects of symptoms resulting in an inability to quantify aspects of illness between or within patients. The bias

towards a presence of illness approach, whilst having the advantage of simplicity for diagnosis, is disadvantageous in assessing distance from threshold of illness or subsequent remission. Thus the quantification of symptoms is desirable for a number of reasons. Beyond allowing a different approach to diagnosis (Rosenman, Korten, Medway, & Evans, 2003), quantification yields additional information across a range of psychotic symptom dimensions. In particular, it allows for the objective observation of changes to a patient's condition. Dimensional assessment allows observation of improvement or decline in several areas, and also allows for a range of research questions to be answered. Importantly, it provides for better comparison of patient profiles between and within patients and diagnostic categories.

There now exist several standardised measures of psychotic symptoms that include a dimensional approach. Measures including the Brief Psychiatric Rating Scale (BPRS: Overall & Gorham, 1962), the Positive and Negative Symptoms Scale (PANSS: Kay, Fixtbein, & Opler, 1987), Scale for the Assessment of Positive Symptoms and Scale for the Assessment of Negative Symptoms (SAPS & SANS: Andreasen, 1982b; Andreasen, 1984), and the Diagnostic Interview for Psychosis (DIP: Castle et al., 2006), are noted to be useful in comprehensive assessment of psychotic disorders (Pratt & Mueser, 2002). These instruments offer quantified and standardised data across a broad range of signs and symptoms and provide clearer diagnostic information. Such measures can be used to assess aspects of psychosis between and within individuals, and contribute necessary data to studies of phenomenology and epidemiology. Research efforts in psychotic illness, particularly schizophrenia, over the past 40 years attest to the utility of such instruments in clinical and research realms (Neale & Oltmanns, 1980; Pratt & Mueser, 2002). Much of this utility rests upon the reliability of the information yielded across the range of patients, and the ability to quantify signs and symptoms. As with all psychological instruments the reliability of such measures is considerably reduced by any factors skewing results.

A difficulty affecting validity and reliability of dimensional measures, and one shared by current diagnostic systems, is that of culture (Dutta et al., 2007). Due to the development of current measures and diagnostic systems upon predominantly western European and American cultural norms, validity of measures when applied to other cultural groups is uncertain. Differences in culture have been demonstrated to have impact upon symptoms experienced (Arnold et al., 2004), the validity of diagnoses, and the way in which psychiatric assessment is conducted (Dutta et al., 2007).

Signs and symptoms of illness may be both experienced differently, or receive different interpretation based on cultural beliefs and practices. As such, there may be cultural experiences which appear as symptom-like or entirely different symptoms (Arnold et al., 2004; Dutta et al., 2007). The construction of current assessment and diagnostic tools upon parameters of western European and American culture does not allow for adequate flexibility for cultural differences in strict application. Administration by western interviewers highlights further possible difficulties. Differences in language and culture have been demonstrated to reduce the validity of assessment and diagnosis in other cultures particularly for schizophrenia (Dutta et al., 2007). Some have suggested that a dimensional approach to symptom assessment provides for greater flexibility, and thus may help to overcome the difficulties posed by cultural differences. (Dutta et al., 2007).

Research with American Indians has demonstrated the difficulty in applying current diagnostic criteria (Beals et al., 2004) to culturally distinct groups. This research has also highlighted the need to modify assessment instruments in order to make them culturally acceptable, and to better reflect understanding of mental health problems in this community (Beals, Manson, Mitchell, Spicer, & A1 SUPERPFP Team, 2003). Interestingly, this research opted to exclude modules assessing for psychosis due to concerns about the validity for assessing psychotic symptoms versus culturally accepted experiences. This exclusion is perhaps not surprising given the significant cultural differences between American Indians and the broader American population, and highlights the significant difficulties for measurement in this area. Psychosis

and psychotic illness are perhaps areas of psychiatric assessment that provide more scope for highlighting cultural differences, and thus reducing validity and reliability of assessment, than in other mental states or illnesses (Dutta et al., 2007).

Given the difficulties encountered above in applying current assessment methods for psychosis to other cultures, several questions remain. These include required modifications to assessment tools in order to make them valid and reliable for separate cultural groups. Such modifications pre-suppose questions remaining about the validity of syndromes themselves for separate cultural groups. Some have argued (Dutta et al., 2007) that the above difficulties highlight the importance of dimensional assessment for symptoms of psychotic illness. This is particularly the case where a difference in culture means there is no validation of diagnoses for the cultural group concerned. Here, dimensional assessment, whilst not free of limitations, potentially offers more meaningful and reliable information than that gained via categorical assessment (Dutta et al., 2007)

3.2 Measurement of psychosis in Aboriginal people

In the absence of data to the contrary, it is likely that the difficulties encountered in American Indian research above parallel with Aboriginal people (Beals, Manson, Mitchell, Spicer, & A1 SUPERPFP Team, 2003; Beals et al., 2004). Both peoples are similar in many ways, particularly: dispossession of land by Europeans; a cultural and spiritual mythology tied to the land; and current high rates of disadvantage. Aboriginal people regard themselves as a culturally distinct group from mainstream Australians (Eckerman et al., 2006; Reser, 1991), and have articulated a different concept of health and mental health (Swan & Raphael, 1995). Furthermore, concerns have been raised about the suitability of current psychiatric assessment techniques, and psychiatric diagnoses, for application to this community (Haswell-Elkins, Sebasio, Hunter, & Mar, 2008; Reser, 1991; Urbis Keys Young, 2001).

These questions stem from a lack of empirical evidence confirming that Aboriginal people experience psychotic symptoms corresponding to the syndromes present in the DSM-IV-TR (American Psychiatric Association, 2000) or ICD-10 (World Health Organization, 1994). Whilst there is acceptance that Aboriginal people experience common psychotic symptoms (Parker & Milroy, 2003; Reser, 1991) and common psychotic illnesses such as schizophrenia (Parker & Milroy, 2003; Swan & Raphael, 1995). There is not yet confirmatory research to suggest the phenomenology or psychotic syndromes experienced by Aboriginal people are the same as those accepted in the broader community via the use of diagnostic manuals.

Thus the emerging evidence that Aboriginal people experience higher rates of psychosis and psychotic illness is on a background of little empirical knowledge of what constitutes psychosis or psychotic illness in this group. Current diagnostic criteria are yet to be validated for this community and it remains possible that the criteria may not apply due to cultural differences. The available evidence has demonstrated differences in the diagnosis of schizophrenia in Aboriginal people by non-Aboriginal clinicians (Mowry, Lennon, & De Felice, 1994). This research such as this raises more questions about cultural relativity, or lack of cultural sensitivity in the cross cultural diagnosis of psychotic illness in Aboriginal people. An important remaining question is whether that Aboriginal people constitute a phenomenologically different sub-group in psychotic illness (Mowry, Lennon, & De Felice, 1994).

A possible way of beginning to answer these questions, and to allow for better interpretation of increased rates of psychosis, is through the use of standardised assessment tools for psychosis with Aboriginal people. Clinical and research use of these measures will yield phenomenological and epidemiological data currently not available and will also yield information assisting in the validation of diagnoses. However, a current impediment to the use of these instruments is a lack of data validating their use in the Aboriginal population.

Concern regarding the lack of validated measures and diagnoses has existed for some time (Burdekin, 1993; Haswell-Elkins, Sebasio, Hunter, & Mar, 2008; Johnston et al., 1991; Urbis Keys Young, 2001). Primary in this concern is that assessment tools may not be suitable for several reasons. Culturally different conceptions of illness, different attributions of symptom like experiences, different ways of communicating about symptoms, and a different phenomenology of symptoms all present difficulties upon which there is little or no data for Aboriginal people. Evidence from American Indian studies (Beals, Manson, Mitchell, Spicer, & A1 SUPERPFP Team, 2003) suggest that cultural differences are problematic for psychosis assessment tools, and instruments are unlikely to be valid in unmodified formats.

Undertaking to validate assessment tools for use with Aboriginal people, particularly by non-Aboriginal clinicians, can be achieved only after negotiating several likely impediments. At a fundamental level, Aboriginal people have a different concept of what constitutes mental health and its relation to overall health (Swan & Raphael, 1995). Thus any discussion of the experiences of Aboriginal people as possible mental health problems, including psychosis, must have parity with these concepts. Other authors (Vicary & Westerman, 2004) have suggested that attributions about what constitutes illness and what causes illness are different in the Aboriginal community. Thus what might be thought of as psychotic symptoms in the non-Aboriginal community are more likely to be attributed to personality (Vicary & Westerman, 2004), spiritual, or to mythological experiences (Bianchi, Cawte, & Kiloh, 1970; Brown, 2001; Reser, 1991). Thus discerning what may be thought of as symptoms of psychosis by non-Aboriginal clinicians is more difficult when they may be seen as normal experiences by Aboriginal people. These difficulties are as apparent for dimensional assessment methods as for others.

Symptom type presents other challenges. As discussed above, the literature provides some documentation of Aboriginal cultural experiences that may appear as positive psychotic symptoms. However, there has been less noted association between Aboriginal cultural experiences and negative psychotic

symptoms. Some authors (Vicary & Westerman, 2004; Westerman, 2004) have noted that Aboriginal people in extreme distress states may appear catatonic and not speak or make eye contact. In this vein there have been suspicions that a proportion of Aboriginal deaths in custody by suicide, may have been attributable to unrecognised psychosis (Johnston et al., 1991). It also remains possible that unrecognised psychosis plays a part in the high rates of overall Aboriginal suicide (Swan & Raphael, 1995).

Similarly there has been little evidence to date of the features of disorganisation or basic symptoms in Aboriginal patients. If Aboriginal people suffer the same broad psychotic symptoms and syndromes as non-Aboriginal people as suggested (Mowry, Lennon, & De Felice, 1994; Parker & Milroy, 2003), then it is to be expected that disorganised symptoms are present in similar proportions. However, differences in culture, language, education, and lifestyle represent significant difficulties for the rating of disorganisation and basic symptoms especially for non-Aboriginal clinicians. Mixtures of English and traditional languages, along with lower rates of educational attainment, and traditionally less structured lifestyles, introduce inherent bias into what may be considered disruptions to speech, behaviour, and neuro-cognitive functioning. This bias may serve to mask true basic or disorganised symptoms or conversely cultural differences may increase the chance that disorganisation or basic symptoms are rated as present.

The above difficulties are significant for categorical assessment or diagnostic systems. However there are added difficulties for dimensional measurement. Beyond the inherent difficulties of estimating severity and intensity, the measurement of frequency and duration of symptoms is potentially problematic in Aboriginal people. Janca and Bullen (2003) have argued that Aboriginal people have a different concept of time and one which is more circular than the linear concept in western cultures. The implications of such conceptual differences for measurement of psychotic symptoms is to be found where events considered to be more important are perceived to have happened more recently. Similarly, those less important may be rated as more distant. Thus symptoms potentially co-occurring may be rated as having

begun more recently or further in the past, dependent on perceived importance. Potentially this also affects the rating of severity and intensity, where the perception of the recency of any one symptom is mediated by relative importance.

The validation of dimensional assessment tools for psychosis and current diagnostic categories for psychotic illness in Aboriginal people is important for several reasons. The validation process aids in a better primary understanding of psychosis in this group, as well as improved assessment and diagnosis, improved treatment, and more accurate epidemiological information. Furthermore, the current lack of validated tools is an impediment to further research addressing important questions of treatment response and course of illness in Aboriginal people.

It is thus imperative that a suitable assessment instrument be validated for Aboriginal people. It is also important that such a validation be for an instrument that provides the highest utility for the current Aboriginal population. The recent published high rates of psychosis amongst the Aboriginal community (Australian Institute of Health and Welfare, 2005, 2006a; Jablensky et al., 2000) must be viewed alongside recent population data. Currently 40% of the current Aboriginal population is 15 years old or under meaning that in the next 10 years 40% of the current Aboriginal population will move through the period of highest incidence period for psychosis, the 15-29 years age range (Yung et al., 2005). Higher rates of psychosis and a significant proportion of this population entering the high incidence period suggest the possibility of an impending significant rise in the number of Aboriginal people suffering psychosis. If such a rise occurs, it will most likely comprise younger people experiencing a first episode of psychosis. High rates of disadvantage and drug use amongst those entering this phase of life support this likelihood (Australian Bureau of Statistics, 2004; Steering Committee for the Review of Government Service Provision, 2005). Therefore any assessment instrument for psychosis, validated for Aboriginal people, should necessarily include early psychosis assessment to be of the highest utility. Additionally, recent early psychosis assessment methods are

well placed to discern psychosis from a range of other emergent psychopathology.

3.3 Measurement of early psychosis

Crucial to the possibility of reducing psychotic illness burden is intervention early enough in illness course to reduce the Duration of Untreated Psychosis (DUP). The success of reducing DUP relies entirely upon identifying those individuals at-risk of incipient psychosis. Researchers in the EP field have achieved early identification via several methods. These methods include identifying those with high genetic risk (a first-degree relative with a psychotic illness) and employing multiple-gate screening and close-in methods (McGorry, Yung, & Phillips, 2003). Multiple-gate screening (Bell, 1992) involves targeting those individuals who have multiple risk factors, such as high genetic risk, sub-threshold psychotic symptoms, and a decline in functioning, rather than individuals with only one risk-factor. The 'close-in' strategy (Bell, 1992; McGorry, Yung, & Phillips, 2003) involves beginning follow-up of patients at the age of maximum incidence (16-29 years) and the shortening of follow-up periods to allow for better observation of the transition to psychosis. Whilst these methods have been demonstrated to be successful in identifying those who are at highest risk for psychosis (McGorry, Edwards, & Mihalopoulos, 1996; Yung et al., 2002) difficulties for this method remain. Firstly, multiple-gate and close-in strategies are associated with high rates of false-positives; individuals identified as high-risk who do not make the transition to psychosis. Secondly, in order to reduce false-positives, specific illness predictors are required.

Attempting to identify those at high risk for psychosis involves a more inclusive approach than the traditional so-called 'wait and see' paradigm (McGorry, 1999). High rates of false-positives (Type I errors) absorb resources and individuals may be harmed via being identified as at-risk for psychosis (McGorry, Yung, & Phillips, 2003). An acknowledged difficulty in delineating individuals who will transit to psychosis from those who will not is

the lack of criteria for entry into an ultra-high risk group (McGorry, Yung, & Phillips, 2003).

Progress has been made in reducing false-positives via research into predictors of transition to psychosis and the subsequent development of ultra-high risk criteria (Yung, Phillips, Yuen, & McGorry, 2004). Predictors include: poor functioning, long duration of symptoms, and high levels of depression and reduced attention (Yung, Phillips, Yuen, & McGorry, 2004). These, combined with: a family history of psychosis; significant recent decrease in functioning; and experience of sub-threshold symptoms, mark individuals as ultra-high risk (Yung et al., 2002). These researchers have employed an operational definition for the threshold of psychosis to serve as a risk end-point: "Essentially the definition of psychosis describes a clinical picture of frank delusions, hallucinations, or formal thought disorder present most of the time for at least one week" (Yung, Phillips, Yuen, & McGorry, 2004, p. 133). Further research has outlined a number of ultra high-risk categories, derived from predictive research. These categories are: attenuated psychosis group; brief limited intermittent psychotic symptoms group (BLIPS); and an ultra-high risk group (Yung, Phillips, Yuen, & McGorry, 2004; Yung et al., 2005). These three groups are defined by specific entry criteria used as inclusion criteria for ultra-high risk clinical services (Miller, McGlashan, Rosen, Cadenhead, Cannon et al., 2003; Yung, Phillips, Yuen, & McGorry, 2004).

The development of a working definition of psychosis for first-episode patients and the delineation of ultra-high risk groups with clear entry criteria marks significant progress in the EP field. In order for this progress to be utilised in fulfilling the aims of the EP paradigm, accurate measurement instruments quantifying sub-threshold symptomatology are required.

3.4 Measurement of at-risk mental states for psychosis

Several instruments quantifying aspects the psychotic prodrome now exist, including the Bonn Scale for the Assessment of Basic Symptoms (BSABS, Gross, Huber, Klosterkotter, & Linz, 1987) and the Structured Interview for Prodromal Symptoms (SIPS) and Scale Of Prodromal Symptoms (SOPS) (Miller, McGlashan, Rosen, Cadenhead, Cannon et al., 2003; Miller et al., 2002). These instruments have demonstrated utility in assessing a range of symptoms in the pre-psychotic prodrome. However, these instruments have reduced utility in clinical and research settings by either assessing only one symptom set, BSABS (Gross, Huber, Klosterkotter, & Linz, 1987), or failing to assess a full range of psychopathology, SIPS & SOPS (Miller, McGlashan, Rosen, Cadenhead, Cannon et al., 2003; Miller et al., 2002).

The Comprehensive Assessment of At-Risk Mental States (CAARMS) (Yung et al., 2003; Yung et al., 2005) is an Australian developed EP instrument assessing at-risk mental states for psychosis via semi-structured interview. The CAARMS contains the term 'at-risk mental state' rather than prodrome. Prodrome has been argued by some (Yung, 2003) to be a high risk concept via the implication of eventual transition to illness and is, in essence, a retrospective term. At-risk mental state for psychosis is preferred as it conveys risk but not certainty of the development of psychosis (Yung, 2003). The CAARMS assesses positive, negative, disorganised, and basic symptoms of psychosis to yield decision rules for entry into the three high-risk of psychosis groups above. Additionally this instrument, unlike more traditional measures of psychotic symptoms and other EP measures, assesses the broader range of psychopathology in recognition that individuals may transit to psychosis from symptoms of non-psychotic disorders.

The CAARMS contains operational criteria, based on the definition above, informing as to whether an individual is currently psychotic. Symptoms are assessed in detail using multiple questions for each symptoms group with each group assessed on dimensional axes of severity and frequency. These axes are in recognition of a multi-dimensional aspect to attenuated and

threshold psychotic symptoms theorised to be on a continuum with normal functioning. Duration of symptoms and association with substance use and stress are also assessed. The CAARMS represents an instrument with good psychometric properties of validity and reliability (Yung et al., 2005). It also represents significant progress in prodromal measurement over the Comprehensive Assessment of Symptoms and History (CASH, Andreasen, Flaum, & Arndt, 1992), Brief Psychiatric Rating Scale (BPRS, Overall & Gorham, 1962), and the notion of basic symptoms (Gross, Huber, Klosterkotter, & Linz, 1987; Huber, 1983; Huber & Gross, 1989) upon which it was developed. The CAARMS provides a topographical map upon which an individual's risk of, or actual transition to, psychosis can be observed over time. Thus the CAARMS, whilst invoking aspects of DSM-IV (American Psychiatric Association, 2000), provides an assessment method by which an individual can be identified as at incipient risk of psychosis and this risk can be measured. Furthermore, the CAARMS allows measurement repeatedly over time to assess for increased or decreased risk. In doing so, the CARRMS meets dual aims of providing high quality clinical information and allowing for high quality research data on precursors of transition to psychosis.

3.5 Measurement of at-risk mental states for psychosis in Aboriginal people

Despite the wide acceptance of the utility of the EP paradigm (Killackey & Yung, 2007; National Early Psychosis Project, 1998) there is no evidence to date about how such a paradigm might be applied to young Aboriginal people. Aboriginal people are worthy of the attention of EP services by way of increased rates of psychosis and a much younger median age (20.5 years vs 36.1 years, Australian Bureau of Statistics, 2004) of the Aboriginal population. Thus it is highly likely that a large proportion of this already at-risk population are now within, or about to enter, the peak incidence range for a first episode of psychosis (15-29 years), targeted by EP services. It is perhaps not

surprising that the EP paradigm has thus far not targeted Aboriginal people given the broader Aboriginal mental health context of reduced access to services and reduced empirical evidence about psychotic illness (The Aboriginal and Torres Strait Islander Research Agenda Working Group, 2003; Urbis Keys Young, 2001). Firmer evidence of an increased rate of psychosis amongst Aboriginal people is relatively recent (Jablensky et al., 2000) and not yet considered robust (Haswell-Elkins, Sebasio, Hunter, & Mar, 2008; Urbis Keys Young, 2001). There remains a very poor understanding of established psychotic illness in Aboriginal people (Mowry, Lennon, & De Felice, 1994; Reser, 1991; Swan & Raphael, 1995) by mainstream non-Aboriginal health services and researchers. Additionally, there are few, if any, specialist services for Aboriginal people suffering psychosis (Urbis Keys Young, 2001), resulting in reduced expertise in this area, and rendering systematic data collection difficult. This critical lack of data extends to uncertainty about the validity of diagnoses of psychotic illnesses and symptoms in Aboriginal people (Reser, 1991; Swan & Raphael, 1995). At a fundamental level there is no established or validated way of assessing or measuring psychosis in Aboriginal people. This appears a continual stumbling block for further research into Aboriginal psychosis. It is therefore not surprising there is a paralleled lack of established assessment methods for Aboriginal people in the EP paradigm. The lack of evidence of EP in Aboriginal people is a proliferation of the broader lack of evidence in established psychotic illness. There remains a serious lack of established knowledge and assessment methods for this illness in Aboriginal people providing little platform to establish an EP evidence base as has been amassed for the broader population. Yet compellingly, there is evidence of a significant increase in risk for psychosis and over half of the current Aboriginal population either in the peak incidence range or its cusp.

The advances in EP research and practice in the last 15 years has widened the gap in knowledge of Aboriginal psychosis rather than narrowed it. Beyond the pre-existing questions of whether current diagnoses and assessment methods are suitable for Aboriginal people are now a series of questions EP

is answering for the broader population but has not addressed to Aboriginal people.

Important questions included in this series are: do young Aboriginal people have a different phenomenology of illness mediated by prodromal differences?; is the length and course of the prodrome significantly different in this group, requiring different approaches to intervention?; and is it possible to reduce DUP in young Aboriginal people to the same effect? The EP paradigm, due in part to the advances in knowledge and measurement, is perhaps best placed to begin answering many of the questions left unexplored by research about psychotic illness in Aboriginal people by focussing on emergent illness. A fundamental step in answering these questions is the validation of assessment methods for EP in Aboriginal people. Such validation provides a platform upon which more detailed research may be carried out to answer the above questions.

The CARRMS provides a possible method to begin to answer these important questions. To this end, the CAARMS has several important advantages over other possible instruments. These include development in an Australian context and psychometric properties derived from the broader Australian population, plus the ability to map small changes in mental state over time. As it is not yet clear what exact role culture plays in the onset and phenomenology of early psychosis, sensitivity of measurement is crucial. The CAARMS has demonstrated sensitivity to change and good predictive validity (Yung et al., 2005). Whilst it is not known if current instruments have the ability to detect at-risk mental states for psychosis in young Aboriginal people, at least un-modified, the CAARMS represents the best available instrument for such a validation. The validation process of the CAARMS for use with young Aboriginal people will yield significant data about the suitability current assessment methods and what modifications may be required to make instruments more culturally sensitive and suitable. Furthermore, the validation of the CAARMS allows for further investigation into important questions such as whether young Aboriginal people at ultra high-risk of psychosis fall into established categories,such as attenuated psychosis and BLIPS (Yung,

Phillips, Yuen, & McGorry, 2004; Yung et al., 2002). With many of these questions answered, the overdue process of thoroughly investigating the similarities and differences between Aboriginal and non-Aboriginal Australians in psychotic illness may begin.

3.6 Summary

Psychotic illness is a common distressing and disabling condition of enormous personal cost to sufferers and their families. Psychotic illness is also of significant cost to society and represents a large proportion of expenditure in mental health and overall health budgets. Research has demonstrated that those who are disadvantaged are not only at higher risk for psychosis but have worse outcomes from psychotic illness when it occurs. The conceptual framework underpinning these findings is the stress-diathesis model. This model suggests that a combination of biological predisposition and a threshold of environmental stress elicit illness. Current standard treatments for psychosis have failed to reduce a significant proportion of the illness burden borne by sufferers.

A paradigm shift in the last 15 years to an early identification and intervention framework in psychotic illness has demonstrated that a reduction of illness burden is possible. The early psychosis approach has highlighted the importance of reducing the duration of untreated Psychosis (DUP) and intervening in the psychotic prodrome as critical to achieving illness reduction or prevention. EP research and practice has demonstrated that it is possible to identify and intervene in those individuals experiencing the first changes to mental state that render them at-risk for psychosis. EP research has also reinforced disadvantage as being of primary importance in identifying those who are at-risk for psychosis.

Aboriginal people are the most disadvantaged group in Australia across all indicators. They have higher rates of almost all mental illness and have been demonstrated to have a higher prevalence of psychotic illness than other

groups. A conceptual model based on the framework of the stress-diathesis model attributes this to the presence of significantly increased levels of disadvantage in this community.

Aboriginal people's mental health is different to that of other Australian's due to cultural differences, a unique socio-political history, and hidden disadvantage. Aboriginal culture contains unique elements that can appear as psychotic-like symptoms causing difficulties in assessment, diagnosis, and treatment. Despite increased risk and prevalence, little research effort has been expended into understanding or investigating psychosis in Aboriginal people. A leading cause and compounding factor has been the lack of psychosis assessment tools validation for this group.

EP has recently provided assessment tools for the early identification of pre-cursor psychotic illness. The CAARMS is an Australian assessment tool validated for identifying those with at-risk mental states for psychosis. It is not currently known if this instrument is valid for use with young Aboriginal people. A combination of the increased risk for psychosis in the Aboriginal community, and the very young median age of this community, makes the identification of accurate assessment methods for early psychosis important. The validation of the CAARMS for use with young Aboriginal people will provide a platform for further research into effective assessment methods for early psychosis in this community and for broader research into Aboriginal psychosis

3.7 Aims and hypotheses

Based on the above review of the literature the aims of this study were:

(a) To investigate whether young Aboriginal people can be effectively assessed for at-risk mental states using existing psychometric measures, notably the CAARMS

(b) To examine aspects of the phenomenology of EP in young Aboriginal people compared to young non-Aboriginal people

The specific hypotheses generated to be tested were:

I. That the CAARMS will be able to detect young Aboriginal people with at-risk mental states for psychosis

II. That the aspects of the phenomenology of EP in young Aboriginal people will be equivalent compared to young non-Aboriginal people

Chapter 4
Method

4.1 Participants

The study included four sub-samples: (1) Aboriginal people with a history of psychosis, (2) Aboriginal people without a history of psychosis (healthy controls), (3) non-Aboriginal people with a history of psychosis, and (4) non-Aboriginal people without a history of psychosis (healthy controls). Participants were drawn from a NSW prison, early psychosis services, educational facilities, and community populations.

The total sample was comprised of 81 participants, 65 males (80.2%) and 16 females (19.2%). The mean age was 22.27 years (SD = 2.6 years), male 22.46 years (SD = 2.72 years), and female 21.5 yrs, (SD= 1.89 years). There were significantly more males in the sample (x^2 = 29.642, df = 1, $p < 0.001$) however, a one-way ANOVA revealed no significant difference between the age of the male and female participants ($F_{(1,79)} = 1.776$, p=0.187).
The proportion of participants from recruitment sources by group is outlined in table 2.

Table 2
Number and proportion of participants recruited from each source

	Recruitment location (%)			
Group	Prison	Community	Educational	Early Psychosis Service
Aboriginal-psychotic	20 (100)	-	-	-
Aboriginal-healthy	10 (50)	4 (20)	6 (30)	-
Non-Aboriginal psychotic	13 (62)	-	-	8 (38)
Non-Aboriginal healthy	6 (30)	14 (70)	-	-

(1) Group 1 Aboriginal people with a diagnosed psychotic illness

This group contained 20 participants drawn from the NSW Department of Corrective Services Metropolitan Reception and Remand Centre (MRRC) in Sydney. The MRRC was chosen due to the presence of a Mental Health Screening Unit (MHSU), which screens approximately 75% of new receptions to NSW prisons for mental health problems.

In the 7 months between 1st January, 2007 and 31st July, 2007, NSW prisons received 336 Aboriginal prisoners (260 male, 76 female) aged 25 years or under, that is 27% of all NSW prison receptions. Of these prisoners, 47 were recorded as having psychotic illness, representing 14% of the Aboriginal prisoners (13% for males and 17% for females) received (Owens, D. & Soei, L., personal communication, January 31, 2008).

Aboriginal participants with psychotic illness were approached to participate by Justice Health staff, who gave each participant a Participant Information Sheet. Participants indicating they were interested in participating were then invited to a research interview. These participants were interviewed in the MHSU (if they were current in-patients), or in a dedicated mental health cell block.

Of these participants, 16 were MHSU inpatients and 4 were housed in a mental health cell block. Forty-seven prisoners met eligibility criteria for this group and 25 were invited to participate. Five prisoners refused to participate, resulting in a response rate of 80% of participants for this sub-sample who were eligible and invited to take part in the study.

There were 16 males and 4 females in this sub-sample. The mean age of the total sub-sample was 23.7 years (SD= 2.8 years, range 19-31 years). There was no gender difference in age (males = 23.75 years, SD = 3.04; females = 23.5 years, SD = 1.73).

(2) Group 2 Aboriginal people without a history of psychosis (healthy controls)

This group contained 20 participants drawn from the MRRC, metropolitan Aboriginal community and educational facilities.

In the 7 months between 1st January, 2007 and 31st July, 2007, NSW prisons received 289 Aboriginal prisoners (226 males and 63 females) who were listed as not suffering psychotic illness, or 86% of all Aboriginal prisoners

received (Owens, D. & Soei, L., personal communication, January 31, 2008). From previous prison statistics (Butler & Allnutt, 2003), estimates suggest that Aboriginal people make up around 22% of all prisoners (both sentenced and non-sentenced), and the whole prison population has a 12-month prevalence for any psychiatric illness of 74%. Therefore 26% of all Aboriginal receptions or 87 prisoners would be expected to arrive in the 7-month period and suffer no psychiatric illness within a stipulated 12-month period.

Healthy Aboriginal participants drawn from the MRRC were recruited as above. Participants drawn from the metropolitan Aboriginal community and educational facilities were approached by either an Aboriginal mental health worker, or Aboriginal academic, and given a Participant Information Sheet. If they indicated interest in the study they were then contacted by phone and an interview arranged at the university.

There were 20 healthy Aboriginal control participants in this sub-sample. Ten participants were recruited from the same MRRC prison population as above, four participants from metropolitan Aboriginal communities and six participants from educational facilities.

Two-hundred and twenty nine Aboriginal prisoners were eligible potential participants for this sub-sample. Eighteen prisoners were identified by Justice Health and Department of Corrective Service's staff as eligible and were invited to participate. Eight eligible participants refused. The response rate for the prisoners in this sub-sample was 55% of identified healthy Aboriginal prisoners. There were 60 eligible participants from educational facilities and educational staff selected 6 eligible participants who were invited to participate. All healthy Aboriginal people between 18 and 25 years from Sydney Aboriginal communities were eligible for the study, and 4 who were personally known to Aboriginal health workers (but not patients) were selected and invited to participate. No participants refused from educational facilities or Aboriginal communities.

There were 15 males and 5 females in this sub-sample. The mean age of the total sub-sample was 21.8 years, (SD= 2.78 yrs, range 18-29 yrs). There was no gender difference in age (males = 22.4 yrs, SD=2.92; females = 20 yrs, SD= 1.22).

(3) Group 3 non-Aboriginal people with a diagnosed psychotic illness

This group contained 21 participants drawn from the MRRC and from the Psychosis in Young People service (PIYP), Northern Sydney and Central Coast Area Health (NSCCAHS).

In the 7 months between 1st January, 2007 and 31st July, 2007 NSW prisons received 92 non-Aboriginal prisoners (65 males & 27 females) 25 years or under who were recorded as suffering psychotic illness (Owens, D. & Soei, L., personal communication, January 31, 2008). These prisoners represented 10% of non-Aboriginal receptions.

The Psychosis in Young People (PIYP) service (one of the four early psychosis services in the Sydney sector of the Northern Sydney Central Coast Area Health Services) had an intake of 35 new early psychosis patients between the beginning of January and end of December, 2007. In the same period the service had a patient load of 63 patients (Beverley Moss, NSCCAHS, personal communication, February 18, 2008) all of whom are aged between 18 and 30 years, and referred from psychiatry units, general hospitals and community services (Darrel Hannam, PIYP, personal communication, February 13, 2008).

Twelve participants in this group were prisoners and were recruited from the MRRC as above. Of the 12 prisoners, 9 were inpatients of the MRRC's Mental Health Screening Unit, and 3 were housed in a special mental health cell block.

The remaining nine participants were PIYP early psychosis patients living in the community. These participants were recruited via an approach made by

early psychosis treatment intervention staff and where participants indicated interest in the study they were then contacted by phone and an interview arranged at their home or the university.

Thirteen participants who were prisoners were invited to participate in the study and one refused resulting in a response rate of 92% of invited non-Aboriginal prisoners with psychotic illness in this sub-sample.

Eleven participants who were patients of PIYP were invited to participate and two refused, resulting in a response rate of 82% for non-Aboriginal PIYP patients in this sub-sample.

There were 20 males and 1 female in this sub-sample. The mean age of the total sub-sample was 22.57 years, (SD = 2.29 years, range 19-26 years). There was no gender difference in age (males = 22.6 years, SD = 2.35; females = 22 years).

(4) Group 4 non-aboriginal people without a history of psychosis (healthy controls)

This group contained 20 participants drawn from the MRRC and the general community. Six participants were prisoners and 14 were living in the community.

In the 7 months between 1st January, 2007 and 31st July, 2007, NSW prisons received 895 prisoners (771 male and 124 female), 803 of which were recorded as not suffering psychosis (706 males & 97 females) or 90% on non-Aboriginal receptions (Owens, D. & Soei, L., personal communication, January 31, 2008). From previous prison studies (Butler & Allnutt, 2003) estimates suggest that the 12-month prevalence of any psychiatric disorder in the NSW prison population is 74%. Thus 26% of the 895 non-Aboriginal prisoners received in this period, or 233 prisoners would be expected to suffer no psychiatric illness in a 12-month period.

All prisoners were recruited as above and were interviewed in their normal cell-block or a prison workshop. The remaining 14 participants were drawn from community sporting teams and were given a Participant Information Sheet by their coach or team-mate. Where they indicated interest in the study they were then contacted by phone and an interview arranged at their home or the university.

There were 233 potential participants in NSW prisons at the time of the study and 7 healthy non-Aboriginal prisoners were invited to participate. One prisoner refused resulting in a response rate of 86% for prisoners in this sub-sample.

All healthy non-Aboriginal people 18-25 years from Sydney who played a sport were eligible to participate in the study and 14 people were invited to participate. No healthy non-Aboriginal participants refused.

There were 14 males and 6 females in this sub-sample. The mean age of the total sub-sample was 21 years, (SD = 1.77 years, range 18-24 years). There was no gender difference in age (males = 20.86 yrs, SD = 1.92; females = 21.33 years, SD = 1.51).

A One-way ANOVA revealed a significant age differences between the four samples ($F_{(3,77)} = 4.43$, $p = 0.006$). The Aboriginal with psychosis group was significantly older than the non-Aboriginal healthy control group, but not the other groups. There were no differences in age between the other groups. However, as the standard deviations of both the Aboriginal with psychosis (SD = 2.79) and non-Aboriginal healthy control groups (SD = 1.77) was relatively small; consequently it was considered that the age difference of 2.7 years, while statistically significantly different, have little clinical significance. All group means for age were under 25 years.

4.2 Psychological instruments

4.2.1 Demographics questionnaire

Participants were required to complete a one-page demographic questionnaire (see Appendix A) designed to yield data on age, marital status, highest level of education attained, current occupation, chronic health data, personal and family mental health, and Aboriginal status. Aboriginal status was assessed by asking participants if they identify as being an Aboriginal person (yes/no). This way of assessing Aboriginal status differs slightly from the current question used by the Australian Bureau of Statistics: "*Are you of Aboriginal or Torres Strait Islander origin?* (Australian Bureau of Statistics, 2004; Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005) The question asked by the demographics questionnaire; *"Do you identify as being an Aboriginal person?"* is closer to the accepted meaning of an Aboriginal or Torres Strait Islander person set out by the Health Data Standards Committee (2006, p. 820)*: "An Aboriginal and Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives".* Furthermore, the question included in the demographics questionnaire precludes the possibility of participants who have Aboriginal heritage but do not culturally identify as an Aboriginal person. As culture was seen as an important distinction for this study, two further questions about Aboriginality were asked: *'Did you grow up in an Aboriginal family?' (Yes/No);* and *'Did you grow up having contact with an Aboriginal community?' (Yes/No).* These questions provided basic data on the levels of contact with Aboriginal culture, amongst identifying participants. As participants were relatively young (Aboriginal mean age = 22.75 years, SD =2.92 years) family and community contact during development were considered important aspects of cultural identification.

4.2.2 The Comprehensive Assessment of At-Risk Mental States (CAARMS)

The CAARMS (Yung et al., 2003; Yung et al., 2005) is a semi-structured interview designed to be used by mental health clinicians to assess a broad range of emergent psychopathology. Specifically, the CAARMS was designed to detect and measure those early psychotic features which place individuals at-risk of transition to psychotic illness. The CAARMS includes seven subscales: disorders of thought content; perceptual abnormalities; conceptual disorganisation; motor changes; concentration and attention; emotion and affect; subjectively impaired energy; and impaired tolerance to normal stress. Each section of the seven sub-scales is scored for symptom severity (anchor points 0 = never to 6 = extreme) date of symptoms onset and offset, frequency and duration of symptoms (anchor points 0 = absent to 6 = continuous), and for symptom association with either substance use or stress. Questions are provided as prompts for gathering symptom information. Severity, frequency and intensity, of symptoms are rated on a Likert scale.

Scores on the first three subscales of the CAARMS (disorders of thought, perceptual abnormalities and conceptual disorganisation) form the basis for CAARMS decision rules as to whether respondents are eligible for entry into the ultra high-risk groups categorising those with the highest risk of transition to psychosis. These categories are: the vulnerability group; the attenuated psychosis group; or the brief limited intermittent psychotic symptoms (BLIPS) group. These subscales also form the basis for decision as to whether a respondent is currently psychotic. The remaining twenty-six sub-scales assess: basic symptoms including motor changes and concentration and attention; general psychopathology including emotion and affect; and impaired tolerance to stress. The CAARMS includes subscale sections for suicidal and aggressive behaviour and these are included in a break-blind decision rule (indicated treatment with anti-psychotic medication or psychiatric admission) for patients at risk to themselves or others.

The CAARMS has been demonstrated to have adequate psychometric properties including good discriminant validity (between ultra high-risk patients

and healthy controls), concurrent validity, predictive validity (for which patients will make the transition to psychosis), and inter-rater reliability (intra-class correlation co-efficient = 0.85) (Yung et al., 2005). The CAARMS has a sensitivity of 0.83, specificity of 0.74, a positive predictive value of 0.12, and a negative predictive value of 0.99 (Yung et al., 2005).

For overall CAARMS scores UHR patients achieve a mean of 2.08 (SD = 0.92) and healthy controls 0.29 (SD = 0.38) demonstrating a large expected difference between UHR individuals and healthy respondents.The January, 2002, monthly version of the CAARMS was used in this study (see Appendix B).

4.2.3 The Brief Psychiatric Rating Scale (BPRS)

The BPRS (Overall & Gorham, 1962) was developed to be a clinically efficient rapid evaluation procedure for assessing symptom change in psychiatric patients. The BPRS is an 18-item semi-structured interview scored on an 8-point likert scale (anchor points 0 = not assessed to 7 = extremely severe). The expanded BPRS (Lukoff, Nuechterlein, & Ventura, 1986) added six additional sub-scales to improve comprehensiveness of the measure for a broader range of patients. The expanded version of the BPRS includes 14 items rated on respondent self-report: somatic concern; anxiety; depression; suicidality; guilt; hostility; elevated mood; grandiosity; suspiciousness; hallucinations; unusual thought content; bizarre behaviour; self-neglect; and disorientation. A further 10 items are rated based on the clinician observed behaviour of the respondent: conceptual disorganisation; blunted affect; emotional withdrawal; motor retardation; tension; uncooperativeness; excitement; distractibility; motor hyperactivity; and mannerisms and posturing. These 24 items are all scored on an 8-point Likert scale (anchor points 0 = not assessed to 7 = extremely severe).

The expanded BPRS has been demonstrated to have good psychometric properties including test re-test and inter-rater reliability (Crippa, Sanches,

Hallak, Loureiro, & Zuardi, 2001) and content, construct, and criterion validity (Catts, 2001; Mueser, Curran, & McHugo, 1997). It is also reported to be sensitive to change (Catts, 2001) and has been widely used in psychiatric research assessing symptoms in schizophrenia (Pratt & Mueser, 2002).

The expanded version of the BPRS, whilst suggested as a semi-structured interview, does not provide specific questions. However, reliability of the BPRS has been shown to increase by using a structured interview guide (Crippa, Sanches, Hallak, Loureiro, & Zuardi, 2001). This study used the expanded BPRS, version 4.0 (Ventura et al., 1993) and included all questions suggested in the manual as prompts for the semi-structured interview (see Appendix C).

4.2.4 The Opiate Treatment Index Recent Drug Use (OTI-R)

The Opiate Treatment Index (OTI, Darke, Ward, Hall, Heather, & Wodak, 1991) is a drug and alcohol measure designed for clinical and research purposes to measure treatment response in drug and alcohol patients. The OTI includes sub-scales assessing: drug use; HIV risk taking behaviour; social functioning; criminality; health status; and psychological adjustment.

The Opiate Treatment Index- Recent Drug Use (OTI-R) is the recent drug use component of the OTI, omitting other OTI sub-scales. The OTI-R assesses the use of 10 classes of drug: heroin; other opioids; alcohol; cannabis; amphetamines; cocaine; tranquilisers; hallucinogens, inhalants; and tobacco. Each class of drug is assessed by asking respondents to name the three most recent sequential occasions of drug use and the amounts on the two most recent occasions. Recent drug use is assessed in the past four weeks immediately prior to interview. Both drug amount scores are added and averaged, then divided by the average of the two periods of time between uses (the two periods between the three last uses). This yields a Q-score for each drug class, the Q representing an index of the amount of a drug used

over time. The number of classes used in the preceding four weeks are added together to yield a poly-drug score.

The OTI-R has been demonstrated to have good psychometric properties (Darke, Hall, Wodak, Heather, & Ward, 1992) including good test re-test and inter-rater reliability (test-re-test all alpha coefficients > 0.86, inter-rater: all alpha's > 0.81) and validity (all R's > 0.43). Further research (Deering & Sellman, 1996) has confirmed the inter-rater reliability and the general utility of the OTI-R for assessment of drug and alcohol use in these patients.

This study used the OTI-R to assess participant's level of drug and alcohol use in the four weeks preceding interview. Where participants were prison inmates, and therefore restricted from accessing drugs and alcohol, they were asked about drug and alcohol use in the four weeks immediately prior to imprisonment. The OTI-R is included at Appendix D.

4.2.5 The Alcohol Use Disorder Identification Test (AUDIT)

The AUDIT (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993) is a 10-item instrument that can be completed by respondents alone or used as a structured interview. The AUDIT (see Appendix E) was designed as a brief screening measure to detect problem drinking and to quantify alcohol use at a much lower threshold than alcohol dependence; dependence threshold representing an identified problem with past measures. The instrument was derived from the World Health Organisation six country Alcohol Dependence Study (including Australia, Saunders & Aasland, 1987) with the intention that it be suitable for use with a range of cultures.

The AUDIT items are all scored between 0 - 4. The Audit yields a total score between 0 - 40 with a clinical cut-off of 8 and above indicating a strong likelihood of hazardous or harmful alcohol consumption (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993).

The instrument has been shown to have good psychometric properties including reliability (Cronbach's alpha for all items > 0.80), sensitivity (overall sensitivity for hazardous and harmful alcohol use = 92%), specificity (overall value = 94%) (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993). Validity of the instrument, determined among reference groups of known alcoholics is high, with 99% of Alcoholic respondents returning a score of 8 (the clinical cut-off) or more.

The AUDIT has been widely used in Australia although some researchers have adopted a slightly modified form, the AusAUDIT (Conigrave & Elvy, 1998). The AusAUDIT altered the weighting of the first two questions to comply with NH&MRC hazardous drinking standards and removed the word 'relative' from the last question; complaints about respondents drinking. Validity data is not available on the AusAUDIT (Degenhardt, Conigrave, Wutzke, & Saunders, 2001), however the obtained psychometric properties of the AusAudit demonstrated reduced specificity on the original scale. The present study used the original AUDIT (Saunders, Aasland, Babor, de la Fuente, & Grant, 1993) as it's purpose was intended to be as a clinical screen (rather than to comply with NH&MRC cut-offs) and to retain the original psychometric properties including the high specificity of the scale.

4.2.6 The Social and Occupational Functioning Scale (SOFAS)

The SOFAS (Goldman, Skodol, & Lave, 1992) (see Appendix F) is a clinician-rated global assessment of an individual's social and occupational functioning, rated out of 100, and is included in the DSM-IV (American Psychiatric Association, 2000). The SOFAS was developed from the Global Assessment Scale (GAS, Endicott, Spitzer, Fleiss, & Cohen, 1976), which in turn was modified to become the Global Assessment of Functioning (GAF, American Psychiatric Association, 2000) currently used in DSM-IV. The SOFAS is intended to focus global assessment on current or past social and occupational functioning, removing the influence of an individual's current or past psychological symptoms. Social and occupational functioning was

separated from psychological functioning in the SOFAS due to concerns that mental impairment unduly influences overall rating, and that psychological, social, and occupational functioning were all being rated on the same scale. This concern related to the contravention of true multi-axial assessment, posed as a central tenet of DSM-IV (Goldman, Skodol, & Lave, 1992).

The SOFAS comprises 10 grouped assessment points ranging from 1 to 100 in 10 point increments. For example: *51-60: Moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers or co-workers).*

Rating the SOAFS involves selecting a number from 1 - 100 that best reflects an individual's functioning either currently, or in the past 12 months, based on information collected from all sources. The SOFAS is intended to be a supplementary measure of individual functioning based on information routinely collected during clinical diagnostic interview. As such there is no structured assessment format provided for use with the SOFAS.

To date, limited data is available on the psychometric properties of the SOFAS. Several authors (Goldman, Skodol, & Lave, 1992; Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000) have suggested that the Global Assessment of Functioning (GAF, American Psychiatric Association, 2000), incorporating much of the SOFAS, has adequate validity but uncertain reliability, particularly inter-rater reliability. In an effort to increase reliability for the present study, a series of questions was derived to assess aspects of social and occupational functioning and yield standardised data points for SOFAS assessment (see Appendix F). Use of these questions converted the SOFAS into a semi-structured interview where data was elicited directly from participants in interview. The SOFAS was included in the present study to provide supplementary data on the current level of social and occupational functioning between the four groups. Thus participants were asked questions about current levels of functioning. Prisoners were asked about current levels of social and occupational functioning (current friendships/relationships, work

opportunities) as if they were being released on the day of the interview. Thus answers were a proxy for their current situation outside of jail.

4.2.7 The General Assessment of Relational Functioning (GARF)

The GARF (Dausch, Miklowitz, & Richards, 1996; Group for the Advancement of Psychiatry Committee on the Family, 1996) (see Appendix G) is a clinician-rated global assessment of overall functioning of a family, or other relational unit, and is included in the DSM-IV (American Psychiatric Association, 2000). The GARF is "used to indicate an overall judgement of the functioning of a family or other ongoing relationship on a hypothetical continuum ranging from competent optimal relational functioning to a disrupted, dysfunctional relationship" (American Psychiatric Association, 2000, p. 814).

The GARF is intended to be a supplementary measure of individual functioning based on information routinely collected during clinical diagnostic interview or to provide a global numerical assessment of detailed family assessment. As such there is no recommended structured assessment format provided for use with the GARF.

The GARF is rated out of 100 via 5 anchor point categories, each covering 20 points. For example:

> ***"41-60 Overall**: Relational unit has occasional times of satisfying and competent functioning together, but clearly dysfunctional, unsatisfying relationships tend to predominate. Communication is frequently inhibited by unresolved conflicts that often interfere with daily routines; there is significant difficulty in adapting to family stress and transitional change. Decision making is only intermittently competent and effective; either excessive rigidity or significant lack of structure is evident at these times. Individual needs are quite often submerged by a partner or coalition. Pain or ineffective anger or emotional deadness interfere with family enjoyment. Although there is some warmth and support for*

members, it is usually unequally distributed. Troublesome sexual difficulties between adults are often present."

The GARF is scored as a composite of three dimensions: joint problem solving; organisation; and emotional climate. Description of each dimension is provided in the scale.

Initial GARF field trials reported significant inter-rater reliability (reliability coefficients not published: Group for the Advancement of Psychiatry Committee on the Family, 1996). Other authors (Dausch, Miklowitz, & Richards, 1996) have shown the GARF to have an adequate mean inter-rater reliability of 0.72 in a sample of families of bi-polar patients. The same study demonstrated significant concurrent validity for the GARF to discriminate between functional and dysfunctional families, although not between types of dysfunction. These authors suggest that the GARF: can be rated reliably by relatively inexperienced raters; the scale can be applied across different family constellations, and that ratings are independent of patient's concurrent illness state (Dausch, Miklowitz, & Richards, 1996).

To increase overall reliability of the GARF for the present study a series of questions was derived to assess details of the three dimensions of general and relational functioning, and to yield standardised data points for GARF assessment (see Appendix G). Use of these questions converted the GARF into a semi-structured interview where data on family was sought directly rather than as part of other assessment. The GARF was included in the present study to provide supplementary data on family functioning between the four groups.

4.3 Procedure

4.3.1 Ethics approval

Ethics approval was granted for the study by: The University of Sydney Human Research Ethics Committee (HREC); The Aboriginal Health and

Medical Research Council (AH&MRC) HREC; The South East Sydney and Illawarra Area Health Service (SESIAHS) HREC; The Northern Sydney and Central Coast Area Health Service (NSCCAHS) HREC; The Justice Health (JH) HREC; The Department of Juvenile Justice (DJJ) Research Ethics Committee; and The Department of Corrective Services (DCS) Prisoner Ethics Committee (see Appendix H).

In addition a memorandum of understanding was drafted and signed between the Hope-Moodgee Aboriginal Mental Health Working Party (HMAMHWP), the SESIAHS Aboriginal Health Unit, and the project team. This document (see Appendix I) outlined the ethical considerations of the study to the Aboriginal people of the La Perouse and districts Aboriginal community, and fulfilled the aims of the NH&MRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (National Health & Medical Research Council, 2003). Principles from this document were applied to all sites where Aboriginal people were recruited.

4.3.2 Participant recruitment

Participants were recruited as outlined in Section 4.1 and the proportion of participants drawn from recruitment sources by group listed in Table 1.

Endeavours were made to have an Aboriginal mental health worker present at interviews with all Aboriginal participants to ensure cultural propriety, and to ensure Aboriginal participants understood all questions. As there were no Aboriginal mental health workers employed at the MRRC this was not possible. However, an Aboriginal co-researcher was present at a proportion of interviews (approximately 20%) to fulfil this role.

Upon interview, each participant was provided with a Participant Information Sheet and asked to read the information in front of the interviewer/s. Participants were then asked if they had any questions before being asked to sign an informed consent form. Participants in the two psychotic groups were

made aware that they were giving consent for their medical record to be accessed. All participants had the conditions of confidentiality explained. Participants who were current prisoners were informed, subject to specified exceptions to confidentiality, personal information would not be passed to either DCS or Justice Health.

4.3.3 Research interviews

All participants completed the demographics questionnaire and were administered the measures. Administration of the CARRMS and BPRS was alternated between consecutive participants with the order reversed to avoid an order effect, with approximately one-half of the sample receiving the CAARMS first (54%).

The administration order of the instruments was: CAARMS, AUDIT, OTI-R, BPRS, SOFAS, GARF. For alternate participants the BPRS preceded the CAARMS, with the administration of the other instruments remaining the same. Interviews took between 40 minutes and 2 ½ hours with an average of approximately 1½ hours.

In addition to recording the answers given by participants any question, word, or concept not understood by participants was recorded as a question not understood.

Participants were given an opportunity to ask any questions they wished (about the instruments, the research, or their own mental health) at the conclusion of the interview. Where the researcher/s had concerns about the participant's mental health, due to either suicidal ideation, psychotic, or depressive symptoms, these were discussed with the participant at the conclusion of the interview. From the prison psychotic illness sample, three participants raised concerns (two due to suicidal ideation, and one from likely psychotic phenomena) and were referred to Justice Health for management. From the community sample one participant raised concerns due to

depressive symptoms and was offered a referral to mental health services but declined.

4.3.4 Medical record audits

Medical record audits were carried out to establish primary diagnoses for participants in the groups with psychotic disorder. Medical record audits also recorded the number of documented psychotic episodes for each participant. Other information such as chronic illness, types of symptoms, and drug use was also recorded. The medical record audit form is included at Appendix J.

4.4 Design

The study was a cross-sectional 2x2 factorial design, comparing 4 groups. This design allowed for examination of differences between the CAARMS and BPRS due to Aboriginality and history of psychotic illness. A power analysis demonstrated that when using the CAARMS as a primary measure 20 participants per group provides 100% power at a significance level of α = 0.05. High power is achieved with relatively small groups due to the large expected disparity between the scores on the CAARMS for psychotic patients versus healthy controls. Initial validation data from the CAARMS (Yung et al., 2005) demonstrated a large disparity in mean scores of a clinical group (2.08, SD = 0.92) versus a healthy control group (0.29, SD = 0.38) .

4.5 Analyses

A number of planned and post-hoc analyses were carried out on the data collected to examine for significant differences between groups. Statistical advice was sought from an epidemiologist (Dr. Brian O'Toole) who also assisted with data analysis. Categorical data was compared using Chi-square tests. Interval data was compared between groups using One-way Analysis Of Variance (ANOVA). A priori planned contrasts were used to examine for an

effect for Aboriginality and psychotic illness on the CAARMS and BPRS. Pearson correlations were used to compare the relationship between CAARMS and BPRS scores.

All statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS version 14.0, LEAD Technologies, 2005).

Chapter 5
Results

5.1 Demographic differences between groups

Demographic data collected from participants were analysed by total sample and by group.

5.1.1 Marital status

The total sample was predominantly single with one only participant reporting being married and one divorced. For the Aboriginal groups, 15% of the psychotic sample and 20% of the healthy sample reported being in a de-facto relationship. There was 5% missing data (n = 4) for the sample for this question. Marital status data by group is summarised in Table 3. A Chi-square test revealed that there were no significant difference between groups on marital status (x^2 = 14.204, df = 9, p = 0.115).

Table 3
Marital status by sub-group.

	Group (%)			
Marital Status	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Single	14 (70)	15 (75)	19 (90.5)	20 (100)
Married	-	-	1 (4.8)	-
Divorced	-	1 (5)	-	-
Widowed	-	-	-	-
De-facto	3 (15)	4 (20)	-	-
Missing	3 (15)	-	1(4.8)	-

5.1.2 Education

Education level attained was recorded as either primary school, high school, post secondary or other: 4.9% of the sample had completed primary school, 56.8% some level of high school, and 37% post-secondary education to some level (12.3% TAFE, & 24.7% University). There were no participants in the

"Other" category, and there was 1.2% missing data (n = 1). These results are represented in Figure 3 below.

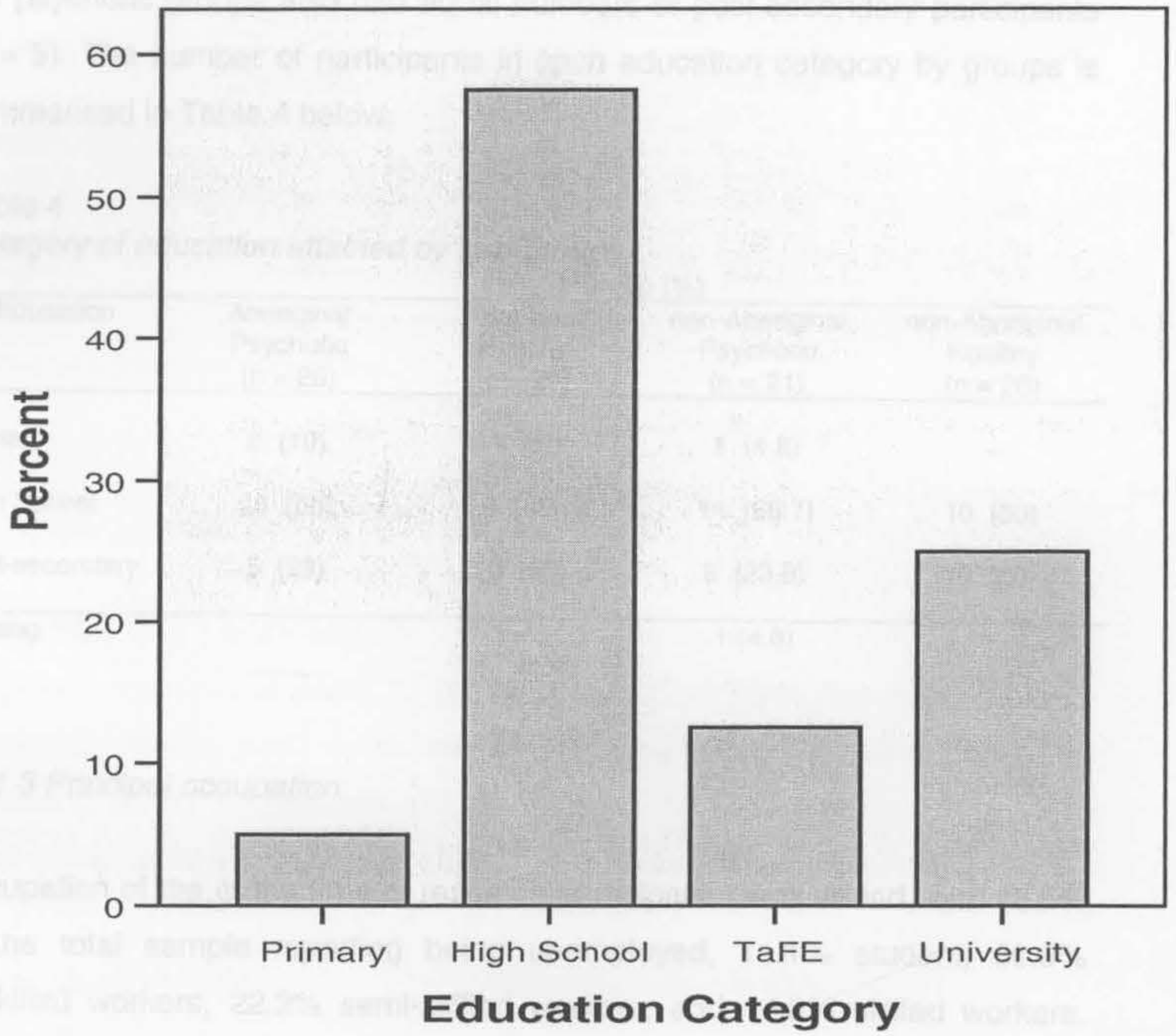

Figure 3. Graph of the proportion of participants in education categories for the total sample.

Education attainment level by group was analysed by category frequency: Chi-square test (x^2 = 6.812, df = 6, p = 0.339) revealed no significant differences between groups. Both healthy control groups (Aboriginal and non-Aboriginal) had equal numbers of post-secondary participants (n = 10), and the psychotic groups also had equal numbers of post-secondary participants (n = 5). The number of participants in each education category by groups is summarised in Table 4 below.

Table 4
Category of education attained by sub-group.

	Group (%)			
Education	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Primary	2 (10)	1 (5)	1 (4.8)	-
High School	13 (65)	9 (45)	14 (66.7)	10 (50)
Post-secondary	5 (25)	10 (50)	5 (23.8)	10 (50)
Missing	-	-	1 (4.8)	-

5.1.3 Principal occupation

Occupation of the at the time of research participation was varied, with 18.5% of the total sample reporting being unemployed, 11.1% student, 30.9% unskilled workers, 22.2% semi-skilled workers, and 14.8% skilled workers. Only 1.2% of the sample, or 1 participant, was a professional and there was 1.2% missing data (n = 1). For participants who were prisoners at the time of interview, occupation immediately prior to their imprisonment was recorded. A Chi-square test revealed there was a significant difference (x^2 = 28.638, df = 15, p = 0.018) between groups on occupation. The Aboriginal psychotic group had significantly more unemployed and significantly less students than other groups. Conversely, the non-Aboriginal healthy control group had significantly less unemployed participants and significantly more students and skilled workers than other groups. The Aboriginal healthy control group had significantly more semi-skilled workers than other groups. The non-Aboriginal psychotic group had significantly more unskilled workers than other groups.

Number and proportion of principal occupations by group are summarised in Table 5.

Table 5
Frequency and proportion of principal occupations by sub-group.

Occupation	Group (%)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Unemployed	8 (40)*	4 (20)	3 (14.3)	0*
Student	0*	3 (15)	1 (4.8)	5 (25)*
Unskilled	5 (25)	4 (20)	10 (47.6)*	6 (30)
Semi-skilled	4 (20)	7 (35)*	5 (23.8)	2 (10)
Skilled	2 (10)	2 (10)	2 (9.5)	6 (30)
Professional	0	0	0	1 (5)
Missing	1 (5)			

* indicates significance at $\alpha = 0.05$

5.1.4 Chronic health

Forty (49.4 %) participants or of the sample reported having a medical condition. However, of these, 37 (46%) reported this medical condition to be a psychiatric illness such as schizophrenia or drug-induced psychosis. The remaining 3 (3.7%) reported: rhinitis, asthma and hepatitis-C. All of these three participants were in the healthy control groups.

5.1.5 Mental health

All non-Aboriginal psychotic participants reported treatment for a mental health problem and all Aboriginal healthy participants reported no treatment. One-quarter of the Aboriginal psychotic participants reported not having been treated despite a diagnosis of psychotic illness recorded in their medical records. (see Table 23). Two participants in the non-Aboriginal healthy control group reported: treatment for ADHD as a child; and consultation with a GP for depression but no treatment, respectively. These results are summarised in Table 6.

Table 6
Number and proportion of participants treated for a mental health problem by sub-group.

Mental Health problem	Group (%) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Yes	15 (75)	-	21 (100)	2 (10)
No	5 (25)	20 (100)	-	18 (90)

5.1.6 Family mental health

Slightly less than 40% of the total sample reported having a family member with a mental health problem. Mothers were the most often reported, accounting for approximately 30% of cases. Psychotic illness was the most often reported mental health problem in a family member, accounting for 53% of the reported problems. This was followed by depression, which accounted for 16%. A Chi-square test revealed there was no significant difference (x^2 = 6.585, df = 3, p = 0.086) between groups on family member with a mental health problem. The proportion of participants with a family member who has a mental health problem by group is summarised in Table 7.

Table 7
Family mental health problem by sub-group.

Family Mental Health problem	Group (%) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Yes	11 (55)	7 (35)	10 (47.6)	4 (20)
No	8 (40)	13 (65)	11 (52.4)	16 (80)
Missing	1 (5)			

5.1.7 Aboriginal identity

Approximately 82% percent of Aboriginal participants reported having grown up in an Aboriginal family and 85% reported having had contact with an Aboriginal community. One participant from the non-Aboriginal psychotic group reported having grown up in an Aboriginal family having an Aboriginal step-parent and extended family. A fifth to a quarter of participants from the non-Aboriginal psychotic (28%, n = 6) and non-Aboriginal healthy groups (20%, n = 4) reported having had contact with an Aboriginal community. These participants reported having an Aboriginal or friend, living near an Aboriginal community, or spending time with an Aboriginal family via friendship. None of these participants reported being part of, or spending a significant amount of time in, an Aboriginal community. The results for Aboriginal identity are summarised in Table 8.

Table 8
Aboriginal identity by sub-group.

	Group (%)			
Aboriginal identity	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Identify as Aboriginal	20 (100)	20 (100)	-	-
Grew up in an Aboriginal family	16 (80)	17 (85)	1 (4.8)	-
Contact with an Aboriginal community	17 (85)	17 (85)	6 (28)	4 (20)

5.2 Drug and alcohol use

5.2.1 Alcohol use

Alcohol use in the last year was measured by the score on the Alcohol Use Disorders Identification Test (AUDIT, Saunders, Aasland, Babor, de la Fuente, & Grant, 1993). The mean AUDIT score for the whole sample was 11.63 (SD=9.19) where the harmful use cut-off of score is 8. The Aboriginal

psychotic group had the higher mean score (M = 14.75, SD = 12.48). A One-way ANOVA revealed no significant between group differences ($F_{(3,77)}$ = 1.198, p=0.316) in scores. Alcohol use was high across the total sample with 59% of the sample scoring 8 or above on the AUDIT and 20% of participants scoring 20 or above. The group means for AUDIT scores are summarised in Table 9.

Table 9
Alcohol use in previous 12-months by sub-group.

	Group (SD)			
Alcohol Use	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
AUDIT Score	14.75 (12.48)	10.009.21)	11.76 (8.26)	10.00 (5.22)

5.2.2 Drug use

Drug use was measured by calculating by Q scores (amount of drug used on last 3 occasions in the previous month divided by time in-between use) on the Revised Opiate Treatment Index (OTI-R, Darke, Ward, Hall, Heather, & Wodak, 1991).The OTI-R yields Q-scores (weighted average scores of the amount of a drug used over the past 30-day period). Where drugs were reported by amount, for example 1.5 grams of heroin instead of the number of hits, conversions were performed using the NSW Drug Trends report (Black, Roxburgh, & Degenhardt, 2006). Poly-drug scores were also calculated by summing the number of types of drugs used in the past 30 days. Where participants were prisoners, drug use in the 30-day period immediately prior to imprisonment was recorded.

Mean Q-scores for each class of drug and poly-drug score, listed by group, are summarised in Table 10 below.

Table 10
Average drug use amounts in the previous one-month by sub-group.

Drug use Amount	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Heroin	0.62 (1.18)	0.71 (1.72)	0.00 (0.01)	0.00 (0.01)
Other Opioid	0.01 (0.03)	0.11 (0.39)	0.08 (0.31)	0.01 (0.02)
Alcohol	4.23 (5.46)	5.77 (11.12)	3.64 (5.51)	3.02 (4.87)
Cannabis	5.56 (8.88)	6.03 (10.33)	3.24 (9.20)	4.83 (21.46)
Amphetamines	0.98 (1.49)	1.70 (5.77)	1.61 (4.20)	0.37 (1.56)
Cocaine	0.09 (0.24)	0.07 (0.30)	0.02 (0.07)	0.10 (0.45)
Tranquillisers	0.25 (1.12)	0.10 (0.38)	0.06 (0.16)	0.00 (0.01)
Hallucinogens	0.05 (0.15)	0.09 (0.26)	0.02 (0.05)	0.02 (0.07)
Inhalants	0	0	0.06 (0.26)	0.38 (1.68)
Tobacco	12.25 (8.44)	11.95 (20.68)	12.91 (9.90)	5.80 (12.63)
Poly drug	4.25 (1.65)	3.00 (2.08)	2.91 (1.67)	2.10 (1.89)

The Aboriginal psychotic group had the highest poly-dug score (number of drugs used) for the previous 30-day period with a mean of 4.25 (SD = 1.65) types used. The non-Aboriginal healthy control group used the least with a mean of 2.1 (SD = 1.89) types used. A one-way ANOVA of OTI-R poly-drug scores revealed a significant difference ($F_{(3,77)}$ = 4.720, p = 0.004) in the number of drugs used over the 30-day period. Tukey post-hoc tests demonstrated a significant difference between the Aboriginal psychotic group, and the non-Aboriginal healthy control group, with the Aboriginal psychotic group using significantly more. Mean differences in poly-drug use scores are shown in Table 11 below.

Table 11
Mean differences in number of drugs used between sub-groups measured by OTI-R poly drug scores.

Poly-drug score mean differences	Group: Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	1.25	1.35	2.15*
Aboriginal Healthy	-1.25	-	0.10	0.90
non-Aboriginal Psychotic	-1.35	-0.10	-	0.80
non-Aboriginal Healthy	-2.15*	-0.9	-0.80	-

* indicates significance at $\alpha = 0.05$

5.3 Social, occupational, and family functioning

5.3.1 Social and occupational functioning

Social and occupational functioning was measured by a global score out of 100 on the Social and Occupational Functioning Assessment Scale (SOFAS, Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000). Mean SOFAS scores by group are summarised in Table 12.

Table 12
Mean social and occupational functioning scores by sub-group.

Social and occupational functioning	Group (SD): Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
SOFAS score	42.25 (13.42)	66.35 (19.24)	53.24 (12.30)	79.70 (10.17)

A one-way ANOVA revealed significant differences between SOFAS scores ($F_{(3,77)} = 25.452$, $p < 0.001$). Tukey post-hoc tests demonstrated no significant difference between the Aboriginal healthy and the non-Aboriginal psychotic groups. However, as seen in Table 13 the non-Aboriginal healthy group had significantly higher scores (M = 79.70, SD = 10.17) than the non-Aboriginal psychotic group (M = 53.24, SD = 12.30). Similarly the Aboriginal healthy

group (M = 66.35, SD = 19.24) had significantly higher scores than the Aboriginal psychotic group (M = 42.25, SD = 13.42). Mean differences in SOFAS scores between groups are summarised in Table 13 below.

Table 13
Mean differences in SOFAS scores between sub-groups.

SOFAS Score	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	-24.10*	-10.99	-37.45*
Aboriginal Healthy	24.10*	-	13.11*	-13.35*
non-Aboriginal Psychotic	10.99	-13.11*	-	-26.46*
non-Aboriginal Healthy	37.45*	13.35*	26.46*	-

* indicates significance at $\alpha = 0.05$

5.3.2 Family functioning

Family functioning was measured by a global score out of 100 on the Global Assessment of Family and Relational Functioning (GARF, Group for the Advancement of Psychiatry Committee on the Family, 1996) Mean GARF scores by group are summarised in Table 14.

Table 14
Mean family functioning scores by sub-group.

Family functioning	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
GARF Score	49.05 (24.71)	62.95 (26.63)	63.81 (23.39)	78.65 (19.18)

A one-way ANOVA revealed significant differences between GARF scores ($F_{(3,76)} = 5.254$, p= 0.002). Tukey post-hoc comparisons demonstrated differences in mean GARF scores between the Aboriginal Psychotic and non-Aboriginal Healthy control groups only, with the Aboriginal psychotic group

having significantly lower GARF scores than the non-Aboriginal healthy control group. Mean differences in GARF scores between groups are summarised in Table 15 below.

Table 15
Mean differences in GARF scores between sub-groups.

Difference in mean GARF scores	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	-13.90	-14.76	-29.60*
Aboriginal Healthy	13.90	-	-0.86	-15.70
non-Aboriginal Psychotic	14.76	0.86	-	-14.84
non-Aboriginal Healthy	29.60*	15.70	14.84	-

* indicates significance at $\alpha = 0.05$

5.4 Mental health

5.4.1 CAARMS psychotic sub-scale results

Scores on the first three sub-scales of the Comprehensive Assessment of At-Risk Mental States (CAARMS, Yung et al., 2005) (disorders of thought content, perceptual abnormalities, and disorganised speech) form the psychotic sub-scale of the CAARMS. Mean scores for the psychotic sub-scale were calculated (comprising the component severity and frequency scores) and are summarised in Table 16 below. A one-way ANOVA revealed a significant difference ($F_{(3,77)} = 33.016$, $p < 0.001$) in mean CAARMS psychotic sub-scale scores between groups.

Table 16
Mean CAARMS psychotic sub-scale scores by sub- group.

	Group (SD)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
CAARMS Psychotic Score	3.80 (1.21)	0.58 (0.84)	2.14 (2.01)	0.23 (0.37)

The scores obtained in this study cannot be compared to the CAARMS validation study (Yung et al., 2005) as this study did not publish psychotic sub-scale scores for participants.

Planned contrasts demonstrated a significant effect on CAARMS psychotic sub-scale scores for both Aboriginality (t = 3.559, df = 77, p = 0.001) and for psychosis (t = -9.066, df = 77, $p < 0.001$). As outlined in Table 16, mean scores obtained in the Aboriginal psychotic and healthy groups were significantly higher than those obtained for non-Aboriginal people. Similarly mean scores of participants in the Aboriginal psychotic and non-Aboriginal psychotic groups were significantly higher than healthy controls. Furthermore, this pattern was observed in the component scores (mean global symptom severity and mean symptom frequency scores) for the CAARMS psychotic subscale. Aboriginal participants (psychotic and healthy) had higher mean component scores for the psychotic subscale than non-Aboriginal participants (psychotic and healthy). Differences between mean CAARMS psychotic sub-scale group scores are summarised in Table 17.

Table 17
Mean differences in CAARMS psychotic sub-scale scores between sub-groups.

CAARMS psychotic subscale mean difference scores	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	3.22*	1.66*	3.58*
Aboriginal Healthy	-3.22*	-	-1.56*	0.36*
Non-Aboriginal Psychotic	-1.66*	1.56*	-	1.92*
non-Aboriginal Healthy	-3.58*	-0.36*	-1.92*	-

* indicates significance at $\alpha = 0.05$

5.4.2 CAARMS overall results

A Mean overall CAARMS score was calculated by averaging scores for all CAARMS component subscales (comprising symptom severity and symptom frequency scores) for each participant. Means were then calculated for each group. A one-way ANOVA demonstrated a significant difference ($F_{(3,77)} = 19.371$, $p < 0.001$) between overall CAARMS group scores. Mean overall CAARMS scores by group are summarised in Table 18.

Table 18
Mean overall CAARMS scores by sub-group.

	Group (SD) Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
CAARMS overall scores	2.19 (0.89)	0.70 (0.80)	1.51 (1.06)	0.39 (0.40)

The obtained scores in this study were compared to the values obtained in the initial CAARMS validation (Yung et al., 2005). Participants identified as at-risk of psychosis in the original study had an average overall CAARMS score of 2.08 (SD = 0.92), while healthy controls obtained a mean overall CAARMS score of 0.29 (SD = 0.38). In this study the non-Aboriginal psychotic group

had a significantly lower mean overall CAARMS score ($t = 2.251$, df = 66, $p = 0.028$) than the initial validation data for an at-risk sample. There was no significant difference between the mean Aboriginal psychotic group score and the at-risk sample ($t = 0.452$, df = 65, $p = 0.653$). The Aboriginal healthy control group had a significantly higher overall mean CAARMS score ($t = 3.559$, df = 77, $p = 0.001$) than the healthy initial validation sample. However, the non-Aboriginal healthy group mean overall CAARMS score was not significantly different ($t = 0.974$, df = 66, $p = 0.334$) to the initial validation study.

Planned contrasts demonstrated a significant effect on the CAARMS overall scores for both Aboriginality ($t = 2.701$, df = 77, $p = 0.009$) and for psychosis ($t = -7.097$, df = 77, $p < 0.001$). As outlined in Table 18, mean group scores obtained by Aboriginal participants (psychotic and healthy) were significantly higher than non-Aboriginal people (psychotic and healthy). Similarly, mean group scores of participants with psychosis (Aboriginal and non-Aboriginal) were significantly higher than healthy controls (Aboriginal and non-Aboriginal). Furthermore, the pattern was consistent in the component scores. Aboriginal people had higher symptom severity scores and higher symptom frequency scores, than non-Aboriginal participants. The same was observed for psychotic participants who had higher symptom severity and frequency scores than healthy controls. Differences between mean CAARMS overall group scores are summarised in Table 19 below.

Table 19
Mean differences in overall CAARMS scores between sub-groups.

	Group (SD)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	1.49*	0.68*	1.80*
Aboriginal Healthy	-1.49*	-	-0.81*	0.31*
non-Aboriginal Psychotic	-0.68*	0.81*	-	1.12*
non-Aboriginal Healthy	-1.80*	-0.31*	-1.12*	-

* indicates significance at $\alpha = 0.05$

5.4.3 Overall BPRS results

Overall BPRS scores were calculated by averaging individual scores obtained on all 24 BPRS items. A One-way ANOVA demonstrated a significant difference ($f_{(3,77)} = 33.852$, $p < 0.001$) between overall BPRS group scores. These scores are summarised in Table 20.

Table 20
Mean overall BPRS scores by sub-group.

	Group (SD)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Overall BPRS score	2.41 (0.47)	1.40 (0.36)	1.99 (0.62)	1.15 (0.13)

Planned contrasts demonstrated a significant effect on BPRS overall scores for both Aboriginality ($t = 3.468$, df = 77, $p = 0.001$) and for psychosis ($t = -9.466$, df = 77, $p < 0.001$). As outlined in Table 20 above, scores obtained by all Aboriginal participants were significantly higher than for non-Aboriginal participants, and scores of participants with psychosis were significantly higher than healthy controls. Differences between mean BPRS overall group scores are summarised in Table 21 below.

Table 21
Mean differences in overall BPRS scores between sub-groups.

	Group (SD)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
Aboriginal Psychotic	-	1.01*	0.43*	1.26*
Aboriginal Healthy	-1.01*	-	-0.58*	0.25*
Non-Aboriginal Psychotic	-0.43*	0.58*	-	0.83*
non-Aboriginal Healthy	-1.26*	-0.25*	-0.83*	-

* indicates significance at $\alpha = 0.05$

5.4.4 CAARMS and BPRS overall score comparison

Comparison of overall scores obtained on the CAARMS and the BPRS using Pearson correlation revealed a positive significant positive correlation between scores ($r = 0.809$, $n = 81$, $p < 0.001$). A scatter-plot graph of these results with a linear regression line of best fit is shown at Figure 4.

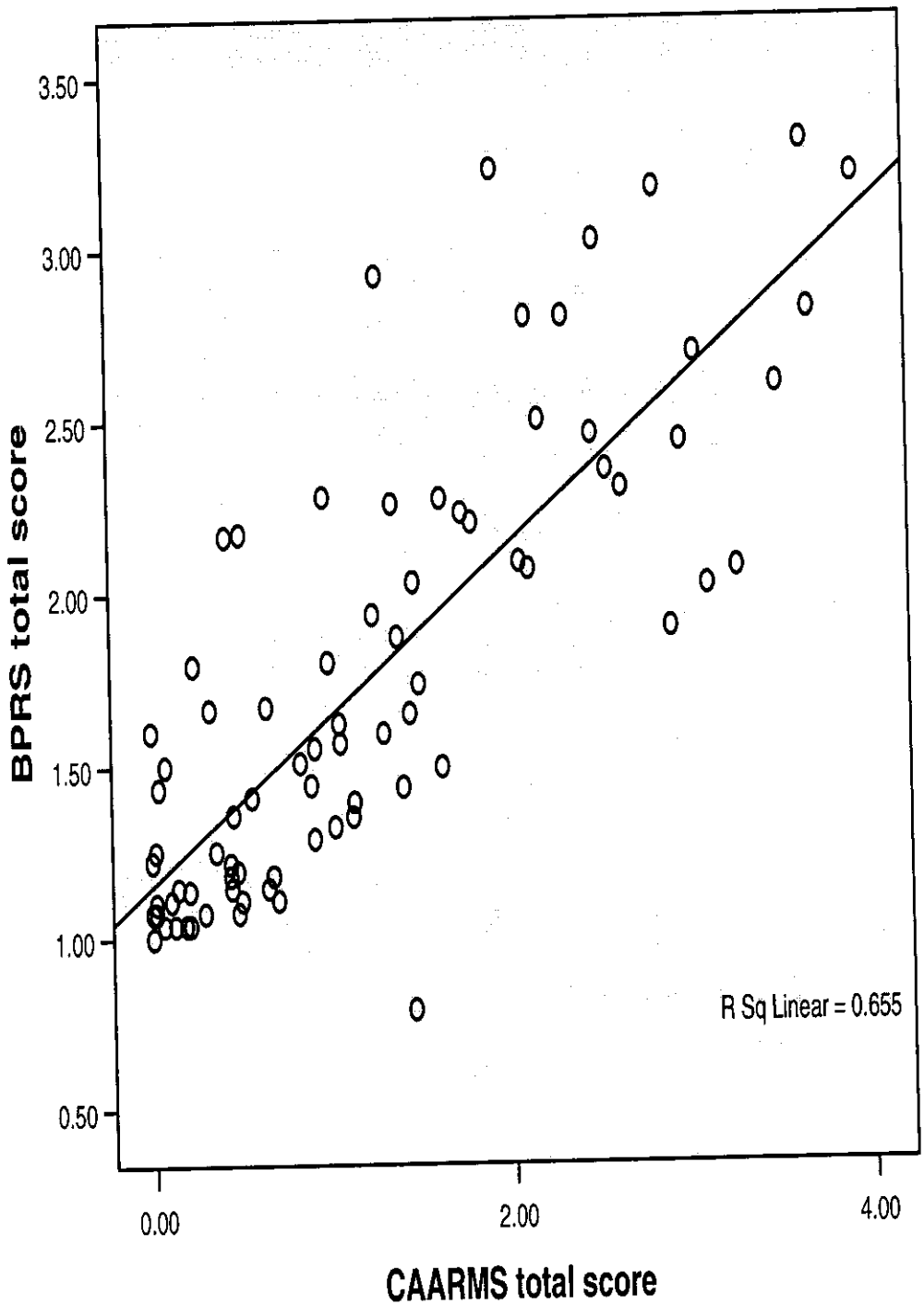

Figure 4. Scatter-plot of CAARMS and BPRS total scores with a regression line of best fit.

The regression line (R^2 = 0.655) revealed a significant positive correlation between the two instruments for the total sample. Separate correlations were calculated for the total CAARMS and BPRS scores for each group. Correlations by group revealed significant positive correlations between the CAARMS and BPRS overall scores for all groups. However, these results must be interpreted with caution as the small sample size in each group reduces statistical power of the correlations. These results are summarised in Table 22.

Table 22
Correlations of overall CAARMS and BPRS scores by sub-groups.

	Group (SD)			
	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
CAARMS overall score vs. BPRS Overall score	0.41*	0.45*	0.86*	0.61*

* indicates significance at α = 0.05

5.5 Medical record data

Medical record data was collected on all participants in both the Aboriginal and non-Aboriginal psychotic groups. Aboriginal status was noted in 95% of medical records, with only two medical records making no reference to the participant's Aboriginality or non-Aboriginality.

For other medical conditions (non-psychiatric), 55% of the Aboriginal psychotic group and one-third of the non-Aboriginal psychotic group had other conditions listed in their medical record. For the Aboriginal psychotic group, Hepatitis C was the most prevalent condition accounting for 30% of reported medical conditions. Asthma was the second most prevalent condition accounting for 20% of sufferers in this group. For the non-Aboriginal psychotic group the conditions noted were similar, with 20% suffering Hepatitis C, and 20% suffering asthma.

Medical record mental health data

All participants in both the Aboriginal and non-Aboriginal psychotic groups had a diagnosis of one or more psychotic illnesses recorded in their medical record. For the Aboriginal psychotic group, 80% had a diagnosis recorded as being made by either a registrar in psychiatry or a consultant psychiatrist. For the remaining 10% of the group (1 participant) had a diagnosis by a medical officer only recorded, and 10% had a diagnosis by a psychologist only recorded. For the non-Aboriginal group 86% (18 out of 21 participants) had a diagnosis recorded by either a registrar in psychiatry or a consultant psychiatrist. The remaining 14% (3 participants) had diagnosis of a psychotic illness recorded by a registered nurse only. Final diagnosis was calculated by selecting the most recent diagnosis made by a medical professional, or where this was not listed, previous diagnosis made by a medical professional. Where there was no diagnosis by a medical professional the most recent diagnosis was recorded. The number of participants per group with each type of psychotic illness final diagnosis is summarised in Table 23. A Chi square test (x^2 = 2.998, df = 5, p = 0.70) revealed no significant difference between the two groups on diagnosis.

Table 23
Proportion of final diagnoses by sub-group

	Group (%)	
Diagnosis	Aboriginal psychotic (n = 20)	Non-Aboriginal psychotic (n = 21)
Psychosis	3 (15)	2 (9.5)
1st episode psychosis	-	1 (4.8)
Drug-induced psychosis	2 (10)	4 (19.0)
Schizophrenia	14 (70)	12 (57.1)
Schizoaffective	-	1 (4.8)
Bi-polar disorder	1 (5)	1 (4.8)

Other data was recorded from participant medical records. The Aboriginal and non-Aboriginal psychotic groups each had one participant recorded as having

primarily negative psychotic symptoms and the rest as primarily positive symptoms. For symptoms secondary to psychotic illness there was no difference between the Aboriginal and non-Aboriginal groups. Both groups had nine participants (45% of the Aboriginal group and 43% of the non-Aboriginal group) with deliberate self-harm as the most prevalent secondary symptom. Depression was the second most prevalent secondary symptom in 30% (n = 6) of the Aboriginal, and 19% (n = 4) of the non-Aboriginal group. Pattern of psychotic symptoms (onset order, most prevalent symptom, most troubling symptom) was recorded for 35% (n = 7) of the Aboriginal group and 57.1% (n = 12) of the non-Aboriginal group.

Medical notes of substance use were recorded for all Aboriginal and non-Aboriginal psychotic participants. The proportions of substance use category is summarised in Table 24 below. A Chi-square test (x^2 = 8.150, df = 3, p = 0.043) demonstrated the Aboriginal psychotic group to have significantly more participants dependent on substances in their medical record then the non-Aboriginal psychotic participants. The non-Aboriginal psychotic group had significantly more participants recorded as abusers of substances than the Aboriginal psychotic group.

Table 24
Proportion of recorded substance use category by sub-group

Substance use category	Group (%) Aboriginal psychotic (n = 20)	Non-Aboriginal psychotic (n = 21)
No use	-	1 (4.8)
Use	3 (15)	3 (14.3)
Abuse	6 (30)*	14 (66.7)*
Dependence	11 (55)*	3 (14.3)*

* indicates significance at α = 0.05 (2-tailed)

Poly-substance use was by far the largest recorded type of substance used with 85% (n = 17) of the Aboriginal psychotic and 81% (n = 17) of the non-Aboriginal psychotic group having poly-substance use recorded. Some form of substance use history was recorded for 85% (n = 17) of the Aboriginal

psychotic and 90.5% (n = 19) of the non-Aboriginal psychotic group. Some documentation of the relationship between substance use and the pattern of psychotic symptoms was more varied, with 40% (n = 8) of the Aboriginal group having this recorded versus 66.7% (n = 14) of the non-Aboriginal group.

5.6 Questions not understood on the CAARMS and the BPRS

The number of questions not understood by each participant on the CAARMS and the BPRS was recorded. Frequencies for the whole sample and for each group were calculated. The percentage of questions not understood by all participants on the CAARMS and the BPRS is shown in Table 25 below.

Table 25
Mean percentage of questions not understood by participants

	% (SD)	
	CAARMS	BPRS
Average percentage of questions not understood per participant	1.2% (1.8)	0.7% (1.1)

Questions not understood by participants on the CAARMS and the BPRS were analysed for differences between groups. Group means are shown in Table 26. A One-way ANOVA demonstrated that there were no significant differences between the mean number of questions not understood between groups on the CAARMS ($F_{(3,77)}$ = 2.024, p= 0.118) or the BPRS ($F_{(3,77)}$ = 0.564, p= 0.641).

Table 26
Sub-group means of CAARMS and BPRS overall scores

	Group (SD)			
Mean no. of questions not understood	Aboriginal Psychotic (n = 20)	Aboriginal Healthy (n = 20)	non-Aboriginal Psychotic (n = 21)	non-Aboriginal Healthy (n = 20)
CAARMS	2.90 (3.34)	2.3 (3.70)	1.76 (2.05)	0.85 (1.04)
BPRS	0.60 (0.88)	0.90 (0.83)	0.62 (0.92)	0.50 (0.83)

5.7 Qualitative data

In addition to collecting quantitative data on study instruments, qualitative data in was also collected. The qualitative data collection comprised the pilot study data and two case-studies generated from participants interviewed during the quantitative data collection phase the study.

5.7.1 Pilot study data

A structured interview was designed (see Appendix K) as a pilot study to gauge young Aboriginal people's ideas and knowledge about the following topics:

i) Perceived differences between Aboriginal non-Aboriginal people's mental health
ii) Schizophrenia and psychosis in Aboriginal people
iii) Asking Aboriginal people about mental health problems
iv) Aboriginal mental health research

Following difficulties in obtaining Aboriginal ethics, and delays to subsequent Area Health Ethics committee approvals, the pilot study was conducted towards the end of the data collection phase. As such, it was used to identify themes and beliefs about Aboriginal mental health and psychotic illness held by young Aboriginal community members. Two young men wishing to be identified as members of the La Perouse Aboriginal community were recruited. These participants agreed after being approached by an Aboriginal youth worker and were selected based on their knowledge and interest in young Aboriginal people. This interview was transcribed (see Appendix L for full transcript) and the following themes identified:

Theme 1: Aboriginal people believe that their mental health is different to non-Aboriginal mental health.

Responses to questions about Aboriginal mental health highlighted the above theme- *"The community would say that Aboriginal mental health is different to non-Aboriginal mental health."*

This indicates that Aboriginal communities and individuals perceive a difference in their mental health compared directly to the broader community. This difference is perhaps based on broader beliefs about culture as evident in: *"I guess Aboriginal people- have beliefs and religions, culture and a spiritual system different from non-aboriginal population."*

Another aspect to the above theme is the differences in mental health being about understanding: *"No, I grew up in a white family and a black family...Because I'm mixed in both worlds, I could answer in both ways- could give it in both perspectives."*

These responses suggest differences in mental heath between Aboriginal and non-Aboriginal people are manifest, at least in part, in perspectives about mental health. The implication is that these different perspectives inform individuals about how to respond depending on who, rather than what, is being asked.

Theme 2: Mental health problems including schizophrenia and psychotic illness are different in Aboriginal people compared to non-Aboriginal people

The respondents illustrated a lay perspective on psychotic illness when asked about what constitutes schizophrenia and psychosis: *"Psychosis- go into another world, like another reality, or not reality but don't come out of it."* (1st respondent) *"Schizophrenia- don't really have control over being aggressive and things like that. Also get twitches and stuff like that."* (2nd respondent).

When asked if an Aboriginal person would appear differently to a non-Aboriginal person, the responses indicate level of contact with Aboriginal culture to be an important factor. *"Depending on the person. You get kooris who are white anyway, urbanised. But then you can get urban kooris still*

caught in between (Aboriginal and non-Aboriginal culture). *Basically I think there is a difference.'*["What If the koori person was closer to the old ways?] *"Yeah, would have an effect on the outcome."*

These responses suggest that the strength of the link to traditional Aboriginal culture may play a part in how symptoms or illness are manifest.
One of the respondents gave an example of how an Aboriginal person with strong ties to traditional culture was assumed to be experiencing psychotic symptoms when other Aboriginal people would likely regard the experiences as normal cultural experiences. *"There was this bloke from the north coast down here admitted to 'X'* (name of a psychiatric hospital). *They were saying he was psychotic, 'cause he was saying that the spirits were coming for him. What he was telling me was pretty much exactly what was actually happening. His grandfather did something bad and there's been a curse put on him and his family that will happen from generation to generation. I told the guy I understood- and then them (the staff)- it looked like the staff were going to lock me up as well, I couldn't believe it! People from where he was from would think the same things about the curse, which pretty much wiped out his whole family. So you do have examples like that; the way they found him- coppers found him, and he tells them so and so is after him and going to come to get him. It didn't help him that he was half-drunk, just an example of how beliefs change things."*

The last part of the above response summarises a possible explanation for why differences occur; that of what is accepted as normal versus what is regarded as abnormal in different cultures. Another response to a related question illustrates this point: *"Stuff has been drummed into you as a kid- you've been told and seen things. If they (Aboriginal people) do have a mental attack it's sort of might be a bit harder to break through to them..."*

Thus the beliefs that have been communicated to individuals as children are accepted by the community, and those retained, are likely to have an effect. Equally, these beliefs are likely to be misunderstood by people from other communities and belief systems.

Theme 3: Aboriginal people need to be asked differently about mental health problems and research into Aboriginal mental health is important.

Responses to questions about how to ask Aboriginal people about mental health illuminated issues of trust and the importance of the approach taken- *"From aboriginal perspective? The way you say it, more emotion involved, like to think I'm a bit more sensitive. The other way* (non-Aboriginal)- *is more forward and direct. You wouldn't say it straight out, you'd have to weave your way through it. Build trust. There's been a lot of mistrust in the past..." "Even if I ask my own Nan a question, and I know she knows answer, but she says I don't know, you don't ask those things (in the Aboriginal community). They give you answers that get you nowhere. You never ask." "They think differently sometimes too- lots to do with education, they think they're being hoodwinked with all these questions in the hospital. I teach at the school and at school, as soon as there's too many questions at once, they* (Aboriginal kids) *start acting up and carrying on. Just the way they ask the question and, also the amount of info they're trying to push on them straight away."*

These responses highlight that many people in the Aboriginal community are mistrustful of those they perceive to be in a position of power, or connected to the government, including health workers. Other responses highlighted that the building of trust is of more importance in the Aboriginal community if personal information about people is to shared- *"Shared experiences, give them something* (about yourself), *then they can give you something (about themselves). Building trust, a relationship they feel comfortable with."*

When asked about Aboriginal mental health research the responses indicated that the respondents saw research as important: *"It's a need."* [Why?] *"Every time I sit round with my mates or whoever, all of a sudden it comes out, they want to get it out of them but it will take a few drinks, they won't sit round and talk about it sober. Could have happened 10 years ago and not have come out."*

Responses also indicated that research should be a shared venture between both the Aboriginal and non-Aboriginal communities. *"Also is important from as soon as we get aboriginal people as academics in mental health it can be done from both points of view."*

The respondents highlighted that for current, research trust in the researchers was important and that finding ways to make Aboriginal people comfortable by using their ways should be a goal of research: *"Trust the best thing. And just our ways, research into how we would ask questions, get them to be comfortable."*

5.7.2 Case studies

Case study data was collected to highlight the difficulties in assessing cultural experiences and symptoms in the context of psychotic illness and health. The data collection process enabled the identification of cases where Aboriginal participants diagnosed with psychotic illness experienced symptoms that overlapped with cultural experiences. Also, this process yielded examples of healthy participants who conversely experience cultural experiences that have the potential to be interpreted as psychotic symptoms. Two case studies representing cultural symptoms in illness and psychotic-like experiences in health are outlined below.

5.7.3 Case study A

Participant 36 was a 20 year old Aboriginal man interviewed in the Mental Health Screening unit at the Metropolitan Reception and Remand Centre. He had been taken into custody a few months prior to the interview. He reported he had left school in Year 9, suffers from Asthma, and had been diagnosed as suffering drug-induced psychosis. He recorded his current medications as 10 mg Zyprexa per day and Ventolin. He recorded his mother as a sufferer of psychotic illness and identified as an Aboriginal man. He reported growing up in an Aboriginal family and having grown up having contact with an Aboriginal

community. He had been transferred to the Mental Health Screening Unit (MHSU) from another NSW prison due to a worsening of his mental state.

During the research interview he responded to items on the CAARMS indicating that he felt he was being watched, had special powers to read body language, and that someone could read his mind. He stated he knew the name of the mind-reading person and that it happened all the time but only when "it looks me in the eyes." When asked if he had had any religious experiences in the past month, he replied that he was cursed and his spirit had been switched with another man. He reported that the elders (his tribal elders) knew about this but his family didn't. He also reported that his grandparents had been important elders of his particular NSW tribe. He also stated he was having dreams that he could not work out the meaning to, and that everything was backward because he had switched to the other side of the mirror. He reported no problems with speech but reported that he could be hypnotised by a three-way conversation and noted deficits in concentration and attention plus forgetfulness about "anything and everything".

When asked to give an account of his problems he stated that he had been the victim of a singing curse, and that the first he knew about it was when a family member told him to go and look in the mirror. When he did he could see that everything was backward and not as it was meant to be. He then concluded that he had crossed over the other side of the mirror, or his spirit had, and that he was trapped on the wrong side of the mirror. He then reasoned that his family must have known about this in order to tell him to look in the mirror, and they did this to make him aware of the curse. He believed the curse was put on him by someone, who he knew but was not prepared to reveal the identity of, and that the curse was able to be enacted when the curser obtained a clipping of his fingernail or one of his hairs. He had since become very careful about how he disposed of these, wrapping them carefully in newspaper in his cell, and warned the interviewer to do the same. When questioned further he reported that he was not worried about the curse because he had already spoken to the elders who had said that they would smoke him to reverse the curse, and that the feather-foot (described by

him as a sorcerer and assassin- a Kadaicha man) was going to sort out the person who had put the curse on him.

His CAARMS psychotic subscale score was 3.17 (slightly less than the overall average score of 3.80 for the Aboriginal psychotic group), whilst his overall CAARMS score was 1.38 (less than the overall average score of 2.19 for the Aboriginal psychotic group). This indicated that his psychotic symptoms were more frequent and severe than other symptoms recorded on the CAARMS. His overall BPRS score was 1.87 (less than the overall average score of 2.41 for the Aboriginal psychotic group). His Audit score was 22 and his OTI-R poly-drug score was 4, having used alcohol, cannabis, amphetamines, and tobacco in the previous 30 days to imprisonment. He was given a SOFAS score of 55 and a GARF of 50.

A medical record audit revealed an intake diagnosis two years before the research interview of schizophreniform psychosis, an unspecified personality disorder, and substance abuse, made by a community psychiatry registrar. His most recent diagnosis in the MHSU was that of psychotic symptoms and substance use by a consultant psychiatrist who noted that many of his experiences may be cultural, or may be distorted cultural beliefs. His medical record noted him to have had a previous psychotic episode and his primary symptoms to be those of paranoia, pseudo hallucinations, auditory hallucinations (voices) and the possibility of distorted cultural beliefs. He had been prescribed Haloperidol and Quietapine at the MHSU and was noted in his medical record to be suffering Hepatitis C, and to have been a daily nicotine, speed, and cannabis user.

This participant represents a good example of an Aboriginal person who is suffering symptoms which are both non-cultural and psychotic (believing he has crossed over to the other side of the mirror) and those which may be cultural experiences (suffering a singing curse, his spirit being trapped elsewhere) or may be distorted cultural experiences which are being manifest as symptoms through his illness. This participant is an important case study as it highlights the difficulty of assessment for those who are not experienced

in Aboriginal culture. Furthermore, his story raises the possibility that Aboriginal people with traditional cultural beliefs may, if they experience psychosis, experience symptoms that cross-over, or are informed by cultural beliefs.

5.7.3 Case study B

Participant 54 was a 20 year old Aboriginal prisoner recruited to the research from a general main prison cell block at the MRRC. He had been received into prison 13 days before the interview and was identified in consultation with the prison Aboriginal drug and alcohol worker as a suitable healthy control participant. The participant reported finishing Year 7 at high school, having no medical or mental health conditions and having no-one in his family who suffered a mental health problem. He identified as being Aboriginal and reported both growing up in an Aboriginal family and having contact with an Aboriginal community.

His score on the CAARMS psychotic subscale was 0.50 (below the average of 0.58 for the Aboriginal healthy control group) and his overall CAARMS score was 1.45 (above the 0.70 average of the Aboriginal healthy group). His elevated overall CAARMS score was due to increased attentional deficit,; social isolation, aggressive behaviours, suicidal ideation, mood swings, and obsessive-compulsive behaviour. His overall BPRS score was 0.79 (below the average of 1.40 for the Aboriginal healthy control group). His Audit score was 0 (reporting he had drunk one 6-pack of beer in the last year). His OTI-R poly drug score was 4 having used heroin, alcohol, cannabis and tobacco in the 30 days prior to imprisonment. He was given a SOFAS score of 50 and a GARF of 70.

This participant reported experiences of hearing his son's voice calling him "Dad". He reported that this occurred only sometimes and that it had only begun since he had been in jail. When questioned he reported that it was not just thinking about his son saying "Dad" but he actually heard it and it made

him turn around to look. He had experienced this mostly when in his cell but later, upon reflection, he questioned whether this was real. He attributed this experience to not having seen his son and desperately missing him due to being in prison. This experience was the single psychotic-like experience reported by this participant and would normally be rated on the CAARMS perceptual abnormalities global rating scale as either 'moderately severe' or 'psychotic but not severe'. This participant received a rating of 'never' or 'absent' on this scale after consideration of the following:

1. There were no other psychotic symptoms reported on either the CAARMS or BPRS.
2. Discussion with the Aboriginal drug and Alcohol worker and a mental health nurse (who had experience working in Aboriginal communities) highlighted that the experience was viewed as a normal cultural experience perhaps precipitated by feelings or guilt and remorse about being away from his son.
3. There is suggestion in the literature that being contacted by relatives, or spirits (including actually hearing their voices) is a normal cultural experience for Aboriginal people and that where these experiences act to promote positive behaviour or outcome in the visited person the experience is not considered by the Aboriginal community as abnormal.

This participant is a good example of experiences which appear as hallmark features of psychosis, yet in the broader context of Aboriginal culture and perceived function of the experiences, are considered well within the range of normal experience within the Aboriginal community. This participant represents one a number of Aboriginal inmates who reportedly hear the voices of, or see images of, their relatives or ancestors. Many of these prisoners explain these experiences as their relatives or ancestors telling them to get their life together, and to do something positive.

Chapter 6
Discussion

The findings of this study have provided preliminary data suggesting that the CAARMS and the BPRS may not suitable for use to detect emergent psychosis in young Aboriginal people. Thus hypothesis 1, that the CAARMS will be able to detect young Aboriginal people with at-risk mental states for psychosis, is not supported. This study revealed that young non-psychotic Aboriginal people score significantly higher on both these measures than non-Aboriginal people with comparable: age; education; drug and alcohol use; and history of psychosis or absence of mental health problems. Use of either the CAARMS or the BPRS in their current form introduces the likelihood of an increased number of Type-1 errors (false positives). Thus, a larger number of young Aboriginal people are likely to be found to be significantly at-risk of psychosis than is actually the case, based on scores on the CAARMS. Similarly, the BPRS in its current form may produce scores that indicate a young Aboriginal person has a significant amount of psychopathology, or that existing pathology is more severe than is actually the case.

Results from this study suggest that the CAARMS does not differentiate the phenomenology of psychotic illness in young Aboriginal people with psychotic illness from those of young non-Aboriginal people with psychotic illness. However, the instrument may not assess culturally specific phenomenon. Therefore, it remains premature at this stage to state with any degree of conviction that that young Aboriginal people have the same phenomenology of psychotic illness as young non-Aboriginal people. While young Aboriginal people with psychosis in this study endorsed items on the CAARMS suggesting an understanding of the symptoms presented, it may be the case that there are unique experiences linked to psychotic illness in young Aboriginal people that the CAARMS does not tap but that are relevant to a psychotic illness. Thus the second hypothesis: that the phenomenology of EP in young Aboriginal people will be equivalent compared to young non-

Aboriginal people, cannot be confirmed or denied from results obtained on the CAARMS in this study.

The results obtained in this study have implications for the identification of suitable detection methods for emergent psychosis in young Aboriginal people. Furthermore, the results are an important finding for psychometric measurement of psychosis and symptoms of mental health in Aboriginal people. These implications and the relationship to the broader context of Aboriginal mental health are discussed below.

6.1 Measurement of psychosis in young Aboriginal people

6.1.1 The Use of CAARMS with young Aboriginal people

One important finding in this study was higher obtained scores for Aboriginal people across both the CAARMS component scores of symptom severity (intensity of the experience) and symptom frequency (how often the experience occurs). This pattern was found on the CAARMS for both the psychotic subscale and other CAARMS psychopathology scales. Thus, Aboriginal participants in this study reported they experienced common psychotic symptoms more intensely and more frequently than the non-Aboriginal participants. They also reported experiencing more symptoms of other forms of psychopathology. A portion of this finding may be accounted for by the likelihood that the Aboriginal psychotic group was more severely unwell at the time of interview. The Aboriginal psychotic group comprised 80% current psychiatric in-patients, versus 45% of the non-Aboriginal psychotic group. However, Aboriginal healthy control participants also scored significantly higher on the CAARMS psychotic sub-scale and overall score than the non-Aboriginal healthy controls, excluding illness severity as an explanatory factor. Thus the CAARMS scores obtained are higher than expected across both Aboriginal groups when compared to the non-Aboriginal groups and the original CAARMS baseline validation data.

The CAARMS differentiated Aboriginal and non-Aboriginal participants with psychosis from healthy controls. Both Aboriginal groups had higher obtained CAARMS scores compared to non-Aboriginal participants and baseline CAARMS validation study data (Yung et al., 2005). Despite the increased CAARMS scores for Aboriginal healthy and psychotic groups the obtained scores differentiated all healthy subjects (Aboriginal and non-Aboriginal) from those with psychotic illness.

Furthermore, it must be noted that for the purposes of preliminary evaluation of the CAARMS for this population, the study was designed to compare groups assumed to have little mental health overlap. Those having either an established psychotic illness (in many cases were hospitalised with psychosis at the time of interview), or those who had no history of mental illness. The CAARMS was designed to be used to detect emergent psychopathology, in particular psychosis, in young people who are at-risk of transitioning from health to psychosis or other mental illness. As such the obtained higher scores for healthy Aboriginal participants suggest that, were the CAARMS to be used in its current form with young Aboriginal people, a higher proportion of these people would be recorded as at-risk for psychosis, or suspected of other psychopathology, than may actually be the case. Thus the utility of the measure in accurately identifying those most at risk of transiting to psychosis is reduced. This reduction in accuracy is via a likely inflated Type-1 error rate. The results obtained in this study demonstrating higher scores suggest that the methods employed by the CAARMS to detect young people at-risk of psychosis are either unsuitable for young Aboriginal people or must be modified for use with young Aboriginal people.

The finding that the CAARMS differentiated Aboriginal participants diagnosed with psychotic illness from healthy controls in this sample suggests that the approach taken by the CAARMS may not be wholly unsuitable. Certainly the participants who suffered psychosis endorsed the experiences suggested by the questions on the CAARMS, indicating that they were experiences that had been encountered. Yet the question remains of why scores for healthy Aboriginal participants are inflated. Results suggest that the Aboriginal

participants understood the questions asked on the CAARMS to the same extent that non-Aboriginal participants did. It remains possible that Aboriginal participants interpreted the meanings of the questions slightly differently, and this led to the reporting of experiences as more intense and frequent than the healthy non-Aboriginal participants. The results suggest the language and concepts found in the CAARMS are understood by Aboriginal participants. However, the wording and expression may need to be revised to better reflect those of Aboriginal culture and to improve the accuracy of the instrument.

Currently the CAARMS does not have statistical norms outlining expected scores for ages or cultures. Despite the absence of norms, there is no evidence to suggest that Aboriginal people who are suffering psychotic illness or are healthy should score higher on measures such as the CAARMS than non-Aboriginal people. There is no published baseline CAARMS data for participants who are currently suffering psychosis. Therefore it also remains possible that the Aboriginal psychotic group scores are consistent with what might be expected for current patients hospitalised with psychotic illness, and who suffer more severe and frequent symptoms than those who are at-risk of psychosis.

The CAARMS results obtained for the non-Aboriginal participants in this study offer some support to this possibility. Non-Aboriginal psychotic participants had higher scores on the CAARMS psychotic sub-scale than baseline CAARMS data, demonstrating they had more intense, severe, and frequent psychotic symptoms than those identified as at-risk for psychosis, as might be expected. Yet, this group had lower overall CAARMS scores than the base-line at-risk group. This finding is in line with current early psychosis theory that psychosis emerges in an undifferentiated form from basic neurocognitive disruption (de Leon, Wilson, & Simpson, 1991; Ebel, Gross, Klosterkotter, & Huber, 1989; Huber & Gross, 1989) or across several types of psychopathology before aggregating into primarily psychotic symptoms (McGorry, 1999; McGorry, Killackey, & Yung, 2007; National Early Psychosis Project, 1998; Yung, Phillips, Yuen, & McGorry, 2004; Yung et al., 2005).

This same pattern is reflected in the Aboriginal psychotic group scores, which decrease from very high on the psychotic sub-scale to around what might be expected for at-risk patients on the overall CAARMS scores. Thus both psychotic groups had higher psychotic sub-scale scores than overall CAARMS scores. This is perhaps to be expected and may reflect that as illness progresses, symptoms become more clearly psychotic in nature whilst other types of psychopathology recede into the background. Despite this, Aboriginal participants still scored significantly higher on psychotic sub-scale and overall CAARMS scores.

If the CAARMS as a detection instrument, and the approach it employs, is to be considered as a suitable means to detect emergent psychosis in young Aboriginal people, then further investigation is required to derive baseline statistics for this group. The CAARMS remains the best available early detection standardised instrument and the only such measure with published Australian data. The scores obtained in this study are difficult to interpret in light of a lack of more comprehensive baselines data. However, this study has shown that use of the CAARMS with young Aboriginal people is likely to produce scores higher than expected from non-Aboriginal data. Thus the CAARMS cannot be considered valid in its current form for use with young Aboriginal people due to the likelihood of increased Type-1 errors. Further data from young Aboriginal people assessed on the CAARMS will yield further information as to the utility of this measure for detecting emergent psychosis in young Aboriginal people.

6.1.2 The Use of the BPRS with young Aboriginal people

The BPRS was employed in this study as a comparison measure of psychopathology to the CAARMS. Scores obtained on the BPRS were significantly positively correlated with CAARMS scores. Thus the pattern of results was the same as for the CAARMS with Aboriginal people. Aboriginal participants scored higher on the BPRS than the non-Aboriginal participants regardless of illness group. Similarly to the CAARMS results, the BPRS

scores differentiated between all participants on the basis on psychotic illness or health.

The BPRS does not contain a psychotic sub-scale but is intended as a brief measure of general psychopathology. The results obtained suggest that the BPRS is able to differentiate young Aboriginal people with psychosis from young healthy Aboriginal people. However, as with the CARRMS results, the scores obtained are higher than those of the non-Aboriginal groups. Therefore the use of the BPRS in its current form with Aboriginal people is likely to result in increased Type-1 errors. As there is no baseline data for psychosis or health on the BPRS, the Type-1 errors likely to occur, should the BPRS be used with young Aboriginal people, are those suggesting that psychopathology is more severe than is actually the case. The results obtained in this study suggest elevated scores on the BPRS over what might be expected when compared to non-Aboriginal people.

There was no significant difference in the number of questions not understood on the BPRS by Aboriginal participants compared to non-Aboriginal participants. The instrument's ability to differentiate between Aboriginal psychotic participants and healthy controls suggests that there is validity for this population for the types of questions asked. Yet the same difficulties arise as noted on the CAARMS: why are scores inflated? The answers may well lie in the interpretation of the questions due to expression and wording not accurately reflecting Aboriginal culture. There is not yet published evidence to suggest that the BPRS methodology is valid for assessing general psychopathology in Aboriginal people. The BPRS, unlike the CAARMS does not assess for frequency of symptoms; instead it makes an assumption that severity is inclusive of frequency. As such the assessment methods employed by the BPRS are less sophisticated than the CAARMS, yet the results are similar. Thus it may be something about the way the questions are worded, asked, or interpreted on the BPRS, which inflates Aboriginal scores.

The BPRS is a current gold-standard measure in use within psychiatric hospitals and drug-trials across Australia. The results obtained in this study

require further investigation across a range of ages and illnesses experienced by Aboriginal people. Such investigation will more clearly ascertain whether the instrument records inflated scores for this population. Until such data is obtained the results from this study suggest it may not be valid for use with young Aboriginal people.

6.2 Other data

Participants in this sample were equivalent across groups on marital status, education, chronic health, and family mental health problems. A significant difference was found on age between the Aboriginal psychotic group and the non-Aboriginal healthy group, who were significantly younger. However both group means were well within the targeted 16-25 years age range and therefore the difference was considered to be of little clinical significance. Significant differences were also found on principal occupation with the Aboriginal psychotic group having significantly more unemployed participants, unskilled workers, and significantly less tertiary students than the other groups. These differences are in line with what might be expected for a sample of Aboriginal prisoners with diagnosed psychotic illness, and reflect statistics from the general Aboriginal and non-Aboriginal population (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005; Steering Committee for the Review of Government Service Provision, 2005).

Differences were also found between Aboriginal and non-Aboriginal groups on a number of other factors in this study. For example, the Aboriginal psychotic group used more types of drugs than the non-Aboriginal healthy group. This result is expected given the Aboriginal psychotic group were all prisoners, versus only 30% of the non-Aboriginal healthy group. This result is likely to reflect that prisoners have higher drug use than the broader community (Butler & Allnutt, 2003) and young Aboriginal people have been shown to have higher drug use than the non-Aboriginal community (Australian Bureau of Statistics, 2004).

Whilst there was significant difference between the Aboriginal psychotic and the non-Aboriginal healthy groups on drug use, there was no significant difference between other groups. Both the Aboriginal psychotic and healthy groups did not differ on drug use nor did the non-Aboriginal psychotic and Aboriginal healthy groups.

Surprisingly, there was no difference found between groups for alcohol use, with the sample as a whole demonstrating alcohol use above the cut-off score for harm. It was expected that participants with psychotic illness would use more alcohol; however the results do not support this. The results obtained are likely to reflect a widespread of pattern of high alcohol use amongst young people regardless of mental health status or culture.

Differences were also found in social and occupational functioning, which assessed participants' social and vocational achievements and aspirations. These results demonstrated that psychosis is associated with lower social and occupational functioning, and that non-Aboriginal healthy participants had significantly higher functioning than healthy Aboriginal participants. These results are consistent with published data demonstrating that Aboriginal people across the board have greater disadvantage. Such disadvantage is expected to be associated with lower social and occupational functioning (Australian Bureau of Statistics, 2004; Steering Committee for the Review of Government Service Provision, 2005). These results are consistent with the expectation that the experience of psychosis lowers social and occupational functioning (Carr et al, 2004). However, the results demonstrate that Aboriginality does not further reduce this functioning. Thus whilst Aboriginal people may have lower social and occupational functioning initially, and presumably from existing higher levels of disadvantage, the reduction in functioning derived from psychotic illness is similar in Aboriginal and non-Aboriginal people.

Differences were also found on GARF scores which assessed general and relational functioning including background family factors. General and

relational functioning was significantly lower in the Aboriginal psychotic group than the non-Aboriginal healthy group. There were no other significant differences between groups on general and relational functioning. This difference is likely to be accounted for by an interaction of two factors. Firstly, Aboriginal people suffer higher levels of disadvantage. Secondly, the Aboriginal psychotic group comprised young participants diagnosed with psychotic illness. Thus the combination of higher rates of family mental health problems (both participant and often family member) and greater disadvantage may act in concert to significantly lower family functioning amongst the Aboriginal psychotic participants in this sample.

Results for medical record data for the Aboriginal and non-Aboriginal psychotic groups demonstrated no differences on diagnosis, chronic health, and symptom type. A difference was found in medical records for substance use between groups. The Aboriginal psychotic group had significantly more participants recorded as dependent on drugs, and the non-Aboriginal psychotic group had more participants recorded as drug-abusers. This result is supported by the results on drugs from participant interviews. These results demonstrated Aboriginal psychotic participants use larger amounts of all drugs except amphetamines, inhalants, and tobacco, when compared to non-Aboriginal psychotic participants. Additionally Aboriginal psychotic participants used significantly more types of drugs in the 30 days prior to interview than other groups further supporting collected medical record data.

6.3 Qualitative data

The qualitative data obtained in this study supports the results obtained on the CAARMS and BPRS. Results from the pilot study suggest the Aboriginal community believe their mental health to be different to non-Aboriginal mental health and thus require different methods of assessment. The pilot study results suggest that a different type of assessment is needed based on different understandings of what constitutes mental health and mental ill-health in the Aboriginal community. Furthermore the pilot study results also

suggest a different approach is required to how questions about mental health should be asked in the assessment of Aboriginal people.

The results of the pilot study predict a difference in the scores obtained on the CAARMS and BPRS based on culture. Whilst there is no overt suggestion to the direction of such a difference, the pilot study results could be interpreted as a prediction that Aboriginal people are less likely to volunteer information on their mental health as part of cultural differences. Thus a prediction from these results is for less, rather than more, endorsement of items on these measures. However, the results suggest that young Aboriginal people in this study endorsed more items than non-Aboriginal participants, and for the CAARMS indicated more intensity and frequency of symptoms. Given these circumstances it is likely there is another unidentified factor or factors accounting for the results on the CAARMS and BPRS, and not covered by the pilot study questions.

In contrast to the above, results from the two case studies of participants included in the quantitative results offer further insight. These results support a prediction that Aboriginal people both with diagnosed psychotic illness, and healthy, will score more highly on the CAARMS and BPRS when compared to non-Aboriginal participants. The case studies demonstrate that Aboriginal people experience a range of phenomena that may be interpreted as psychotic symptoms by non-Aboriginal people. In the context of psychotic illness and health these experiences are likely to inflate CAARMS and BPRS scores as items are endorsed and subsequently recorded as illness, where they may actually be normal cultural experiences. These case studies predict that these instruments may be over-sensitive to what is regarded as symptomatology by non-Aboriginal mental health clinicians and do not include decision rules as to what constitutes symptoms and cultural experiences in assessing Aboriginal people.

6.4 Limitations

Despite the findings of significantly increased scores on the CAARMS and BPRS for Aboriginal participants, these results must be viewed in the context of several limitations to the study sample and methodology.

6.4.1 Sample limitations

The sample obtained for this study was a mixed sample of participants who were drawn from the community or from the NSW prison system. Difficulties in obtaining young Aboriginal psychotic participants from the community resulted in all Aboriginal psychotic participants being prisoners and most being psychiatric in-patients. By comparison, just over a one-third of the non-Aboriginal psychotic group were drawn from the community, and just under half were in-patients. Thus it is likely that the Aboriginal psychotic sample were more severely unwell than the non-Aboriginal psychotic sample.

There was a similar pattern in the healthy groups where half of the healthy Aboriginal group were prisoners, compared to just under one-third of the healthy non-Aboriginal group. It has been demonstrated (Butler & Allnutt, 2003) that prisoners have worse mental health then the broader community and as such it remains possible that healthy Aboriginal prisoners, despite screening for mental health problems, may have increased symptomatology over non-Aboriginal patients from the community.

Despite efforts to match groups as closely as possible on demographic variables, differences occurred between groups in the sample. Just under 20% of the sample were female and thus the results obtained cannot be generalised to young Aboriginal women. The Aboriginal psychotic group was significantly older than the non-Aboriginal health group and whilst the small difference in group means is thought to be of little clinical significance, there remains a difference. Differences also exist between the Aboriginal psychotic group and non-Aboriginal healthy group in terms of education, occupation,

drug use, social and occupational functioning, and family functioning. Whilst these factors are broadly representative of recorded differences found between these groups in the community, they serve to reduce the ability to compare and thus generalise of the results of the study.

6.4.2 Methodological limitations

Several measures were employed to standardise the methodology of the study. These included the study interviewer undertaking training in the CAARMS and the use of standardised questions to assess the BPRS, SOFAS, and GARF. However several methodological limitations remain. A single interviewer who was not blind to the health, nor culture of the participants interviewed, completed the study. Thus a scoring bias remains possible.

Repeated efforts were made to involve a trained Aboriginal mental health worker in the project to assist in conducting interviews and to provide advice on Aboriginal mental health. Few Aboriginal mental health workers exist within mainstream health or Aboriginal Medical Services. The few workers potentially available were unable to dedicate time to the study. At the time the research was conducted in the Metropolitan Reception and Remand Centre (January, 2007 to November, 2007) there were no Aboriginal mental health workers employed at the centre. This situation remains problematic for research in this area and for Aboriginal mental health in this centre. An Aboriginal academic, with broad experience of Aboriginal culture and young Aboriginal people, participated in the study as a co-researcher. This co-researcher was similarly not blind to the health, nor culture of the participants. Due to work commitments the co-researcher was present at approximately 20% of all interviews, distributed evenly across all groups. Thus a limitation to the study is a lack of Aboriginal mental health representation during a significant proportion of the interviews conducted. To combat this, advice on Aboriginal mental health was sought from: the MRRC Aboriginal drug and alcohol worker; MRRC mental health nurses with experience of working in

Aboriginal communities; and Aboriginal mental health workers from mainstream health and Aboriginal medical services.

6.5 Implications and relation to the broader context

The results of this study, demonstrating Aboriginal people score significantly higher on the CAARMS and the BPRS, have implications for the assessment of psychosis in this population. There is no evidence to date about the course of early psychosis in young Aboriginal people or suitable methods to assess emerging psychosis in this population. The question of whether Aboriginal people have a different phenomenology of psychotic illness remains. The CAARMS is recognised as the most effective measure for assessing risk of psychosis in young non-Aboriginal people. However, the results obtained in this study have questioned the usefulness for young Aboriginal people of mean scores for young people at-risk of psychosis derived from the CAARMS baseline validation data. In its current form the use of the CAARMS with young Aboriginal people may produce elevated scores and a subsequent risk of increased Type-1 error. This research serves to highlight the lack of knowledge about risk of psychosis and early psychosis in Aboriginal people. It further serves to highlight how little is currently known about assessing Aboriginal people using psychometric measures.

Significantly higher scores on the BPRS for young Aboriginal people also questions the use of existing psychiatric assessment measures for illness in the Aboriginal population. Furthermore the obtained results highlight the need for obtaining separate Aboriginal baseline sores for these measures.

A broader implication, and one argued before (Swan & Raphael, 1995; Urbis Keys Young, 2001), is that the approach taken by psychometric measures in assessing psychiatric symptoms may not be valid for Aboriginal people at all. This argument is difficult to sustain for several reasons. Firstly, all mental health assessment, regardless of culture, proceeds upon behavioural observation and questions about experiences. The formalising of this process

via standardisation does not significantly alter the way this crucial information is gathered. Thus whilst the questions asked by the CAARMS or the BPRS may be the wrong questions in terms of language or meaning, this possibility does not serve to undermine the approach. Secondly, the current study demonstrated that both the CAARMS and BPRS robustly differentiated Aboriginal participants with psychosis from healthy Aboriginal participants. Thus whilst the ability of the CAARMS to delineate correctly the point at which young Aboriginal people become at-risk of psychosis is still in question, the results provide evidence that the approach is sound. Following from this, if the approach is sound and instruments such as the CAARMS can incorporate baselines for Aboriginal people, or be altered to produce similar baselines to non-Aboriginal people, this should be pursued. The CAARMS offers a comprehensive standardised approach to assessing the range of psychopathology a young person may be experiencing. Furthermore, it provides the ability to identify those at-risk of psychosis and map this risk across time. The preliminary results demonstrating the CAARMS' ability to differentiate healthy young Aboriginal people from those with psychotic illness are encouraging. The results suggest that this instrument represents, with Aboriginal baselines or alterations, an assessment tool for detecting psychosis in the young Aboriginal populations that is lacking at present.

A better knowledge of psychosis amongst Aboriginal people is dependent on suitable assessment and measurement methods to yield high-quality data. Yet instruments cannot be used as the lack of knowledge has resulted in questions about the suitability of the instruments.

The results from this study provide a platform, albeit limited, upon which further research could proceed. Such research may highlight whether instruments such as the CAARMS could be used in current form with revised baselines, or adapted, for use with young Aboriginal people. Instruments such as the CAARMS may also be useful in answering questions of the phenomenology of psychotic illness in young Aboriginal people by exploring similar and possible unique symptoms. Such research is important for several reasons. Currently there is no evidence as to how best to assess or treat

young Aboriginal people with emergent psychosis. It is not known whether the symptoms they suffer, the course of illness, or indicated treatments, are equivalent to those confirmed for young non-Aboriginal people. Providing more impetus for such research are recent findings that Aboriginal people suffer higher rates of psychotic illness than the non-Aboriginal population (Australian Bureau of Statistics and Australian Institute of Health and Welfare, 2005), and that a large proportion of the Aboriginal population (40%) will move into the highest incidence for psychosis bracket (16-29 years) within the next 15 years (Australian Institute of Health and Welfare, 2006b). Thus if research into early psychosis detection in young Aboriginal people is not given priority, it is likely there will be increased numbers of young Aboriginal people with emergent psychotic illness who remain undetected. Early psychosis research has demonstrated (McGorry, 1994; McGorry, Killackey, & Yung, 2007) that early detection is critical to improving illness course or effecting prevention of illness altogether. A continued lack of research is likely to result in increased numbers of young Aboriginal people who suffer chronic psychotic illness with attendant disability. The CAARMS remains the best assessment method available and warrants further research consideration for use with young Aboriginal people.

Beyond the detection of early psychosis, the results presented by this study can be interpreted in the wider context of what is known about psychosis amongst Aboriginal people. The results obtained are in contrast with those of the only published research on the diagnosis of schizophrenia in Aboriginal people (Mowry, Lennon, & De Felice, 1994). This research suggested that Aboriginal people were under-diagnosed, and were less likely to be found to be suffering symptoms such as bizarre delusions. However, this research used retrospective medical record analysis and the diagnoses recorded did not use standardised instruments. This previous research demonstrated that cultural differences between patient and clinician, affect diagnosis. It may be that routine clinical diagnostic interview is not sensitive enough to psychotic symptoms in Aboriginal people. The CAARMS was developed to be an extremely sensitive instrument with the ability to emergent psychotic

symptoms. Thus the sensitivity may conversely be too high in the presence of Aboriginal culture in comparison to routine clinical diagnostic interview.

The current study has highlighted other aspects of Aboriginal mental health. The current focus on the determinants of Aboriginal mental ill-health as being accounted for by factors of disadvantage can be traced back to ethno psychiatrists such as Kiloh and Cawte (Bianchi, Cawte, & Kiloh, 1970; Cawte, 1964; Kiloh, 1975). There is little doubt that disadvantage, coupled with a detrimental socio-political history, is by far the largest component of the increased rates of mental illness amongst the Aboriginal community. The results of this study are consistent with disadvantage as being an important risk factor for psychosis in the Aboriginal community and support the stress-diathesis model of psychotic illness (Zubin & Spring, 1977) for Aboriginal people. The work begun by early researchers into identifying clinical features of mental illness amongst Aboriginal people has seemingly not been continued. The result has been, and Westerman is a notable exception here (Vicary & Westerman, 2004; Westerman, 2003, 2004), that the focus of Aboriginal mental health research and policy has been on addressing the social determinants of ill-health.

What is missing from this policy and research is a sound knowledge base about what does and does not constitute Aboriginal mental ill-health. This lack extends to how Aboriginal mental health should be assessed, and how it should be treated. Given the current high rates of mental illness amongst the Aboriginal population, and the lack of success in improving the social determinants over several years of sustained government effort (Steering Committee for the Review of Government Service Provision, 2005; Urbis Keys Young, 2001), a renewed research effort in identifying and treating Aboriginal mental health problems is warranted. Research into how best to assess mental health in Aboriginal people, and therefore highlight clinical similarities and differences, is imperative to identifying effective treatments. The validation or development of standardised measures is central to amassing an evidence base that makes effective assessment and treatment possible.

However, research into Aboriginal mental health is difficult for a number of reasons. It has now been noted consistently that the lack of an existing evidence base for Aboriginal mental health means there is little to inform researchers of where or how research efforts should be focussed (Haswell-Elkins, Sebasio, Hunter, & Mar, 2008; Swan & Raphael, 1995; The Aboriginal and Torres Strait Islander Research Agenda Working Group, 2003; Urbis Keys Young, 2001). In essence, the tools available to researchers in non-Aboriginal mental health have not yet been validated or developed for Aboriginal mental health researchers. Furthermore, there is little preliminary data to suggest how to validate or develop these tools to create research directions. In addition researchers must fulfil certain requirements in order to conduct research in Aboriginal communities. These requirements include satisfying the six guidelines to ethical conduct in Aboriginal research published by the NH&MRC (National Health & Medical Research Council, 2003). The difficulties of researching psychiatric patients and illness are well documented (Rundell & Wise, 2002), and marked by barriers to the research process. Where these patients are intended to be Aboriginal an additional set of ethical requirements (including Aboriginal community consultation and approval, and satisfaction of the six NH&MRC guidelines) makes a difficult research process more time-consuming and difficult to complete. The result of combining these factors is such research is less likely to be undertaken.

The concerns about the likelihood of significant progress being made in Aboriginal mental health research at a high quality clinical research level are numerous. Beyond the difficulties noted above are the compounding difficulties of a lack of an existing knowledge base. A primary difficulty for researchers lies in identifying and involving clinicians with suitable expertise in Aboriginal mental health. The current lack of Aboriginal mental health workers and the almost exclusive absence of Aboriginal mental health nurses, psychologists, and psychiatrists, exclude professionals routinely consulted and involved in mental health research. Ideally, more qualified Aboriginal researchers would be available from mental health backgrounds to pursue this type of research. However, there is a current training gap of Aboriginal people at a clinical mental health level. Closing this gap must be considered a

priority. Whilst it remains, a sufficient supply of Aboriginal researchers with suitable skills is destined to still be some way off.

The above all serve to reduce the likelihood of important Aboriginal mental health research being completed. The present study experienced all of the above difficulties and serves to highlight perhaps why there is an existing lack of this type of research. Additionally, the researchers in this study were surprised at the difficulty the research encountered in obtaining Aboriginal ethics approval. The continued questioning of the scientific value, expertise, consultation, methodology, and Aboriginal participation in this research by the peak NSW Aboriginal ethics body, in contrast to approvals provided by mainstream academic institutions, was not only a discouragement to the researchers but an impediment to all but the completion of the research.

There are valid concerns to be addressed in the conduct of all Aboriginal research. Past abuses cannot, and should not, be ignored. The Aboriginal community should be the final arbiters over what research is deemed useful and ethical. However, the very real danger of proliferating the current lack of Aboriginal mental health research is apparent. The existing gap in knowledge about the assessment and treatment of Aboriginal people's mental health will be widened where researchers are discouraged rather than encouraged to answer questions about Aboriginal mental health. Research such as the present study are important in providing a platform to inform further research and illuminate effective Aboriginal mental health assessment and treatment methods. The cost to Australian society of not completing such research is to fail to reduce the suffering of Aboriginal people with mental health problems and possibly increase suffering further.

6.6 Conclusion

This study has provided preliminary data suggesting that the CAARMS and BPRS may not be currently suitable for use in detecting emergent psychosis or measuring psychopathology in young Aboriginal people. Within the

limitations of this study, the results suggest an increased likelihood of Type-1 errors (false positives) with the current form of the CAARMS if used with young Aboriginal people. Thus the CAARMS may have reduced ability to identify and predict incipient risk of psychosis if used with young Aboriginal people. Consistent with findings of the CAARMS, the results on the BPRS highlight similar concerns about the validity of this instrument for use with this population. Increased scores on the BPRS may serve to portray young Aboriginal people as ill or as suffering an inflated severity of psychopathology. Furthermore these results raise concerns about the validity of all current psychiatric instruments and highlight the possibility of inflated scores if used with young Aboriginal people.

However, results from this study also demonstrated that both the CAARMS and BPRS were able to differentiate young Aboriginal sufferers of psychotic illness from healthy controls. Thus the CAARMS may be of use in identifying and measuring young Aboriginal people at-risk of psychosis with the addition of baseline validation data for young Aboriginal people known to be risk of psychosis. Alternately, the CAARMS may require modification to reduce scores to comparable non-Aboriginal baseline levels.

The identification of suitable instruments to assess and measure psychosis and risk of psychosis in young Aboriginal people should be a research priority. The existing high rates of psychosis in the Aboriginal community and the significant proportion of the community entering the peak incidence range for psychosis, combined with high levels of disadvantage, make such research an imperative. The CAARMS remains the best available instrument for these purposes, and further research will highlight how it may be made suitable for use with young Aboriginal people.

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Appendices

Appendix A

Demographics questionnaire

DEMOGRAPHIC DATA

Thank you for completing the following questionnaire. It will provide us with your contact details and with demographic information that will be used in the form of group data, so there will be no identification of individual participants. Your name will not appear on any of the other questionnaires, as we will use a number code to match the questionnaires. All information provided will be kept strictly confidential.

Date of Birth:_____ Age:_____

Sex: Male ☐ Female ☐

Marital status: Single ☐ Married ☐ Divorced ☐ Widowed ☐ Defacto ☐

Country of origin: _____ Main language spoken at home: _____

Highest education level achieved: ☐ Primary ☐ High school (Please state grade:_____)

☐ TaFE ☐ University ☐ Other_____

Principal Occupation: _____ Time in your current position:_____

Have you ever been diagnosed with a medical condition? If so, please list: _____

_____

Names and dose of any medications you are taking: _____

_____

Have you ever been treated for a mental health problem? Yes ☐ No ☐

Does anyone in your family suffer from a mental health problem? Yes ☐ No ☐

If so, Who?_____ What problem?_____

Do you identify as being an Aboriginal person? Yes ☐ No ☐

Did you grow up in an Aboriginal family? Yes ☐ No ☐

Did you grow up having contact with an Aboriginal community? Yes ☐ No ☐

Which of the following areas did you grow up in? Outback ☐ Rural ☐ Metropolitan ☐

Office Use Only

Code: _____ Group: _____Date:_____

Appendix B

The Comprehensive Assessment of At-Risk Mental States for Psychosis (CAARMS)

COMPREHENSIVE ASSESSMENT OF AT RISK MENTAL STATES

(CAARMS)

MONTHLY VERSION
January 2002

A. Yung, L. Phillips, P. McGorry, J. Ward, K. Donovan, K. Thompson

THE PACE CLINIC
University of Melbourne,
Department of Psychiatry

Melbourne, Australia

Patient Name:	CRF #:
Date:	Rater:

OVERVIEW OF THE CAARMS

Aims:

- To determine if an individual meets the criteria for an 'At Risk Mental State'
- To rule out, or confirm criteria for acute psychosis
- To map a range of psychopathology and functioning factors, over time in young people at ultra high-risk of psychosis

Structure of the CAARMS:

- Ratings are made on a range of subscales that target different areas of psychopathology and functioning. From these ratings it is then possible to extract information relating to the above aims.

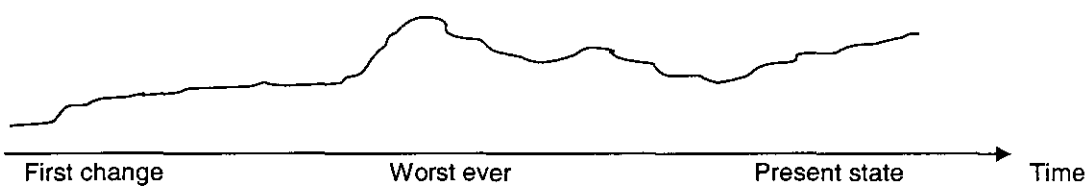
Overview of Symptoms and Functioning - Longitudinal Change:

- At the first interview (not follow-up interviews), the CAARMS aims to obtain a general overview of the history of change from the premorbid state in the respondent. All available information should be used.
- Record the **time of first noted change** - date and age of respondent in years:

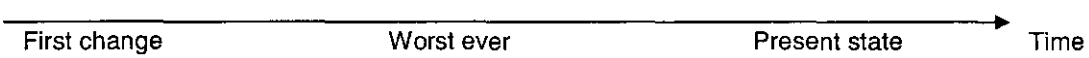
  Date: .....
  Age: .....

- Note first ever symptoms or signs:
  .....
  .....
  .....
  .....
  .....

- Overview of course since then - map on timeline e.g.:



- Current time line:



1: POSITIVE SYMPTOMS

1.1 DISORDERS OF THOUGHT CONTENT

Delusional Mood and Perplexity ('Non Crystallized Ideas')

- Have you had the feeling that something odd is going on that you can't explain? What is it like?
- Do you feel puzzled by anything? Do familiar surroundings feel strange?
- Do you feel that you have changed in some way?
- Do you feel that others, or the world, have changed in some way?

Non-Bizarre Ideas ('Crystallized Ideas')

- Ideas of Reference: Have you felt that things that were happening around you had a special meaning, or that people were trying to give you messages? What is it like? How did it start?
- Suspiciousness, Persecutory Ideas: Has anybody been giving you a hard time or trying to hurt you? Do you feel like people have been talking about you, laughing at you, or watching you? What is it like? How do you know this?
- Grandiose Ideas: Have you been feeling that you are especially important in some way, or that you have powers to do things that other people can't do?
- Somatic Ideas: Have you had the feeling that something odd is going on with your body that you can't explain? What is it like? Do you feel that your body has changed in some way, or that there is a problem with your body shape?
- Ideas of Guilt: Do you feel you deserve punishment for anything you have done wrong?
- Nihilistic Ideas: Have you ever felt that you, or a part of you, did not exist, or was dead? Do you ever feel that the world does not exist?
- Jealous Ideas: Are you a jealous person? Do you worry about relationships that your spouse/girlfriend/boyfriend has with other people?
- Religious Ideas: Are you very religious? Have you had any religious experiences?
- Erotomanic Ideas: Is anyone in love with you? Who? How do you know this? Do you return his/her feelings?

Bizarre Ideas ('Crystallized Ideas')

- Made thoughts, feelings, impulses: Have you felt that someone, or something, outside yourself has been controlling your thoughts, feelings, actions or urges? Have you had feelings or impulses that don't seem to come from yourself?
- Somatic Passivity: Do you get any strange sensations in your body? Do you know what causes them? Could it be due to other people or forces outside yourself?
- Thought Insertion: Have you felt that ideas or thought that are not your own have been put into your head? How do you know they are not your own? Where do they come from?
- Thought Withdrawal: Have you ever felt that ideas or thought are being taken out of your head? How does that happen?
- Thought Broadcasting: Are your thoughts broadcast so that other people know what you are thinking?
- Thoughts Being Read: Can other people read your mind?

DISORDERS OF THOUGHT CONTENT- GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic and Severe**
No disorders of thought content.	Mild elaboration of conventional beliefs as held by a proportion of the population	Vague sense that something is different, or not quite right with the world, a sense that things have changed but not able to be clearly articulated. Subject not concerned/ worried about this experience.	A feeling of perplexity. A stronger sense of uncertainty regarding thoughts than 2. **OR** Odd or unusual thoughts but whose content is not entirely implausible- may be some logical evidence. More evidence than rating of 4. Content of thoughts not original i.e. jealousy, mild paranoia.	Unusual thoughts, which can be easily dismissed. Clearly idiosyncratic beliefs, which although 'possible' have arisen without logical evidence. Less evidence than rating of 3 (eg referential ideas that certain events, objects or people have a particular and unusual significance.)	Unusual thoughts about which there is some doubt (not held with delusional conviction), or which the subject does not believe all the time. May result in some change in behaviour, but minor.	Unusual thoughts containing original and highly improbable material held with delusional conviction (no doubt). May have marked impact on behaviour.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

1.2 PERCEPTUAL ABNORMALITIES

Visual Changes

- Distortions, illusions: Is there a change in the way things look to you? Do things somehow look different, or abnormal? Are there alterations in colour, or brightness of objects (things seeming brighter, or duller in colour)? Are there alterations in the size and shape of objects? Do things seem to be moving?
- Hallucinations: Do you have visions, or see things that may not really be there? Do you ever see things that others can't, or don't seem to? What do you see? At the time that you see these things, how real do they seem? Do you realise they are not real at the time, or only later?

Auditory Changes

- Distortions, illusions: Is there any change in the way things sound to you? Do things somehow sound different, or abnormal? Does your hearing seem more acute, or have increased sensitivity? Does your hearing seem muted, or less acute?
- Hallucinations: Do you ever hear things that may not really be there? Do you ever hear things that other people seem not to (such as sounds or voices)? What do you hear? At the time you hear these things, how real do they seem? Do you realise they are not real at the time, or only later?

Olfactory Changes

- Distortions, illusions: Does your sense of smell seem to be different, such as more, or less intense, than usual?
- Hallucinations: Do you ever smell things that other people don't notice? At the time, do these smells seem real? Do you realise they are not real at the time, or only later?

Gustatory Changes

- Distortions, illusions: Does your sense of taste seem to be different, such as more, or less intense, than usual?
- Hallucinations: Do you ever get any odd tastes in your mouth? At the time that you taste these things, how real do they seem? Do you realise they are not real at the time, or only later?

Tactile Changes

- Distortions, illusions, hallucinations: Do you ever get strange feelings on, or just beneath, your skin? At the time that you feel these things, how real do they seem? Do you realise they are not real at the time, or only later?

Somatic Changes

NOTE: Probes also used to rate Impaired Bodily Sensation, p.26

- Distortions, illusions: Do you ever get strange feelings in your body (eg feel that parts of your body have changed in some way, or that things are working differently)? Do you feel/think that there is a problem with some part, or all of your body, i.e. that it looks different to others, or is different in some way? How real does this seem?
- Hallucinations: Have you noticed any change in your bodily sensations, such as increased, or reduced intensity? Or unusual bodily sensations such as pulling feelings, aches, burning, numbness, vibrations?

PERCEPTUAL ABNORMALITIES - GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Psychotic but not severe**	6 **Psychotic and severe**
No abnormal perceptual experience.		Heightened, or dulled perceptions, distortions, illusions (eg lights/ shadows). Not particularly distressing. Hypnogogic/ hypnopompic experiences	More puzzling experiences: more intense/vivid distortions/ illusions, indistinct murmuring, fleeting shadows etc. Subject unsure of nature of experiences. Able to dismiss. Not distressing. Derealisation/ depersonalisn	Much clearer experiences than 3 such as name being called, hearing phone ringing etc, but may be fleeting/ transient. Able to give plausible explanation for experience. May be associated with mild distress.	True hallucinations i.e. hearing voices or conversation, feeling something touching body. Subject able to question experience with effort. May be frightening or associated with some distress.	True hallucinations which the subject believes are true at the time of, and after, experiencing them. May be very distressing

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

1.3 DISORGANISED SPEECH

NOTE: Probes also used to rate Alogia, p. 17

Subjective Change:

- Do you notice any difficulties with your speech, or ability to communicate with others?
- Do you have trouble finding the correct word at the appropriate time?
- Do you ever use words that are not quite right, or totally irrelevant?
- Have you found yourself going off on tangents when speaking and never getting to the point? Is this a recent change?
- Are you aware that you are talking about irrelevant things, or going off the track?
- Do other people ever seem to have difficulty in understanding what you are trying to say/trouble getting your message across?
- Do you ever find yourself repeating the words of others?
- Do you ever have to use gesture or mime to communicate due to trouble getting your message across? How bad is this?
- Does it ever make you want to stay silent and not say anything?

Objective Rating of Disorganised Speech

- Is it difficult to follow what the subject is saying at times due to using incorrect words, being circumstantial or tangential?
- Is the subject vague, overly abstract or concrete? Can responses be condensed?
- Do they go off the subject often and get lost in their words? Do they appear to have difficulty finding the right words?
- Do they repeat words that you have used or adopt strange words (or 'non-words') in the course of regular conversation?

DISORGANISED SPEECH- GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic**
Normal logical speech, no disorganisation, no problems communicating or being understood.		Slight subjective difficulties eg problems getting message across. Not noticeable by others.	Somewhat vague, some evidence of circumstantiality, or irrelevance in speech. Feeling of not being understood.	Clear evidence of mild disconnected speech and thought patterns. Links between ideas rather tangential. Increased feeling of frustration in conversation.	Marked circumstantiality, or tangentiality in speech, but responds to structuring in interview. May have to resort to gesture, or mime to communicate.	Lack of coherence, unintelligible speech, significant difficulty following line of thought. Loose associations in speech.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

2: COGNITIVE CHANGE ATTENTION/CONCENTRATION

2.1 SUBJECTIVE EXPERIENCE (HUBER'S BASIC SYMPTOM)

Concentration and Attention Problems:

- Have you had difficulty concentrating (difficulty listening to others, watching television, reading)?
- Is it more of an effort to think about, or concentrate on things?

Selective Attention Problems:

- Is it difficult to pay attention to just one thing?
- Are you distracted by other things easily?
- Have you been feeling overwhelmed, or confused by all the things that have been happening in the environment around you?

Thought Form Problems:

NOTE: See also Alogia, p. 17

- Do your thoughts ever seem to stop, get blocked, or disappear (e.g. do you have 'trances', or 'blank spells')? Can you describe this more fully?
- Do you ever experience racing or confused, jumbled thoughts?
- Do other things, as well as your thoughts, seem to stop e.g. attention, hearing, sight, memory, speech, or movement?
- Do you ever lose your sense of personal identity? What do you think was the cause of this?

Comprehension Difficulties:

- Do you have trouble following what others are saying?
- Do you sometimes require sentences to be repeated, especially long sentences?
- Do you sometimes not understand figures of speech and so on?
- Is this a change for you, or have you always had trouble with this?
- Do you ever have trouble picking up the emotional tone of conversations (eg not recognising sarcasm, or irony)?
- Is it ever hard to understand non-verbal forms of communication i.e. gestures? How bad is this?

Memory Problems:

NOTE: See also Dissociative Symptoms, p.36

- Have you had memory problems?
- Have you ever felt as if there were large gaps in your memory?
- Are they present all the time, or do they come and go? Have you noticed if the memory problems come at times of stress?

SUBJECTIVE COGNITIVE CHANGE- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No subjective difficulty with concentration /attention.	Subject aware of some changes, but attributable perhaps to extraneous factors. Subject has difficulty in pinpointing changes.	Mild, but definite problems eg some difficulty concentrating while reading, or watching TV. Concentrating requires more effort. **OR** Slight impairment in memory, but passing.	Subjectively feeling muddled, or confused, racing, or slowed thoughts, difficulty understanding conversations. Occ. episodes of thought blocking. **OR** Memory problems more evident but do not interfere with everyday functioning.	Subjective feeling of being unable to think properly, confused, unable to understand others. More regular episodes of thought blocking **OR** Memory difficulties impair conversation, results in frequent misplacing of items.	Marked inattentiveness, feeling confused and overwhelmed at times, distracted by other things in the environment. Frequent episodes of thought block. **OR** Memory difficulties noted by others, distressing.	Subject reports extreme difficulty focussing on interview. Interview suspended due to impossibility of patient to concentrate or severe thought blocking. **OR** Severe memory problems.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

2.2 Observed Cognitive Change

Observed Inattentiveness During Interview

- Subject appears inattentive - looks away during interview, does not pick up the topic during a discussion, shifts focus of attention.
- Attention may be drawn to noise in adjoining room, objects around the room, interviewer's clothing etc

Observed Inattentiveness During Mental Status Testing

- The subject may perform poorly on simple tests of intellectual functioning in spite of adequate education and intellectual ability.
- This is assessed by having the subject spell the word 'world' backwards and by serial 7s or serial 3s for a series of 5 subtractions.
- **D L R O W**
- **100, 93, 86, 79, 72**
- **100, 97, 94, 91, 88**

Observed Cognitive Change – Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No abnormalities observed.	Some questionable inattentiveness - may be explained by other events.	Mild problems with concentration. Objectively may be observed to shift focus of attention from interview 1 to 3 times. Not quite understanding what others are saying or the emotional tone of the conversation.	Moderate concentration problems during interview. Mild disruption to flow of interview as a result.	Poor concentration and attention significantly affect ability to perform tasks. Distractibility clearly observed to interfere with flow of the interview. .	Severe concentration and attention difficulties Extremely difficult to conduct interview, or pursue a topic due to preoccupation with irrelevant stimuli or	Inability to concentrate at all. Impossible to conduct interview due to preoccupation with irrelevant stimuli.

3: EMOTIONAL DISTURBANCE

3.1 SUBJECTIVE EMOTIONAL DISTURBANCE (HUBER'S BASIC SYMPTOM)

Impaired Emotional Functioning:

NOTE: See also Anhedonia, p. 20; Depression, p.30

- Have you noticed any change in your feelings, or emotions e.g. feel like you have no feelings, feel your emotions are 'empty', or that your emotions are somehow not genuine?
- Has there been any change in the way you are using your emotions?
- Have you still been able to enjoy things, or experience pleasure?
- Do you find that even when something sad happens, you are no longer able to feel sadness? Or when something happy happens, you can no longer feel happy?

Change in Affect:

Facial expressions:

- Have you noticed any change in your facial expressions?
- Have people commented on your facial expression, saying it is blank, or hard to know what you are thinking?

Eye contact:

- Has there been a change in the way you interact with other people e.g. do you find it hard to look at people when you speak to them?
- Has anyone commented on this?

Speech:

- Have you noticed a change in the way you talk, such as your voice becoming monotonous?
- Have people told you that you have a monotonous way of talking?
- Do they seem to find you boring?

Inappropriate affect:

- Have you ever felt different on the inside from the way you look to others?
- Like your appearance was uncoordinated with your emotions? Would you smile, or laugh when talking about something that was sad, or not funny at all?

SUBJECTIVE EMOTIONAL DISTURBANCE - SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No subjective change in feelings, or emotions.		Subjectively sporadic, mild, but definite problems reported eg not able to enjoy things as much as previously. Some feeling of blunting of emotional responses. Affect is inappropriate, but not sustained.	Subjectively, more frequent, or continuous problems. Some feeling of blunting of emotional responses. More pervasive feeling of inappropriate affect, but subject able to control somewhat.	Subject describes more marked change in emotions eg not able to express, or experience feelings as before. Sense of distance when with others. Inappropriate affect more difficult to hide from others.	Subject describes feeling of having no feelings, or emotions feel empty, or not genuine. Unable to feel sad at all. Severe degree of distance from others. Inappropriate affect interferes with relationships.	Subject reports constant emotional blunting, OR Inappropriate affect.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

3.2 OBSERVED BLUNTED AFFECT

NOTE: Incorporate informant information as well as interviewer's impression

- Rate observed evidence of blunting of affect. For example, diminished facial expressions, reduced emotional tone in speech, reduced expressive movements and gestures.
- The rater may also feel a diminished ability to engage the subject.

OBSERVED BLUNTED AFFECT – SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe, not psychotic**	6 **Extreme/ psychotic**
No abnormalities observed by interviewer, or others.		Slight degree of constriction of affect may be observed.	Observable constriction of emotional field. Avoidance or failure to display feelings. Reduced emotional expressivity. Interviewer feels a sense of 'distance', or decreased rapport.	More marked degree of dullness or blockade. Definite decrease in sense of rapport observed by interviewer. May have been reported, or commented on by informants.	Minimal evidence of affective display	Gross blunting of affect. No spontaneous emotional expression observed during interview. Definitely reported by informants.

Onset date:..... Offset date:.....
(Do not score if relying on interviewer's report only- -3 on database)

Frequency and Duration
(Do not score if relying on interviewer's report only- -3 on database)

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

3.3 OBSERVED INAPPROPRIATE AFFECT

NOTE: Incorporate informant information as well as interviewer's impression

- Also rate clear cut inappropriate affect (affect clearly discordant from the content of speech, or ideation (e.g. giggling when speaking of something sad).

OBSERVED INAPPROPRIATE AFFECT- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No abnormalities observed by interviewer, or others.		Mild inappropriate affect during interview, or reported occasionally by others. Subject appears able to control.	More pervasive inappropriate emotion displayed. Does not dominate interview. Subject appears able to control somewhat.	More often reported by others- distracting during interview.	Inappropriate affect reported frequently. Interferes with social relationships and flow of interview.	Inappropriate affect throughout interview. Severely impacts on ability to conduct interview. Reported by others as occurring most of the time.

Onset date:..... ***Offset date:***.....
(Do not score if relying on interviewer's report only- Enter-3 on database)

Frequency and Duration
(Do not score if relying on interviewer's report only- enter –3 on database)

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

4: NEGATIVE SYMPTOMS

4.1 ALOGIA

NOTE: Refer also to Cognitive Change, p.10; Disorganised Speech, p. 8

- Have you noticed problems trying to form conversations - i.e. hard to find words, thought blocking?

- Are the subject's responses to questions vague, or convey little information? Does the subject take a long time to respond to questions, but when prompted, displays an awareness of the question?

ALOGIA - SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No observed, or reported changes in speech.	Subject unsure about recent changes. Changes may be attributable to external factors, but subject unsure.	Very mild changes in ability to speak spontaneously Subject reports feeling "blocked" in their thinking. Difficulty finding words for thoughts. Not reported by others.	Difficulty expressing self in words - finding words, or more regular instances of thought blocking Observable by others, but not constant difficulty. Subject responds to prompting.	More marked poverty of speech, or thought blocking Does not significantly interfere with school, or work functioning.	Unable to express oneself adequately, or severe thought blocking May experience infrequent periods of mutism as a result of word finding and expression difficulties.	Marked poverty of speech or thought blocking. Seriously hinders flow of interview. Subject may be mute at times. Interferes significantly with ability to perform in social, occupation and educational settings.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

4.2 AVOLITION/APATHY (HUBER'S BASIC SYMPTOM)

Subjective Experience:

- Have you felt lacking in energy- mental and physical? Are you tired, or lacking in motivation, or 'get up and go'? Lack of will power? Lack of physical strength?
- To what extent does this interfere with activities such as going to school/work and other everyday tasks? How are you spending your days?

Observed Avolition/Apathy:

NOTE: Refer also to disorganising/Odd/Stigmatising Behaviours, p.22

- Has the subject indicated difficulty maintaining the level of his/her usual social, or occupational/educational commitments?
- Does the subject appear to be looking after him/herself adequately- cleanliness/hygiene/general self-care?

Avolition/Apathy - Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Mod. Severe**	5 **Severe**	6 **Extreme**
No observed, or reported changes in energy.	Subject unsure about recent changes. Changes may be attributable to external factors, but unclear.	Feeling fatigued, things are an effort. May not initiate activities as much as previously. Still able to perform everyday tasks. Does not interfere with school work, or work attendance.	Feeling of reduced energy, or will power. Decreased attendance at school/work, or not performing usual tasks to usual ability. Not everyday and not reported by others.	More marked reduction in energy/motiv-ation. Some interference with normal functioning eg tasks take longer to do, subject doesn't bother to do some things. May miss school, or work a few times a week or frequently run late. May be unable to attend to personal hygiene as usual,	Daily reduction in energy, drive, will power, physical strength, or motivation. Interferes with normal functioning eg missing school, or work most day. Spends significant portions of time lying around. Clear impact on personal hygiene	Extreme and continuous disability eg unable to perform normal tasks, confined to house, no will power, or volition. Unable to attend school/work at all due to motivation. Marked impact on personal hygiene

Onset date:..... Offset date:.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

4.3 ANHEDONIA

NOTE: Refer also to Depression, p. 30

- Have you been able to enjoy social activities/work/study as much as usual?
- Have you noticed a decrease in your level of interest in things you usually enjoy?
- Has this interfered with your ability to perform activities, e.g. going to school/work/participating in events?

ANHEDONIA- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No observed, or reported changes in affect, speech, activity level, or attentiveness.	Some mild decrease in interest in events, but may be attributable to external cause (i.e. dislikes topic at school).	Some mild decrease in interest or enjoyment of activities. Not interfering with ability to perform them.	Moderate reduction in interest or enjoyment of activities such as school/work. May affect school/work performance.	Some regular experience of pleasure or humour but decreased in extent and quality. May impact on work/school attendance. Others concerned by associated withdrawal and isolation.	Rarely gains sense of enjoyment/ interest from tasks. At times able to enjoy something, but short lived. Poor attendance at school/work. Very noticeable by others.	No enjoyment or interest at all in tasks. Marked lack of interest. Isolated and withdrawn.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

5: BEHAVIOURAL CHANGE -

Consider informant information as well as subjective report

5.1 SOCIAL ISOLATION

- Have you stayed at home more often than usual recently? Has this been by choice?
- Have you felt uncomfortable around others recently?
- Have you wanted to be alone more than usual recently? Has there been a reason for this? Have others commented on this?
- Have you missed important social events/school/work due to this?

Questions for informants:

- Has the subject been staying at home, perhaps in their room alone, more often than in the past? If so, do you know the reason for this?
- Have they missed social events/work/school due to this?
- Do they appear to want to spend time alone at present (more so than usual)?

SOCIAL ISOLATION- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No change in level of social activity.		Subject feels that she/he does not want to fulfill all social/role functions. Wanting to be alone, but able to motivate self.	Isolating self at times, but not marked. Able to fulfill main role functions involving interactions with others. May miss some social activities.	Intolerant of being around others for long periods of time. Social withdrawal commented n by others. May miss 2-3 days week of school/work because of wanting to be alone.	Missing more days than not of work/school, spending greater part of day alone.	Isolated from others for extended periods (i.e. days)

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

5.2 Impaired Role Function

NOTE: See also Depression, P. 30

- Have you been able to attend school/work as usual recently?
- Has your school/work performance dropped recently?
- Have you been less interested in your work/school recently? Have others commented on this? Is there a reason for this? (Phrase questions appropriately i.e. for job seekers etc)

Questions for Informants:

- Have you noticed a change in attendance at work/school recently?
- Does the subject appear as capable at achieving normal tasks as usual?

Impaired Role Function- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No recent change in role function.		Subject reports mild impairment in performance of usual activities. Not noted by informants.	Usual tasks performed with less care than usual. Missing occasional day of work/school. Noted as mild by informants.	Around half of usual time spent on normal daily tasks. Decreased quality of task performance noted by others.	Marked impairment of role functioning. Spending about half of day in aimless activity.	Subject attempting no role function whatsoever

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

5.3 Disorganising/Odd/Stigmatising Behaviours

NOTE: See also Avolition, p.18; OCD, p.35; Social Isolation, p. 20

- Has there been anything about your lifestyle recently that others might regard as unusual, or odd? (Attempt to sensitively assess peculiar behaviours such as hoarding, talking to self, odd movements etc.)
- Have you been able to look after yourself as well as usual (Bathing, eating etc)? Has this been reported by others?

Questions for Informants:

- Have you noticed the subject behaving in an odd manner recently?
- Have you felt there is something strange about their behaviour? Has this been commented on by others?
- Have you noticed that they are hoarding goods, talking to self, moving in a bizarre fashion etc?

Disorganised/Odd/Stigmatising Behaviour- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No change in behaviour noted by subject, informants, or in interview.		Some reduction in self care, social isolation, but not marked. Subject able to motivate self to rectify this change. Slightly odd behaviour that would not normally attract attention of others, or conducted in private.	May require pressure from others to maintain social/ occupational commitments, or self care. Able to be motivated. Occasional odd behaviour that is noticeable by others (ie. giggling to self).	Mildly eccentric behaviour - clearly noticeable by others (ie talking to self/hoarding Not constant.	Clearly bizarre behaviour that attracts attention of others. Sometimes resulting in intervention by others.	Very poor self care. Eccentric behaviours dominate clinical picture. May result in intervention by others. Odd behaviours may have negative impact on physical health. Extreme social isolation.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

5.4 Aggression/Dangerous Behaviour

- Have you been feeling angry, or irritable recently? Has there been a reason for this? Have you felt more irritated than usual at small things? Have you been in more arguments with others than usual recently? Have you been taking more risks (i.e. when driving) recently than usual? Have others commented that your behaviour is becoming risky, or unsafe? Have you felt like striking out at people or objects recently (more so than usual)?
- Have you become so angry at someone that you have had thoughts of hurting them, or destroying their property? Have you acted on these thoughts?

Questions for Informants:

- Has the subject been acting in an aggressive or dangerous manner recently? Have there been any recent episodes of anger outbursts/physical confrontation? Is this how the subject normally behaves? Have others commented on a change in their level of anger, or irritability? Has the subject destroyed property lately (in association with anger)? Have you felt safe with the subject recently (i.e. when driving, at otherwise normal times)?

Aggression/Dangerous Behaviour- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No aggressive, or dangerous behaviour reported by the subject or others.		Slight irritability but not associated with rise in aggressive behaviour. May be attributed to events by subject.	More marked increase in irritability/anger towards self/others. May be expressed verbally, or physically in restrained manner (i.e punching pillow etc). May be noted by subject only.	Marked increase in irritability towards others expressed in increased propensity to verbal confrontations with threat of physical aggression. Noted by others and subject.	Aggressive behaviour results in property damage, or harm to others. Subject reports some level of control over anger.	Dangerousness in conjunction with anger at very destructive level, resulting in some considerable physical damage to others, or property. Dominates clinical picture. May attract attention of police etc.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

6: MOTOR/PHYSICAL CHANGES

6.1 SUBJECTIVE COMPLAINTS OF IMPAIRED MOTOR FUNCTIONING
(HUBER'S BASIC SYMPTOM)

Disorganised Movement:

- Have you noticed any change in the way you are moving e.g. clumsiness, lack of coordination, trouble organising your activities, or movements, loss of spontaneous movements?
- Have you noticed if your ability to perform some movements is distracted by other things?
- Does it require more effort or energy to perform some movements?

Mannerisms, Posturing:

- Have you developed any new movements, or poses (e.g. developed a nervous habit, a characteristic way of doing something, mimicking others, assuming certain postures)? What is your explanation for this?

SUBJECTIVE MOTOR CHANGE- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No abnormal movements, or somatic difficulties reported by subject.		Mild changes only. Feeling clumsier, more uncoordinated than usual, feeling slightly slowed down. Occasional grimace, or mildly unusual gait	Experiences noted in column 1, but the subject feels a more noticeable change. Reports control over	Changes such as loss of coordination. Movements distracted by other things. Different gait, new poses, tics or mannerisms Loss of some previous abilities.	Experiences noted in column 4, but more distressing. May include episodes of mutism, bizarre postures, copying others movements.	Clearly distorted, or idiosyncratic movements, which dominate the clinical picture. Gross mannerisms, bizarre postures. Mute, or almost mute, with only very occasional spontaneous movements.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

6.2 Informant Reported or Observed Changes In Motor Functioning

Disorganised Movement:

- Have you noticed any change in the way you are moving e.g. clumsiness, lack of coordination, trouble organising your activities, or movements, loss of spontaneous movements?
- Have you noticed if your ability to perform some movements is distracted by other things?
- Does it require more effort or energy to perform some movements?

Mannerisms, Posturing:

- Have you developed any new movements, or poses (e.g. developed a nervous habit, a characteristic way of doing something, mimicking others, assuming certain postures)? What is your explanation for this?

Observed Motor Change- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No abnormal movements, or somatic difficulties observed or reported by others.		Others report mild changes such e.g more clumsy, uncoordinated than usual, occasional grimace, or mildly unusual gait.	Experiences noted in column 1, but more marked. Subject appears to have some control over them.	Others report that subject having difficulty performing usual tasks i.e driving. Also has developed new movements i.e. gait, new stance/ mannerisms. Some mimicking may also be reported.	Episodes of mutism and bizarre posturing reported. Not sustained- subject able to stop with assistance and effort.	Clearly distorted, or idiosyncratic movements which dominate the clinical picture. Gross mannerisms, bizarre postures. Mute, or almost mute, with only very occasional spontaneous movements.

6.3 Subjective Complaints Of Impaired Bodily Sensation
(Huber's Basic Symptom)

NOTE: Refer also to p. 6 Perceptual Abnormalities

- Subjects say that there is something wrong with their bodily sensations.
- This includes disagreeable, but qualitatively normal sensations e.g pulling sensations, aches, pains, itching, burning, numbness, or qualitatively abnormal, unusual, or bizarre sensations may be described such as 'rustling' sensations in the eyes, vibrations, crawling sensations
- Do you ever get strange feelings in your body (eg feel that parts of your body have changed in some way, or that things are working differently)?
- Do you feel/think that there is a problem with some part, or all of your body, i.e. that it looks different to others, or is different in some way? How real does this seem?

Impaired Bodily Sensation- Severity Rating Scale

0 **Absent**	1 **Questionable**	2 **Mild,**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
Subject reports no change noticed in bodily sensations.		Subject notices occasional slight differences in bodily sensations. Not constant, able to ignore.	More intense changes to bodily sensations reported. Less able to ignore.	Occasional bizarre bodily sensation. Subject unsure of experience.	Subject reports more unusual, or bizarre sensations. Very distracting,	Subject reports extremely bizarre and unusual bodily sensations. May be distressing.

Onset date:**.....** ***Offset date:*****.....**

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

6.4 Subjective Complaints Of Impaired Autonomic Functioning
(Huber's Basic Symptom)

Subjects may complain of something wrong with one, or more of their autonomic systems such as:

- The feeling of the heart racing, or going too slow, breathing too fast, or too deeply,
- Nausea,
- Increased sensitivity to the weather,
- Having to urinate more often, constipation,
- Poor sleep etc.

Impaired Autonomic Functioning: Severity Rating Scale

0 **Absent**	1 **Questionable**	2 **Mild,**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
Nothing reported.		Subject reports occasional change to autonomic functioning – e.g. fleeting panic sensations. No real impact on usual activities.	More enduring changes perceived – e.g. poor sleep over a number of nights. Mild interference with usual activities.	Numerous changes may be experienced simultaneously. Moderate interference with usual activities	Changes in autonomic functioning are distressing. Results in more marked disruption to usual activities	Subject reports constant and intense changes to autonomic functions. Very distressing.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7: GENERAL PSYCHOPATHOLOGY

7.1 MANIA

NOTE: See also Dangerous Behaviour/Aggression, p. 23

- Would you describe your mood as 'high', or 'hyper' recently?
- Have you been feeling excessively cheerful and had more energy than usual? How long has this feeling lasted?
- Have you felt out of control at these times?
- Has this feeling been in response to a substance, or event that has occurred (i.e. finished exams, new boyfriend/girlfriend etc)?
- Have you been able to stay awake doing things for longer periods of time than usual?
- Have you been sleeping less than usual?
- Have you found yourself spending more money than usual, or acting in ways you would not normally (i.e. heightened sexual drive, reckless behaviour etc)?
- Have you found your self, or have others described you, talking more than usual and faster than usual?
- Have people commented on your mood, or energy, saying you seem more energetic than usual, or out of control?
- Have you been feeling more irritable than usual recently? Has there been a reason for this?
- Have you been feeling better about yourself recently?
- Have you felt that you are special in some way, or have special powers, or skills?

MANIA- SEVERITY RATING SCALE

0 Never, absent	1 Questionable	2 Mild	3 Moderate	4 Moderately severe	5 Severe	6 Extreme
No observed, or reported elevation in mood. No change in self - opinion/ energy.		Cheerful without much reason. Unaccountable feelings of well-being that persist or Mild lability in mood Evidence of over-confidence with no real reason –within normal limits **&/OR** Some mild irritability	Reports excessive feelings of well-being, or cheerfulness without underlying reason Inappropriate to circumstances sometimes. More marked level of excitement. More prominent feels of self-importance. Overvalued ideas not delusional **&/OR** Moderate irritability	More persistent feelings of optimism, happiness, or elevated mood. Mood able to be shifted only with difficulty. Subject aware of inappropriateness of feelings. Behaviour may reflect the heightened mood. Clear cut grandiosity/belief in special powers - not all the time. More marked irritability evident/reported by others.	Mood elevated and inappropriate most of the time. Some delusional beliefs about own powers/ abilities. Highly distractable/ loosening of associations. Interview difficult.	Subject reports feeling elated, euphoric, marked increase in energy, restlessness. Behaviour may be destructive-excessive spending of money/sexual activity etc. Delusional beliefs of grandiosity/ power. Easily distractable, interview very difficult. Subject obviously irritable.

Onset date:..... Offset date:.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.2 DEPRESSION

NOTE: Refer also to: Avolition, p.19; Anhedonia, p.20; Role Functioning, p.22; Suicidality, p.34

- How would you describe your mood recently?
- Have you been feeling sad, or low? How often have you felt this way?
- Out of 10, what would be your average mood? Your lowest mood?
- Have you been able to enjoy activities, or feel good about yourself at all?
- How have you been feeling about the future (assess helplessness/hopelessness)?
- Has your interest in activities/events been lower than usual?
- Have you been able to complete, or start tasks you have been set (assess motivation)?
- How has your sleep been recently (assess change in sleep pattern/insomnia)?
- What has your appetite been like recently? Have you lost any weight?
- Have any events occurred recently that might account for these feelings (death/relationship issues/job/school)?

DEPRESSION- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No reported depressed mood. No physical signs of depression.		Some feelings of sadness. Does not dominate clinical picture. Able to distract self from depressive thoughts. Depressive themes not spontaneously volunteered.	Evidence of more sustained lowered mood. More difficult to shift mood. Lowered mood may be impacting on level of motivation, but not significantly interfering with role functioning. May be slightly tearful, or sad expression in interview.	Stronger observational evidence of lowered mood. Reduced ability to react to pleasurable events. More regular 'tearful episodes'.	Severe depression - mood not able to be shifted. No evidence of delusional component. Some suicidality, but not acted upon. Biological changes consistent with lowered mood evident (appetite/sleep disturbance). Very low energy.	Abject misery. Delusional component to mood – i.e nihilistic. More marked feelings of suicidality and associated behaviour.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.3 Suicidality and Self Harm

- Have you had any thoughts recently about harming, or killing yourself? How often have you felt this way?
- Have you had any thoughts of what you would do to achieve this?
- Have you acted on those thoughts at all? What happened?

Suicidality- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
Not present.		Occasional thoughts of being tired of living. Occasional thought of self harm. No suicidal thoughts, or plans.	Feeling of being better off dead. Suicidal thoughts, with only vague plan. Able to be distracted from thoughts with some effort. **OR** Minor actions of self harm (slight scratches etc).	Thoughts of suicide more frequent with associated plan. May be more seriously considering attempt with specific plan. **OR** Impulsive attempts using non-lethal method, or with knowledge of potential for being found.	Clear expression of wanting to kill self. **OR** Potentially serious, or lethal attempt with knowledge of possible rescue.	Specific plan and attempt. **OR** Serious attempt that clearly could have been fatal.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.4 Mood Swings/Lability

- Have you experienced mood swings recently?
- Have you felt that your moods have been up and down for no apparent reason?
- Do you find yourself happy one moment, and sad the next (or irritable), with no explanation?
- How often does this happen?
- Has this occurred in response to drugs, or events that have happened? Have others commented on this?
- How often has this occurred?

Mood Swings- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No evidence, or reported mood swings.		Subject reports feeling mood changes more easily than usual. More marked changes in response to external events. Not noticed/reported by others.	Subject reports more extreme changes in mood. Feeling that mood is out of control some of the time.	More pervasive experience of mood swings. Noted by others. Distressing. Interferes with normal activities.	Mood swings experienced more days than not. Significant interference with normal activities.	Subject reports that mood changes constantly and completely out of control. Unable to maintain normal level of activity.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.5 ANXIETY

- Have you been feeling nervous, or anxious recently? Has there been a reason for this? How often have you felt this way?
- How long does this feeling remain for?
- Have you felt panicky lately?
- Have you had times when you have felt breathless, heart racing, sweaty palms, tingling fingers, for no apparent reason?
- Do you have a phobia/are you afraid of dogs, spiders, enclosed places, crowds etc?
- Have you felt nervous around others recently (differentiate social anxiety from suspiciousness)?

ANXIETY- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No evidence, or reporting of anxiety.		Minor worries. Able to distract self from these. **&/OR** Mild physical signs of anxiety.	Moderate concerns, but level of anxiety is within appropriate range for event **&/OR** Moderate physical symptoms of anxiety.	Level of anxiety interfering slightly with normal activities. Some preoccupation with trigger. **&/OR** More marked physical signs.	More marked preoccupation with fears, sense of dread. **&/OR** Intrusive, distressing physical symptoms of anxiety	Level of anxiety disabling, feeling of panic, terrified.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.6 OCD SYMPTOMS

- Do you have distressing, or intrusive thoughts that go round and round in your head that you cannot stop?
- Do you have any repetitive behaviours that you feel compelled to perform?
- Do you have anything that you do to stop 'bad things' from occurring (rituals/superstitions etc)?
- Do you have to have things a certain way, or you feel extremely anxious?
- Do you repeatedly check things, like light switches/gas/electrical appliances are switched off/doors locked etc?

OCD SYMPTOMS- SEVERITY RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No obsessional thoughts, or ruminations. No compulsive behaviour.		Some reported ruminating or compulsions, but not interfering with normal activities. Not time consuming Able to be distracted.	Some compulsive behaviours in response to obsessional thinking, but subject able to control. **&/OR** Compulsions do not distract from other activities.	Obsessional thinking distracting. interferes with ability to perform normal work/study. **&/OR** Compulsions not restricted to home, or private environment	Obsessional thinking or compulsions markedly distressing. **&/OR** Compulsions almost constantly - noticed by others.	Obsessional thoughts have quasi-delusional quality. **&/OR** Compulsions interfere with other activities, or are threatening to physical health (ie, hoarding garbage, excessive cleansing of body).

Onset date:..... Offset date:.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.7 Dissociative Symptoms

Depersonalisation:

Have you experienced yourself as being unreal, as if you were outside your own body?
Or that part of your body did not belong to you?

Derealisation:

NOTE: See also Nihilistic Ideas, *p.4*
Have you had the feeling that things around you were unreal?

Dissociative Memory Problems:

NOTE: See also Cognitive Change, p.10
Have you ever found yourself a long way from your usual range of travel without any memory of how you got there?
Were you under stress then?

Dissociative Symptoms- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No reported feelings of depersonalisation/ dissociation.		Mild feeling of depersonalisation/ derealisation. Not distressing, or distracting.	More marked dissociative experiences. Some concern expressed by subject about these, but not marked concern.	Dissociative experiences associated with heightened concern/ Distress about these experiences.	Distress as a result of dissociative experiences. Interferes somewhat with usual activities (i.e. has to leave work/school/ social situation).	Feelings of depersonalisation/derealisation extremely distressing. Feeling of extreme distance from others. Marked periods of time when subject not able to describe what they have been doing, where they have been etc.

Onset date: ..... ***Offset date:*** .....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

7.8 Impaired Tolerance To Normal Stress
(Huber's Basic Symptom)

- Have you noticed a change in the way you have been coping with everyday stress?
- Have you felt less able to cope with, or tolerate everyday stress than before?
- When subjected to everyday stressors have you found yourself becoming excitable, uneasy, tense, nervous or anxious?
- Have you found that ordinary stressors increase other difficulties you have been experiencing?

Impaired Tolerance to Stress- Severity Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Extreme**
No subjectively impaired tolerance to normal stress.		Mild, or rare feeling of not coping as well as before.	Feeling mildly stressed in response to situations which would normally be coped with easily. Mild anxiety with everyday stressors, but still able to cope with them.	More marked feeling of high anxiety, or tension with everyday stressors, but able to perform everyday tasks. Feeling unable to cope with more stressful situations. May feel anxious for no reason infrequently.	Feelings of high anxiety, or tension with everyday stressors. Sometimes anxious for no reason at all.	Extreme disability eg even trivial events, or minor concerns result in feelings of being overwhelmed and panicked. Very anxious all of the time, even if there is no apparent reason. Unable to adapt to novel situations.

Onset date:..... ***Offset date:***.....

Frequency and Duration

0	1	2	3	4	5	6
Absent	Less than once a month	Once a month to twice a week – **less** than one hour per occasion	Once a month to twice a week – **more** than one hour per occasion **OR** 3 to 6 times a week - **less** than one hour per occasion	3 to 6 times a week - **more** than an hour per occasion **OR** daily – **less** than an hour per occ.	Daily – **more** than an hour per occ. **OR** several times a day	Continuous

Pattern of Symptoms

0	1	2
No relation to substance use/stress noted	Occurs in relation to substance use/stress and at other times as well	Noted only in relation to substance use/stress

8: INCLUSION CRITERIA

INTAKE CRITERIA CHECKLIST

Group 1: Vulnerability Group *This criterion identifies young people at risk of psychosis due to the combination of a trait risk factor and a significant deterioration in mental state and/or functioning*	**YES**	**NO**
• **Family history of psychosis** in first degree relative **OR Schizotypal Personality Disorder** in identified patient	☐	☐
PLUS		
• **30% drop in GAF** score from premorbid level, sustained for a month	☐	☐
PLUS		
• **Change in functioning** occurred within last year and maintained at least a month	☐	☐
CRITERION MET FOR GROUP 1 – Vulnerability Group	☐	☐

Group 2: Attenuated Psychosis Group *This criterion identifies young people at risk of psychosis due to a subthreshold psychotic syndrome. That is, they have symptoms which do not reach threshold levels for psychosis due to subthreshold intensity (the symptoms are not severe enough) or they have psychotic symptoms but at a subthreshold frequency (the symptoms do not occur often enough).*	**YES**	**NO**
2a) Subthreshold intensity:		
• **Severity Scale Score of 3-5** on *Disorders of Thought Content* subscale, **3-4** on *Perceptual Abnormalities* subscale **and/or 4-5** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of 3-6** on *Disorders of Thought Content, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS for **at least a week** • **OR Frequency Scale Score of 2** on *Disorders of Thought Content, Perceptual Abnormalities* and *Disorganised Speech* subscales of the CAARMS **on more than two occasions (experienced a minimum of four times in total)**	☐	☐
2b) Subthreshold frequency:		
• Severity Scale Score of 6 **on *Disorders of Thought Content* subscale,** 5-6 **on *Perceptual Abnormalities* subscale** and/or 6 **on *Disorganised Speech* subscales of the CAARMS**		
PLUS		
• **Frequency Scale Score of 1-3** on *Disorders of Thought Content, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS (for both categories)		
• **Symptoms present in past year** and for not longer than five years	☐	☐
CRITERION MET FOR GROUP 2 – Attenuated Psychosis Group	☐	☐

Group 3: BLIPS Group *This criterion identifies young people at risk of psychosis due to a recent history of frank psychotic symptoms which resolved spontaneously (without antipsychotic medication) within one week.*	**YES**	**NO**
• **Severity Scale Score of 6** on *Disorders of Thought Content* subscale, **5 or 6** on *Perceptual Abnormalities* subscale **and/or 6** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of 4-6** on *Disorders of Thought Content, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales	☐	☐
PLUS		
• **Each episode of symptoms is present for less than one week** and symptoms spontaneously remit on every occasion.	☐	☐
PLUS		
• **Symptoms occurred during last year** and for not longer than five years	☐	☐
CRITERION MET FOR GROUP 3 – BLIPS Group	☐	☐

9: PSYCHOSIS THRESHOLD /ANTI-PSYCHOTIC TREATMENT THRESHOLD

	YES	NO
• **Severity Scale Score of 6** on *Disorders of Thought Content* subscale, **5 or 6** on *Perceptual Abnormalities* subscale **and/or 6** on *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS		
• **Frequency Scale Score of greater than or equal to 4** on *Disorders of Thought Content, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales	☐	☐
PLUS		
• Symptoms present for **longer than one week**	☐	☐
PSYCHOSIS THRESHOLD CRITERION MET	☐	☐

STUDY WITHDRAWAL ('BREAK BLIND') THRESHOLD

	YES	NO
• **Severity Scales Score of 5 or above** on *Aggression/Dangerous Behaviour* **and/or** *Suicidality/Self Harm* Subscales	☐	☐
• **NOTE:** This should be considered independently from level of psychosis		

Appendix C

The Brief Psychiatric Rating Scale (BPRS)

ID:.....
Date:.....
Location:.....

BPRS

1. Somatic Concern.

- Have you been concerned about your physical health?
- Have you had any physical illness or seen a medical doctor lately?
- What does your doctor say is wrong? / How serious is it?
- Has anything changed about your appearance?
- Has it interfered with your ability to perform your usual activities and/or work?
- Did you ever feel that parts of your body had changed or stopped working?
- How often were you concerned about *(Pt's description)*?
- Have you expressed any of these concerns to others?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

2. Anxiety.

- Have you been worried a lot during the past month?
- Have you been nervous or apprehensive?
- What do you worry about?
- Are you concerned about anything? What about finances, the future?
- When you are feeling nervous, do your palms sweat, heart beat fast, have shortness or breath, tremble, feel like you are choking?
- How much of the time have you been *(Pt's description)*?
- Has it interfered with your ability to perform your usual activities/work?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

3. Depression.

- How has your mood been recently?
- Have you felt depressed (sad, down, unhappy, as if you didn't care) ?
- Are you able to switch your attention to more pleasant topics when you want to?
- Do you find that you have lost interest in or get less pleasure from things you used to enjoy, like family of friends, hobbies, watching TV, eating?
- How long do these feelings last?
- Has it interfered with your ability to perform your usual activities/work?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

4. Suicidality.

- Have you ever felt that life wasn't worth living?
- Have you ever thought about harming or killing yourself?
- Have you ever felt tired of living or as though you would be better off dead?
- Have you ever felt like ending it all?
- How often have you thought about *(Pt's description)*?
- Did you, or do you, have a specific plan?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

5. Guilt.

- Is there anything you feel guilty about?
- Have you been thinking about past problems?
- Do you trend to blame yourself for things that have happened?
- Have you done anything that you're still ashamed of?
- How often have you been thinking about *(Pt's description)*?
- Have you disclosed your feelings of guilt to others?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

6. Hostility.

- How have you been getting along with people (your family, co-workers, etc)?
- Have you been irritable or grumpy lately? (How did you show it? Do you keep it to yourself?)
- Were you ever so irritable that you would shout at people or start fights or arguments? (Have you found yourself yelling at people you didn't know?)
- Have you hit anyone recently?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

7. Elevated mood.

- Have you felt so good or high that other people thought that you were not your normal self?
- Have you been feeling cheerful and 'on top of the world' without any reason?
- Did it seem like more than just feeling good?
- How long did that last?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

8. Grandiosity.

- Is there anything special about you?
- Do you have any special abilities or powers?
- Have you thought you might be somebody rich or famous?
- How often have you been thinking about *(Pt's description)*?
- Have you told anyone about what you have been thinking?
- Have you acted on any of these ideas?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

9. Suspiciousness.

- Do you ever feel uncomfortable in public?
- Does it seem others are watching you?
- Are you concerned about anyone's intentions towards you?
- Is anyone going out of their way to give you a hard time, or trying to hurt you?
- Do you feel in any danger?
- How often have you been concerned that *(Pt's description)*?
- Have you told anyone about these experiences?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

10. Hallucinations.

- Do you ever seem to hear your name being called?
- Have you heard any sounds or people talking to you or about you when there has been nobody around?
- What does/do the voices say? Did it have a voice quality?
- Do you ever have visions or see things that others do not see?
- What about smell odours that others do not smell?
- Have these experiences interfered with your ability to perform your usual activities/work?
- How do you explain them? How often do they occur?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

11. Unusual thought content.

- Have you been receiving any special messages from people or from the way things are arranged around you?
- Have you seen any references to yourself on TV or in the newspapers?
- Can anyone read your mind?
- Do you have a special relationship with God?
- Is anything like electricity, X-rays, or radio waves, affecting you?
- Are thoughts put into your head that are not your own?
- Have you ever felt under the control of another person or force?
- How often do you think about *(Pt's description)*?
- Have you told anyone about these experiences? How do you explain the things that have been happening *(specify)*?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

12. Bizarre behaviour.

- Have you done anything that has attracted the attention of others?
- Have you done anything that could have gotten you into trouble with the police?
- Have you done anything that seemed unusual or disturbing to others?
- How often did you *(Pt's description)*?
- Did *(specify)* interfere with your normal activities/work?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

13. Self-neglect.

- How has your grooming been lately?
- How often do you change your clothes?
- How often do you take showers?
- Has anyone (parents/staff) complained about your grooming or dress?
- Do you eat regular meals?

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

14. Disorientation.

- May I ask you some questions we ask everybody?
- How old are you?.....
- What is the date today? [+ or –2].....
- What is this place called?.....
- What year were you born?.....
- Who is the prime minister?.....

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

Probe for 16.

- Have you heard any good jokes lately?
- Would you like to hear a joke?

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Observed behaviour

15. Conceptual disorganisation.

Speech: disconnected, vague, disorganised
Rating of: tangentiality, circumstantiality, sudden topic shifts, incoherent, derailment, thought blocking, neologisms, other speech disorders
Do not rate: content.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

16. Blunted affect.

Restricted range in emotional expressiveness of face, voice, and gestures. Marked indifference or flatness even when discussing distressing topics. In case of euphoric or dysphoric patients rate blunted affect if a flat quality is also present.

- See probe.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

17. Emotional withdrawal.

Deficiency in patient's ability to relate emotionally during the interview situation. Use your own feelings as to the presence of an 'invisible barrier' between patient and interviewer. Include withdrawal apparently due to psychotic processes.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

18. Motor retardation.

Reduction in energy level evidenced by slowed movements and speech, reduced body tone, decreased number of spontaneous body movements. Rate on the basis of observed behaviour of the patient only. Do not rate on the basis of the patient's subjective opinion of his own energy level. Rate regardless of medication effects.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

19. Tension.

Observable physical and motor manifestations of tension, 'nervousness', and agitation. Self-reported experience of tension should be rated under the item on anxiety. Do not rate if restlessness is solely akathisia, but do rate if akathisia is exacerbated by tension.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

20. Uncooperativeness.

Resistance and lack of willingness to cooperate with the interview. The uncooperativeness might result from suspiciousness. Rate only uncooperativeness in relation to the interview, not behaviours involving peers and relatives.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

21. Excitement.

Heightened emotional tone, or increased reactivity to interview or topics being discussed, as evidenced by increased intensity of facial expressions, voice tone, expressive gestures or increases in speech quantity and speed.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

22. Distractibility.

Degree to which observed sequences of speech and actions are interrupted by stimuli unrelated to the interview. Distractibility is rated when the patient shows a change in the focus of attention or a marked shift in gaze. Patient's attention may be drawn to noise in the adjoining room, books on shelf, interviewer's clothing etc. Do not rate circumstantiality, tangentiality, or flight of ideas. Also, do not rate rumination with delusional material. Rate even if the distracting stimulus cannot be identified.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

23. Motor hyperactivity.

Increase in energy level evidence in more frequent movement and/or rapid speech. Do not rate if restlessness is due to akathisia.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

24. Mannerisms and posturing.
Unusual and bizarre behaviour, stylised movements or acts, or any postures which are clearly uncomfortable or inappropriate. Exclude obvious manifestations of medication side-effects. Do not include nervous mannerisms that are not odd or unusual.

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N/A	1 Very Mild	2 Not Present	3 Mild	4 Moderate	5 Mod. Sev.	6 Severe	7 Ext. Severe

Notes:

Appendix D

The Opiate Treatment Index- Recent drug use (OTI-R)

OTI Recent Drug Use (Revised)

Name _____ **Code no.** |__|__|__|__|__|

Date of interview: **day** ____ **month** ____ **year** ____

INSTRUCTIONS:

Do not include drugs used on the day of this interview.

Please fill in the ACTUAL DATES on which each drug was used [e.g., 10th Feb] in order to facilitate calculation of the periods between use dates.

It may be useful to have a calendar or a diary handy during the interview, for reference, and to aid prompting of the subject.

The time frame for the OTI Recent Drug Use form is the past 28 days. If the most recent date of use of a given drug was more than 28 days prior to the interview, then the remaining information for that particular drug does not need to be recorded.

For all of the questions of the type "How many tablets / snorts / hits ...", please CROSS OUT the options that DON'T apply.

Calculate the Q values **after** the interview. The collected data are used to estimate recent consumption (Q) using the formula:

$$Q = \frac{Q1 + Q2}{T1 + T2}$$

Q = average amount per day
Q1 = amount consumed on the last use occasion
Q2 = amount consumed on the second last use occasion
T1 = interval between the last day of drug use and the next-to-last use day
T2 = interval between the second-last and third-last days of drug use

For each category, if the subject says that their last use of the drug was **more than a month (28 days) ago**, record **Q = zero** for that category.

If the subject has only used a drug on only one or two days in the past 28 days, Q is calculated by dividing the total amount used on the use day(s) by 28.

DRUG USE SUMMARY (Q-scores)

Heroin		Cocaine	
Other Opioids		Tranquillisers	
Alcohol		Hallucinogens	
Cannabis		Inhalants	
Amphetamines		Tobacco (cigs per day)	

Polydrug Score: number of above drug classes used in past 4 weeks (out of 10) _____

Now I'm going to ask you some questions about your drug use.

I would like to emphasise that the information you give me is completely confidential.

Heroin: First, I'd like to ask you some questions about heroin (smack, hammer, horse, scag).

1. On what date did you last use heroin? _____
2. How many hits / smokes / snorts did you have on that day? _____ hits / smokes / snorts
3. On which date before that did you use heroin? _____
4. And how many hits / smokes did you have on that day? _____ hits / smokes / snorts
5. And when was the date before that? _____

5a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

5b. On how many days in the past 4 weeks have you used any heroin? _____ days

QI = Q2 = TI = T2 = Q =

Other Opioids: These questions are about your use of opioids other than heroin (eg, street methadone, done, morphine, pethidine, codeine, physeptone).

*In the case of liquid preparations, try to determine the number of times the subject took the drug, **not** the number of bottles taken.*

6. On what date did you last use opiates other than heroin? _____
   *(Include **illicit** methadone; exclude **legally** obtained methadone)*
7. How many pills, doses etc. did you have on that day? _____ pills / doses
8. On which date before that did you use opiates other than heroin? _____
9. And how many pills, doses etc. did you have on that day? _____ pills / doses
10. And when was the date before that? _____

10a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

*NOTE: Include only cost of other opioids obtained **illicitly** - not on prescription.*

QI = Q2 = TI = T2 = Q =

Alcohol: These questions are about your use of alcohol.

11. On what date did you last drink alcohol? _____

12. How much alcohol did you drink on that day?

(Ask about all categories. Figures in square brackets are numbers of standard drinks in one unit)

Wine (13%)	Spirits (40%)	Lite Beer (2.5%)	Mid Strength Beer (3.5%)	Reg. Beer (4.8%)	Fortified Wine (17.5%)
		7 oz / 200 ml [0.5]	7 oz / 200 ml [0.7]	7 oz / 200 ml [1.0]	
100ml glasses [1.3]	30ml nips [1.2]	10 oz / 285ml [0.7]	10 oz / 285ml [1.0]	10 oz / 285ml [1.4]	port glasses (60ml) [1]
750ml bottles [9.8]	Doubles [2.4]	15 oz / 425ml [1.1]	15 oz / 425ml [1.5]	15 oz / 425 ml [2]	750ml bottles [13.1]
2 lt. flagons [26]	750ml bottles [30]	cans / stubbies (375ml) [0.9]	cans / stubbies (375ml) [1.3]	cans / stubbies [1.8]	2 lt. flagons [35]
_____lt. casks [13 per litre]		750ml bottles [1.9]	750ml bottles [2.6]	750ml bottles [3.6]	

13. On which date before that did you drink alcohol? _____

14. And how much did you drink on that day?

Wine (13%)	Spirits (40%)	Lite Beer (2.5%)	Mid Strength Beer (3.5%)	Reg. Beer (4.8%)	Fortified Wine (17.5%)
		7 oz / 200 ml [0.5]	7 oz / 200 ml [0.7]	7 oz / 200 ml [1.0]	
100ml glasses [1.3]	30ml nips [1.2]	10 oz / 285ml [0.7]	10 oz / 285ml [1.0]	10 oz / 285ml [1.4]	port glasses (60ml) [1]
750ml bottles [9.8]	Doubles [2.4]	15 oz / 425ml [1.1]	15 oz / 425ml [1.5]	15 oz / 425ml [2]	750ml bottles [13.1]
2 litre flagons [26]	750ml bottles [30]	cans / stubbies (375ml) [0.9]	cans / stubbies (375ml) [1.3]	cans / stubbies [1.8]	2 lt. flagons [35]
____litre casks [13 per litre]		750ml bottles [1.9]	750ml bottles [2.6]	750ml bottles [3.6]	

15. And when was the date before that?_____

QI = Q2 = TI = T2 = Q =

Cannabis: These questions are about your use of marijuana (cannabis, dope, grass, hash, pot).

16. On what date did you last use marijuana ? _____

17. How many joints, bongs, cones, etc. did you have on that day? _____ joints / bongs / cones

18. On which date before that did you use marijuana? _____

19. And how many joints, bongs, etc. did you have on that day? _____ joints / bongs / cones

20. And when was the date before that? _____

20a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

QI = Q2 = TI = T2 = Q =

Amphetamines: These questions are about your use of amphetamines (speed).

21. On what date did you last use amphetamines? _____
22. How many tablets, snorts, hits etc. did you have on that day? _____ tabs / snorts / hits
23. On which date before that did you use amphetamines? _____
24. And how many tablets, snorts, hits, etc., did you have on that day? _____tabs / snorts / hits
25. And when was the date before that? _____
25a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

QI = Q2 = TI = T2 = Q =

Cocaine: These questions are about your use of cocaine (coke, snow, crack).

26. On what date did you last use cocaine? _____
27. How many snorts, hits, smokes etc. did you have on that day? _____ snorts / hits / smokes
28. On which date before that did you use cocaine? _____
29. And how many snorts, hits, smokes etc. did you have on that day? _____ snorts / hits / smokes
30. And when was the date before that? _____
30a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

QI = Q2 = TI = T2 = Q =

Tranquillisers: These questions are about your use of tranquillisers (e.g. "Benzo's", Serepax, Rohypnol, Mogadon, Valium, Normison).

31. On what date did you last use tranquillisers? _____
32. How many pills did you have on that day? _____ pills
33. On which date before that did you use tranquillisers? _____
34. And how many pills did you have on that day? _____ pills
35. And when was the date before that? _____

QI = Q2 = TI = T2 = Q =

[NOTE: Original questions numbered 36-40 relating to barbiturates have been deleted.]

Hallucinogens: These questions are about your use of hallucinogens (e.g. LSD, acid, ecstasy, magic mushrooms).

41. On what date did you last use hallucinogens? _____
42. How many tabs, pills, etc. did you have on that day? _____ pills
43. On which date before that did you use hallucinogens? _____
44. And how many tabs, pills, etc. did you have on that day? _____ pills
45. And when was the date before that? _____
45a. What was the average cost of **a typical day's use** (or estimated cost if not purchased) $_____

QI = Q2 = TI = T2 = Q =

Inhalants: These questions are about your use of inhalants (e.g. amyl nitrite / rush, glue, aerosols, petrol, nitrous oxide). *Do not include asthma sprays.*

46. On what date did you last use inhalants? _____
47. How many sniffs did you have on that day? _____ sniffs
48. On which date before that did you use inhalants? _____
49. And how many sniffs did you have on that day? _____ sniffs
50. And when was the date before that? _____

QI = Q2 = TI = T2 = Q =

51. **Tobacco.** Finally, if you smoke cigarettes, how many do you usually smoke each day? _____

Appendix E

The Alcohol Use Disorders Identification Test (AUDIT)

AUDIT

Client _____

Date _____

Score _____

---

1. How often do you have a drink containing alcohol (Score)

Never (0)
Monthly or less (1)
Two to four times a month (2)
Two to three times a week (3)
Four or more times a week (4)

2. How many drinks containing alcohol do you have on a typical day when you are drinking?

1 or 2 (0)
3 or 4 (1)
5 or 6 (2)
7 to 9 (3)
10 or more (4)

3. How often do you have six or more drinks on one occasion?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

4. How often during the last year have you found that you were not able to stop drinking once you had started?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

5. How often during the last year have you failed to do what was normally expected from you because of drinking?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

7. How often during the last year have you had a feeling of guilt or remorse after drinking?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?

Never (0)
Less than monthly (1)
Monthly (2)
Weekly (3)
Daily or almost daily (4)

9. Have you or someone else been injured as a result of your drinking?

(0)

No (0)
Yes, but not in the last year (2)
Yes, during the last year (4)

10. Has a relative or friend, or a doctor or other health worker been concerned about your drinking, or suggested you cut down?

No (0)
Yes, but not in the last year (2)
Yes, during the last year (4)

Appendix F

The Social and Occupational Functioning Assessment Scale (SOFAS)

Subject:.....

Group:.....

Social and Occupational Functioning Assessment Scale (SOFAS)

Consider social and occupational functioning on a continuum from excellent functioning to grossly impaired functioning. Include impairments in functioning due to physical limitations, as well as those due to mental impairments. To be counted, impairments must be a direct consequence of mental and physical health problems; the effects of lack of opportunity and other environmental limitations are not to be considered.

Code	(**Note:** use intermediate codes when appropriate, e.g. 45, 68, 72
100 | 91	Superior functioning in a wide range of activities
90 | 81	Good functioning in all areas, occupationally and socially effective.
80 | 71	No more than a slight impairment in social, occupational, or school functioning (e.g. infrequent interpersonal conflict, temporarily finding behind in schoolwork).
70 | 61	Some difficulty in social, occupational, or school functioning, but generally functioning well, has some meaningful interpersonal relationships.
60 | 51	Moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers or co-workers).
50 | 41	Serious impairment in social, occupational, or school functioning (e.g. no friends, unable to keep a job).
40 | 31	Major impairment in several areas, such as work or school, family relations (e.g. depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, id defiant and is failing at school
30 | 21	Inability to function in almost all areas (e.g., stays in bed all day; no job, home, or friends).
20 | 11	Occasionally fails to maintain minimal personal hygiene; unable to function independently.
10 | 1	Persistent inability to maintain minimal personal hygiene. Unable to function without harming self or others or without considerable external support (e.g., nursing care and supervision).
0	Inadequate information

Social and Occupational Functioning Assessment Scale (SOFAS), DSM-IV, American Psychiatric Association, 1994.

SOFAS Questions:

1. Tell me about your social group, your friends. Do you have enough friends? Do you have enough social events to go to, people to hang-out with?

2. Do you feel like you can rely on your friends? Could you go to them with problems? Are you able to make new friends when you want to? Are you a good friend? What are you like in a relationship?

3. Is there anything holding you back socially? Is there anything about your social sphere that you would change or feel you need to improve? What would your friends say?

4. What about study/work? Do you perform well at study/work? Are you where you want to be now in terms of study work?

5. Do you feel you have the necessary resources to do well at study or work? Is there an aspect of work/Study that you need to improve on? What sort of feedback do you get from your boss/teachers?

6. Is there anything holding you back in terms of working or studying? Are there things that would have to change for you to be successful or more successful in work/study?

Appendix G

The Generalised Assessment of Relational Functioning (GARF)

Subject:.....Group:.....

Global Assessment of Relational Functioning (GARF) Scale*

Instructions: The GARF scale can be used to indicate an overall judgement of the functioning of a family or other ongoing relationship on a hypothetical continuum ranging from competent, optimal relational functioning to a disrupted, dysfunctional relationship. The GARF scale permits the clinician to rate the degree to which a family or other ongoing relational unit meets the affective or instrumental needs of its members in the following areas:

A Problem solving – skills in negotiating goals, rules and routines; adaptability to stress; communication skills; ability to resolve conflict.

B Organisation – maintenance of interpersonal roles and subsystem boundaries; hierarchical functioning; coalitions and distribution of power, control and responsibility.

C Emotional climate – tone and range of feelings; quality of caring, empathy, involvement, and attachment/commitment; sharing of values; mutual affective responsiveness, respect and regard; quality of sexual functioning

Note: Use specific, intermediate codes when possible, for example 45, 68,72. If detailed information is not adequate to make specific ratings, use midpoints of the five ranges, that is 90, 70, 50, 30 or 10.

81-100 Overall: Relational unit is functioning satisfactorily from self-report of participants and from perspectives of observers.

Agreed on patterns or routines exist that help meet the usual needs of each family/couple member; there is flexibility for change in response to unusual demands or events; and occasional conflicts and stressful transitions are resolved through problem-solving communication and negotiation.

There is a shared undertaking and agreement about roles and appropriate tasks, decision making is established for each functional area, and subsystem (eg parents-spouses, siblings and individuals).

There is a situationally appropriate, optimistic atmosphere in the family; a wide range of feelings is freely expressed and managed within the family; and there is a general atmosphere of warmth, caring and sharing of values among all family members. Sexual relations of adult members are satisfactory.

61-80 Overall: Functioning of relational unit is somewhat unsatisfactory. Over a period of time, many but not all difficulties are resolved without complaints..

Daily routines are present but there is some pain and difficulty in responding to the unusual. Some conflicts remain unresolved but do not disrupt family functioning.

Decision making is usually competent, but efforts at control of one another are often greater than necessary or are ineffective. Individuals and relationships are clearly demarcated but sometimes a specific subsystem is depreciated or scapegoated.

A range of feeling is expressed, but instances of emotional blocking or tension are evident. Warmth and caring are present but are marred by a family member's irritability and frustrations. Sexual activity of adult members may be reduced or problematic.

41-60 Overall: Relational unit has occasional times of satisfying and competent functioning together, but clearly dysfunctional, unsatisfying relationships tend to predominate.

Communication is frequently inhibited by unresolved conflicts that often interfere with daily routines; there is significant difficulty in adapting to family stress and transitional change.

Decision making is only intermittently competent and effective; either excessive rigidity or significant lack of structure is evident at these times. Individual needs are quite often submerged by a partner or coalition.

Pain or ineffective anger or emotional deadness interfere with family enjoyment. Although there is some warmth and support for members, it is usually unequally distributed. Troublesome sexual difficulties between adults are often present.

21-40 Overall: Relational unit is obviously and seriously dysfunctional; forms and time periods of satisfactory relating are rare.

Family/couple routines do not meet the needs of members; they are grimly adhered to or blithely ignored. Life cycle changes, such as departures or entries into the relational unit generate painful conflict and obviously frustrating failures of problem solving.

Decision making is tyrannical or quite ineffective. The unique characteristics of individuals are unappreciated or ignored by either rigid or confusingly fluid coalitions.

There are infrequent periods of enjoyment of life together; frequent distancing or open hostility reflect significant conflicts that remain unresolved and quite painful. Sexual dysfunction among adult members is commonplace.

1-20 Overall: Relational unit has become too dysfunctional to retain continuity of contact and attachment.

Family/couple routines are negligible (eg no mealtime, sleeping or waking schedule); family members often do not know where others are or when they will be in or out; there is a little effective communication among family members.

Family/couple members are not organised in such a way that personal or generational responsibilities are recognised. Boundaries of relational unit as a whole and subsystems cannot be identified or agreed on. Family members are physically endangered or injured or seriously attacked.

Despair and cynicism are pervasive; there is little attention to the emotional needs of others: there is almost no sense of attachment, commitment or concern about one anothers welfare.

0: Inadequate information.

* Table from DSM-IV, American Psychiatric Association, Washington, 1994

GARF Questions:

1. Tell me about your family. Who's in your family?, where did/do you live? What was your childhood like in terms of your family as a family?

2. **Problem Solving:** What was your family like at solving everyday problems? Were there rules and routines? Did the family cope okay with stress? What was the communication like in the family? How did the family resolve conflict?

3. **Organisation:** Did people in the family stay within their roles?- e.g. parents or children? Was their a hierarchy? Were there coalitions or factions in the family? Was their control and responsibility?

4. **Emotional tone:** Did you feel cared about/loved in your family? By everyone? Did you feel the family was interested in you? Were you taught morals by your parents? Did people get on in the family? Did your family respect one another?

5. Was/Is there anything about your family that was not so good? Was/Is there something about your family that you would change?

Appendix H

Institutional human research ethics committee's approvals

Participant information statement

Participant consent form

Participant cash receipt form

The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee
http://www.usyd.edu.au/ethics/human/

Chairman:
Associate Professor Stewart Kellie
Telephone: (02) 9845 2141
Facsimile: (02) 9845 2171
Email: stewartk@chw.edu.au

Manager:
Gail Briody
Telephone: (02) 9351 4811
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Human Secretariat
Telephone: (02) 9036 9309
(02) 9036 9308
(02) 9351 4474
Facsimile: (02) 9036 9310
Email: r.todd@reschols.usyd.edu.au
Rooms L4.13/L4.14, Main Quadrangle – A14

05 October 2004

Professor A Blaszczcynski
Clinical Psychology Unit
Transient Building – F12
The University of Sydney

Dear Professor Blaszczcynski

I am pleased to inform you that the Human Research Ethics Committee at its meeting on 27 September 2004 approved your protocol entitled **"Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees"**

Details of the approval are as follows:

Ref No.:	***09-2004/2/7642***
Approval Period:	***September 2004 – September 2005***
Completion Date of Project:	***31 May 2006***
No. of Participants:	***120***
Authorised Personnel:	***Professor A Blaszczcynski***
	Mr B Hamilton

To comply with the *National Statement on Ethical Conduct in Research Involving Humans*, and in line with the Human Research Ethics Committee requirements this approval is for a 12-month period. At the end of the approval period, the HREC will approve extensions for a further 12-month, subject to a satisfactory annual report. The HREC will forward to you an Annual Progress Report form, at the end of each 12-month period. **Your first report will be due on 30 September 2005.**

Conditions of Approval Applicable to all Projects

(1) Modifications to the protocol cannot proceed until such approval is obtained in writing. (Refer to the website www.usyd.edu.au/ethics/human under 'Forms and Guides' for a Modification Form).

(2) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.

(3) All research subjects are provided with a Participant Information Sheet and Consent Form, unless otherwise agreed by the Committee.

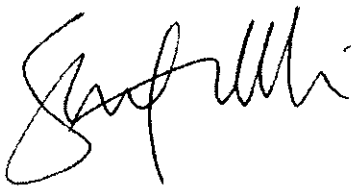
(4) The Participant Information Sheet and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee.

(5) The following statement must appear on the bottom of the Participant Information Sheet. ***Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney, on (02) 9351 4811.***

(6) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of seven years.

(7) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



Associate Professor Stewart Kellie
Chairman, Human Research Ethics Committee

Encl. Subject Information Statement – pilot study
Consent Form – pilot study
Discussion questions for pilot study
Subject Information Statement
Comprehensive Assessment of at Risk Mental States (CAARMS), Monthly Version January 2002
Brief Psychiatric Rating Scale (version 4.0)
Social Occupational Functioning Assessment Scale (SOFAS)
Audit
OTI Recent Drug Use (Revised)

Cc: Mr Blake Hamilton, Clinical Psychology Unit, Transient Building –F12, The University of Sydney

Human Research Ethics Committee
www.usyd.edu.au/ethics/human
Senior Ethics Officer:
Gail Briody
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The University of Sydney

NSW 2006 Australia

18 September 2007

Professor A Blaszczynski
Clinical Psychology Unit
School of Psychology
Transient Building – F12
The University of Sydney

Dear Professor Blaszczynski

Title: ***Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees***

Ref No.: ***09-2004/7642***

The Executive Committee at its meeting on 4 September 2007 considered your correspondence dated 19 July 2007 and the approval letter from Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee.

Please take this as final approval to conduct your research.

Yours sincerely

John Watson

Associate Professor J D Watson
Chairman
Human Research Ethics Committee

cc Professor Carol Armour, Pro-Vice-Chancellor Research, Office of the Vice-Chancellor & Principal, Pharmacy Building – A15, The University of Sydney

Mr Blake Hamilton, Clinical Psychology Unit, Transient Building – F12, The University of Sydney

Aboriginal Health and Medical Research Council of NSW

AH&MRC ETHICS COMMITTEE

6 July 2007

Mr Blake Hamilton
Clinical Psychology Unit
Ground Floor, Transient Building F12
University of Sydney NSW 2006

Dear Mr Hamilton

Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees
(490/04)

At its meeting on 25 June 2007, the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee considered your application for ethics approval for the above project.

The Committee agreed to approve the application, subject to the conditions below.

Standard Conditions of Approval

1. The approval is for the period from 1 July 2007 until 30 June 2008, with extension for an additional period on submission of a report on the research by 30 June 2008.
2. All research participants are to be provided with a relevant Participant Information Statement and Consent Form in the format provided with your application.
3. Copies of all signed consent forms must be retained and made available to the Ethics Committee on request.
4. Any changes to the staffing, methodology, timeframe, or any other aspect of the research relevant to continued ethical acceptability of the project must have the prior written approval of the Ethics Committee.
5. The research must continue throughout to comply with the *National Statement on Ethical Conduct in Research Involving Humans* (April 2007).
6. A final draft report must be provided to the AH&MRC Ethics Committee to be vetted for compliance with ethical and cultural criteria prior to:
   - any submission for publication; and/or
   - any dissemination of the report.

7. A copy of the final published version of any publication is to be provided to the AH&MRC Ethics Committee.

Special Conditions of Approval

8. The Committee's approval has been given on the basis that (as indicated in the revised proposal of 8 May 2007) the major objectives of the study are essentially limited to identifying potential issues and problems in the use of the CAARMS instrument with Aboriginal people and that it will *not* be used to claim *validation* of the instrument for general use with Aboriginal people (which was an objective of the original proposal of November 2004).
9. The researcher is to ensure that any Aboriginal Community Controlled Health Service (ACCHS) that services a DJJ or DCS institution in which the research takes place is to be informed that the research is to be undertaken, as the ACCHS may be working with some of the young people being interviewed.

Can you please acknowledge receipt of this letter and your acceptance of the above conditions within 14 days?

We would also appreciate your agreement that the AH&MRC may, on request, obtain access to the data obtained from the research in order to assist the future development of policy and programs in Aboriginal health.

In assessing your application, the Committee sought advice from an experienced clinical psychologist familiar with CAARMS. The advisor considered your proposal to meet the ethical requirements for conducting a research study, but did make a number of suggestions to enhance the methodology of the study. A copy of the substance of the advice is provided for your consideration.

We take this opportunity to wish you well in your research.

On behalf of the AH&MRC Ethics Committee,

Yours sincerely

Val Keed
Chairperson

DARMSPA (490/05)
- Advice Provided to AH&MRC Ethics Committee

The proposed research project endeavours to investigate an area of great clinical concern for young people. While much research has focussed on clinical and functioning profiles for older persons with established psychotic illnesses, it is by researching the early stages of the illness in young people that true early intervention and prevention of disability may be achieved. Recent research is seeking to address this in the non Aboriginal population but to date research of this area has not been undertaken in an Aboriginal population. The student researcher is to be commended for his 'persistence' in adapting his research protocol to gain greater cultural sensitivity for Aboriginal people. The phenomenology of psychosis is complex and difficult to define for accurate assessment as it cannot be directly observed. As a clinician or researcher one relies upon the ability of the individual to describe their internal and often puzzling experiences. Researching this in a culture other than one's own adds another layer of complexity. Mr Hamilton rightly describes his proposed research as being a study to provide preliminary data on the validity of the CAARMS in assessing psychotic experiences of young Aboriginal people. From this perspective I would urge Mr Hamilton to retain the pilot phase of his proposed research as open interviews with Aboriginal youth will provide rich data to inform his key research question and future research studies.

In this report I limit my comments to areas I believe Mr Hamilton should address prior to commencing his research study. The correspondence suggests data collection has already commenced but I presume this is in the non Aboriginal groups. I will refer to the open interviews with Aboriginal youth as the 'pilot phase' and the four group validation study as the 'main study'. The reader should be aware that my expertise currently sits with child and adolescent mental health research rather than research in the Aboriginal population. I therefore focus my comments on methodological and clinical ethical concerns.

Recruitment process

The proposal very carefully addresses potential concern for ensuring participation is voluntary – a critical issue when conducting research in a prison setting. In clinical settings and in prisons, it is important to separate the research from standard clinical care. The proposed recruitment process addresses this adequately.

Distress and clinical concern in participants

The protocol shows that potential distress and clinical concern in participants has been thoroughly considered. The documents show a clear process to address these issues should the situation arise.

Sample

While the protocol states the age range of 16-25 years for the pilot phase open interviews, there is no age stated for the main study. The protocol requires clarification on the following:

1. age range for main study;
2. settings x subgroups:
   There are four settings described for recruitment but it is not clear as to which subgroup will be recruited from each site. The protocol states the sites will be used for the following parts of the project:
   (a) NSCCAHS – non Aboriginal persons with psychotic illness
   (b) SESIAHS – main study and the only site for the pilot phase

(c) JH, DCS – main study
(d) Adol Health, JH, DJJ – main study

It is unclear as to which subgroup participants from sites (b – d) for the main study will be placed. The protocol refers to healthy controls being recruited from youth groups or sporting organisations. It is important to specify sources of recruitment for each subgroup, namely: (i) Aboriginal persons without psychotic illness; (ii) Aboriginal persons with psychotic illness; (iii) non Aboriginal persons without psychotic illness; and (iv) non Aboriginal persons with psychotic illness.

Design

The study proposes to investigate the validity of the CAARMS for assessing psychotic experiences in young Aboriginal people. The design to test the hypotheses is a series of multiple comparisons:

1. CAARMS compared to BPRS;
2. Healthy controls compared to individuals with psychotic diagnosis (as per medical record)
3. Aboriginal compared to non Aboriginal persons

It would have been useful for the reader had the proposal included any existing evidence on the relationship of the BPRS to the CAARMS. Such evidence could assist in the interpretation of the data in this sample. The 2 x 2 design described by comparisons 2 and 3 shown above, requires control for potential confounding variables such as gender, age (due to variability of diagnosis in younger persons with psychotic experiences) and social/role functioning (variability due to recruitment of non psychotic persons from prisons compared to youth or sporting groups). In addition to statistical control of confounding variables, the study could be strengthened by matching healthy controls and persons with psychotic illness on such variables at the time of recruitment.

Pilot phase

The proposed pilot phase of open interviews with a small group of Aboriginal youth, aged 16-25 years, without psychotic illness has the potential of providing preliminary qualitative data on developing research methodology and questions to be applicable to Aboriginal youth. The proposal is to interview two groups comprising five Aboriginal youth. From my research experience investigating self harm in homeless youth, I would recommend being more flexible and therefore offering individual interviews if preferred to group sessions or smaller groups. While it is acknowledged that the proposal is for a Masters' research project and therefore must fit within the time constraints of such a program, the pilot phase is important.

Summary and recommendations

It is my opinion that Mr Hamilton's research proposal addresses ethical requirements for conducting a research study. However I am unable to comment on the ability of the proposal to meet specific ethical standards for research within an Aboriginal population. I recommend clarification of recruitment as stated above, including control for potential confounds. In so doing, the research protocol will be strengthened and the researcher will be better positioned to draw conclusions from his data. Mr Hamilton has well addressed important ethical concerns of voluntary nature of participation, potential variations in literacy and methods for dealing with the possibility of distress in participants.

Justice Health

Justice Health Administration PO Box 150, Matraville NSW 2036
Phone: (02) 9289 2977 - Fax: (02) 9311 3005 - ABN 70 194 595 506

Adolescent Health
C/- Department of
Juvenile Justice
Ground Floor,
64 - 76 Kippax Street
SURRY HILLS NSW 2010

Ph: (02) 9215 3355
Fax: (02) 9215 3350

Centre for Health
Research in Criminal
Justice
Suite 302, Level 2
Westfield Tower,
Eastgardens Shopping
Centre,
152 Bunnerong Road,
PAGEWOOD NSW 2144

Ph: (02) 8372 3000
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Statewide Forensic
Mental Health
Suite 702, Level 7,
491 Kent Street
SYDNEY NSW 2000

Ph: (02) 8295 7000
Fax: (02) 8295 7099

Forensic Executive
Support Unit
Suite 702, Level 7,
491 Kent Street
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Ph: (02) 8295 7000
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Forensic & Prison
Hospital Project
Suite 802, 8th Floor
15 Castlereagh Street
SYDNEY NSW 2000

Ph: (02) 9232 0665
Fax: (02) 9221 6545

Ref: GEN80/05

Professor Alex Blaszczcynski
Research Fellow
Psychology Clinic
School of Psychology (F12)
UNIVERSITY OF SYDNEY NSW 2006

Dear Professor Blaszczcynski

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

The Committee met on 15 June, and gave approval to your application.

The Committee requested to alert you to the fact that inmates with Drug & Alcohol issues might attend treatment services from Justice Health, or from Department of Corrective Services Alcohol & other Drugs' counsellors.

According to the *National Statement on Ethical Conduct in Research Involving Humans*, a regular report is required on all approved projects. You will be required to report on your progress, by 30 June 2007. The report template will be emailed to you.

Additionally, researchers must immediately report anything which might warrant review of the approval, including:

a) Serious or unexpected adverse effects on participants;
b) Proposed changes in the protocol; or
c) Unforeseen events that might affect continued ethical acceptability of the project.

You are also requested to inform the Human Research & Ethics Committee if the research project is discontinued prematurely.

Should you require further information, please do not hesitate to contact me on (02) 8372 3000.

Yours sincerely

Associate Professor Sandra Egger
CHAIRPERSON
HUMAN RESEARCH & ETHICS COMMITTEE

3 July 2006

Justice Health

Justice Health Administration PO Box 150, Matraville NSW 203
Phone: (02) 9289 2977 - Fax: (02) 9311 3005 - ABN 70 194 595 50

Adolescent Health Administration
Suite 103, Level 1
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Ph: (02) 9288 9009
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Adolescent Community Forensic Mental Health Service
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Forensic Executive Support Unit

Community & Court Liaison Service

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SYDNEY NSW 2000

Ph: (02) 8295 7000
Fax: (02) 8295 7099

Community Forensic Mental Health
7 F Street
No... arramatta
NSW 2151

Ph: (02) 8838 6290
Fax: (02) 9683 7315

Governance Unit
Suite 303, Level 2
Westfield Office Tower
Eastgardens Shopping Centre
152 Bunnerong Rd
PAGEWOOD NSW 2035

Ph: (02) 8372 3033
Fax: (02) 9344 4230

Forensic & Prison Hospital Project
Project Demountable
PO Box 519
MATRAVILLE NSW 2036

Ph: (02) 9289 2186
Fax: (02) 9289 2183

Professor Alex Blaszczcynski
Chair in Psychology
Psychology Clinic
School of Psychology (F12)
University of Sydney NSW 2006

Dear Professor Blaszczcynski

This letter represents our agreement to coordinate access to patient records relating to inmates in the custody of the Department of Corrective Services and detainees in the custody of the Department of Juvenile Justice in conjunction with your research project.

As outlined, we will provide access to files providing there is specific consent for such access, signed by the patient. The consent form you have provided meets this purpose.

Should you wish to discuss this further, I may be contacted on (02) 9289 2972.

Yours sincerely

John Hubby
Director Corporate Services and Finance
3 September 2007

cc Blake Hamilton

Justice Health

Justice Health Administration PO Box 150, Matraville NSW 203
Phone: (02) 9289 2977 - Fax: (02) 9311 3005 - ABN 70 194 595 50

Ref: GEN80/05
Doc: S291/07

Professor Alex Blaszczcynski
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Forensic & Prison Hospital Project
Suite 802, 8th Floor
15 Castlereagh Street
SYDNEY NSW 2000

Ph: (02) 9232 0665
Fax: (02) 9221 6545

Dear Professor Blaszczcynski

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

The Committee received the requested documents and granted approval to your application out of session.

According to the *National Statement on Ethical Conduct in Research Involving Humans*, a regular report is required on all approved projects. You will be required to report on your progress, by 31 October 2008. The report template will be emailed to you.

Additionally, researchers must immediately report anything which might warrant review of the approval, including:

a) Serious or unexpected adverse effects on participants;
b) Proposed changes in the protocol; or
c) Unforeseen events that might affect continued ethical acceptability of the project.

You are also requested to inform the Human Research & Ethics Committee if the research project is discontinued prematurely.

The National Statement on Ethical Conduct in Human Research is available on http://www.nhmrc.gov.au/publications/synopses/_files/e72.pdf, for your information.

Please note that though Justice Health ethics approval has been granted, the administrative requirements regarding the conduct of the study are yet to be considered by Justice Health. For advice on receiving Justice Health administrative approval and support, please contact Ms Devon Indig, A/Research Manager Centre for Health and Research in Criminal Justice on (02) 8372 3010.

Should you require further information, please do not hesitate to contact me on (02) 8372 3000.

Yours sincerely

Associate Professor Sandra Egger
CHAIRPERSON
HUMAN RESEARCH & ETHICS COMMITTEE

8 October 2007

NSW Department of Corrective Services

Professor Blaszczynski
Clinical Psychology Unit
Ground Floor
Transient Building F12
UNIVERSITY OF SYDNEY NSW 2006

06/4102

Dear Professor Blaszczynski

I refer to your research application entitled *"Detection of at-risk mental states for psychosis in young Aboriginal and non-*Aboriginal *drug and alcohol service attendees"* which seeks to determine whether a measure detecting possible psychosis in young non-aboriginal people can be used with young Aboriginal people.

I am pleased to inform you that conditional approval has been given for your research project. The approval is given on the following grounds:

- The researchers are to contact Corporate Research, Evaluation and Statistics to ascertain which correctional centre/s would be the most suitable to conduct the research; and
- that $20 be paid to each participant in recognition of time, and loss of wages.

This approval is dependent upon your compliance with the attached "Terms and Conditions of Research Approval" (Attachment 1).

I wish you every success in your endeavours.

Yours sincerely

Ian McLEAN
Acting Commissioner

28th September 2006

cc: Deputy Commissioner, Offender Management & Operations
Director, Aboriginal Support & Planning Unit
Principal Advisor, Psychology
Principal Advisor, AOD

NORTHERN SYDNEY
CENTRAL COAST
NSW HEALTH

27th February 2006

Professor A Blaszczynski
Clinical Psychology Unit, Transcient Building F12
University of Sydney
Sydney NSW 2006

Dear Professor A Blaszczynski,

Re: 0512-246M - - A Blaszczynski, B Hamilton
detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees.

Thank you for providing information as requested by the Northern Sydney Health Human Research Ethics Committee Executive, on the 9th December 2006. I am pleased to inform you that your protocol has now been approved. The approval includes:

- Subject Information Sheet, Version 1a dated 16th January 2006
- Consent Form, Version 1a dated 16th January 2006
- Invitation to participate, Version 1a dated 27th February 2006

The HREC recommends that you consult with your Medical Defence Union to ensure that you are adequately covered for the purpose of conducting this clinical trial.

In order to comply with the *Guidelines for Good Clinical Research Practice (GCRP) in Australia*, and in line with NSH HREC policy, may I remind you that it is the Chief Investigator's responsibility to ensure that:

1. You notify the HREC of the completion of the study at this site and submit a final report (including final results) when available.
2. The HREC is notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. This includes notifying the HREC of any changes to the staff involved with the protocol.
3. All serious and unexpected adverse events are reported to the HREC within 15 working days.
4. The HREC is notified of the outcome of all submissions of this protocol to other Ethics Committees.

As at 18th May, HREC approval is now valid for four (4) years from the date of the approval letter. **Your approval will expire on the 27th February 2010.** Investigators are requested to submit a progress report annually. **Your first progress report will be due on the 31st October 2006.**

Investigators are required to ensure that the usual Infection Control Policies and Procedures for Royal North Shore Hospital and Community Health Service apply.

Yours sincerely,

Ms Trisha Brisley
Chairperson
Human Research Ethics Committee

Research Office
Royal North Shore Hospital
Level 4, Vindin House
St Leonards NSW 2065
Telephone 02 9926 8106 Facsimile 02 9926 6179

Northern Sydney Central Coast Area Health Service
ABN 48344669728

SOUTH EAST HEALTH
South Eastern Sydney Area Health Service

HUMAN RESEARCH ETHICS COMMITTEE – Northern Network

Room G71, EBB
Cnr High & Avoca Strs
RANDWICK NSW 2031
Tel: 9382 3587
Fax: 9382 2813

30 July 2007

Professor Alex Blaszczcynski
Ground Floor
Transient Building F12
University of Sydney NSW 2006.

Dear Professor Blaszczcynski

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non- Aboriginal drug & alcohol service attendees. Ref: 05/217

The Human Research Ethics Committee is in receipt of your letter dated 24 July 2007 in relation to the above study. Following consideration Executive approval was given on 30 July 2007 for:

- **Confirmation in writing of AH&MRC Approval.**
- **Provision of the Signature of Scientific Merit and a letter of support from Dr. Kotze Director of Area Mental Health.**
- **A letter of support from Barbara Caine, Aboriginal Mental Health Worker.**
- **A signed Memorandum of understanding between the research team, Aboriginal Community members and the Aboriginal Health Unit manager fulfilling NHMRC Aboriginal Research Requirements.**
- **Provision of the Signatures of the Research team.**
- **Provision of a completed Application Form**

This interim decision will be placed before the full Committee for Ratification at the next meeting on 28 August 2007.

This Human Research Ethics Committee is duly constituted, operates, complies with and is conducted according to the National Health and Medical Research Council's (NHMRC) "National Statement on ethical conduct in Research Involving Humans" and is guided by the ICH Harmonised Tripartite, Good Clinical Practice Guidelines and the "World medical Association Declaration of Helsinki 2000. The approval is valid for 5 years.
Approval has been granted for this study to commence. Approval has been given for 5 years.

It is the responsibility of the Chief Investigator to furnish the Human Research Ethics Committee with a progress report every 12 months for the duration of the study and a final report on completion of the study. Any advertising or media articles must be submitted for ethics approval prior to media release. The Committee must be notified of any Serious Adverse Events or Unexpected Events that occur in relation to this study.

Yours sincerely

Kim Breheny
Executive Officer
Human Research Ethics Committee – Northern Section

NSW DEPARTMENT OF
Juvenile Justice

Level 24, 477 Pitt Street
SYDNEY NSW 2000

PO Box K399
HAYMARKET NSW 1240

Telephone: 02 9219 9400
Facsimile: 02 9219 9500
Email: djj@djj.nsw.gov.au
www.djj.nsw.gov.au

Doc Ref: D06/07639
File Ref: 04/10354-02
Contact Name: Eric Heller-Wagner
Telephone: 9219 9515

Mr Blake Hamilton
Clinical Psychology Unit
Ground Floor, Transient Building F12
The University of Sydney
SYDNEY NSW 2006

Dear Mr Hamilton

DETECTION OF AT-RISK MENTAL STATES FOR PSYCHOSIS IN YOUNG ABORIGINAL AND NON-ABORIGINAL DRUG AND ALCOHOL SERVICE ATTENDEES

The Research Steering Committee has approved your application to conduct research in the Department of Juvenile Justice. You may now proceed with the implementation of your research.

Please find attached a signed copy of the DJJ Research Agreement for your records.

Please ensure that your project meets the requirements outlined in your application and adheres to the conditions outlined in the attached Research Agreement. Any variations will need to be submitted to the DJJ Research Steering Committee for review.

Congratulations and good luck with your research.

Yours sincerely,

Jennifer Mason
Director General

NSW DEPARTMENT OF
juvenile justice

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Telephone: 02 9219 9400
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www.djj.nsw.gov.au

Doc Ref: D07/00792
File Ref: 04/10354-03
Contact Name: Eric Heller
Telephone: 9219 9515

Mr Blake Hamilton
Clinical Psychology Unit
Ground Floor, Transient Building F12
The University of Sydney
SYDNEY NSW 2006

Dear Mr Hamilton

RE: REQUEST FOR VARIATION ON AGE OF CONSENT FOR APPROVED RESEARCH PROJECT "DETECTION OF AT-RISK MENTAL STATES FOR PSYCHOSIS IN YOUNG ABORIGINAL AND NON-ABORIGINAL DRUG AND ALCOHOL SERVICE ATTENDEES"

The Department of Juvenile Justice has considered your request for a variation to the approved research project named above. The requested variation was to lower the age limit required for both parental and individual consent from all those under the age of 18 years to all young people under the age of 16 years.

The department has approved your request. You will need to obtain written parental/guardian consent for all young people under the age of 16 years only.

Thank you for submitting this request to the Department of Juvenile Justice and continuing to adhere to the conditions of approval to conduct research in the department.

Yours sincerely,

Jennifer Mason
Director General

19.2.07

School of Psychology
University of Sydney

SUBJECT INFORMATION STATEMENT

Research Project

Title: Detection of at-risk mental states for psychosis in young Aboriginal and non- Aboriginal drug and alcohol service attendees.

1. What is the study about?

Psychosis is a mental health problem that involves changes to a person's thinking and experience of the world. Currently there is no effective way to detect the early changes in thinking and experience associated with psychosis in Aboriginal people. A new questionnaire has been developed to detect these early changes in thinking and experience. This questionnaire has been used for non-Aboriginal people. This study aims to find out whether this questionnaire can also be used for Aboriginal people. The study aims to understand whether the questionnaire is a helpful way to ask young Aboriginal and non-Aboriginal people about some of the changes in thinking and experience that may be a risk for psychosis.

2. Who is carrying out the study?

The study is being carried out by a student researcher from the Department of Psychology at the University of Sydney. The name of the student researcher is Blake Hamilton (9351 2629). The study is being supervised by Professor Alex Blaszczynski (9351 7612). If you wanted to contact any of the researchers for further information, you could contact them on the above telephone numbers.

3. What does the study involve?

If you agree to participate in this research you will be asked to attend an appointment at either, your Aboriginal health service, mental health service, drug and alcohol service, or the Sydney University psychology clinic.

When you come for the appointment you will be asked questions about yourself, such as your age and level of education. You will also be asked questions about how you get on with your family and friends, your drug and alcohol use, and topic related to your mental health and any problems experienced. The researchers will also ask if they can have permission to access your medical records.

Psychology Clinic
School of Psychology (F12)
University of Sydney NSW 2006
Telephone: (02) 9351 2629
Fax: (02) 9351 7328

You will only have to come for one appointment and will not be asked to come for any further appointments or complete any additional questionnaires. You will be reimbursed $20 to cover travel expenses and in consideration of your time.

4. How much time will the study take?

The study will involve one appointment, which will take between 1 and 1 ½ hours.

5. Can I withdraw from the study?

Being in this study is completely voluntary – you are not under any obligation to agree to participate. If you decide to take part in the study and then change your mind, you can withdraw at any time and for any reason. You will be free to withdraw your consent and discontinue your participation in the study at any time. If you decide to withdraw from the study your decision will be readily accepted and will not affect your present of future treatment at your Aboriginal health service, mental health service, drug and alcohol service, or the Sydney University psychology clinic. Furthermore your decision to withdraw from the study will not affect your relationship with the University of Sydney, or associated health services, in any way.

6. Will anyone else know the answers I give?

No. All information will be kept strictly confidential within the research team. Nobody will know the responses you give except as required by law. These exceptions are if you tell the researcher of plans to hurt yourself or others. The research team will assign a special number to the answers you give and your information will be related to that number only. Your responses will not contain your name or any other identifying information.

7. Will the study benefit me?

You will not directly benefit from the study. The information you give will help us to understand how to better ask Aboriginal and non-Aboriginal people about the changes in thinking and experience that might put people at risk for psychosis.

8. Can I tell other people about the Study?

Yes, please feel free to tell anyone you want to about the study.

9. What if there is a problem?

The study involves minimal risk to you. Some people may become upset in talking about mental health problems. If this occurs the researchers will offer you a referral to a mental health worker.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics and Biosafety Administration, University of Sydney on (02) 9351 4811.

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University of Sydney NSW 2006

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Fax: (02) 9351 7328

School of Psychology
University of Sydney

CONSENT FORM

I,....., give consent to my participation in the research project
Name (please print)

Title: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees.

In giving my consent I acknowledge that:

1. The procedures required for the project have been explained to me (including the researchers accessing my medical records), and any questions I have about the project have been answered to my satisfaction,

2. I have read the Subject Information Statement and have been given the opportunity to discuss the information and my involvement in the project with family and or/ friends;

3. I am aware of the risks and inconveniences associated with the project.

4. I understand that I can withdraw from the study at any time, without affecting my treatment or my relationships with the researcher(s) now or in the future;

5. I understand that my involvement is strictly confidential and no information about me will be used in any way, which reveals my identity.

Signed:.....

Name:.....

Witness:.....

Name:.....

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics and Biosafety Administration, University of Sydney on (02) 9351 4811.

For further information you may contact one of the researchers at the Department of Psychology, University of Sydney.

- Blake Hamilton (9351 2629).
- Professor Alex Blaszczynski (9351 7612).

Psychology Clinic
School of Psychology (F12)
University of Sydney NSW 2006

Telephone: (02) 9351 2629
Fax: (02) 9351 7328

School of Psychology
University of Sydney

Cash Reciept

I,....., Name (please print)

Certify that I have received a cash amount of $20 being for my participation in the research project named below.

Title: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees.

Signed:.....

Name:.....

Date:.....

Witness:.....

Name:.....

Date:.....

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics and Biosafety Administration, University of Sydney on (02) 9351 4811.

For further information you may contact one of the researchers at the Department of Psychology, University of Sydney.

- Blake Hamilton (9351 2629).
- Professor Alex Blaszczynski (9351 7612).

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School of Psychology (F12)
University of Sydney NSW 2006

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Appendix I

Memorandum of understanding between the project team, South Eastern Sydney Illawarra Area Health Service Aboriginal Health Unit, and the HOPE-Moodgee Aboriginal Mental Health Working Party,

School of Psychology
University of Sydney

Outline of DARMSPA Research Project NH&MRC Ethical Considerations for Aboriginal Research

This document outlines the ethical considerations by the Detection of at-risk mental states for psychosis in young Aboriginal people project (DARMSPA) to fulfil the aims of the NH&MRC Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research (National Health & Medical Research Council, 2003).

This document forms a memorandum of understanding between the project, the La Perouse and districts Aboriginal community, and the SESIAHS Aboriginal Health Unit to protect and value Aboriginal culture in conducting this research. This outline has been prepared in consultation with the HOPE-Moodgee Aboriginal mental health working party (HMAMHWP), Ms. Gail Daylight, Manager of Aboriginal Health SESIAHS, and Ms. Barbara Caine, Aboriginal Mental Health Professional SESIAHS and community member.

The NH&MRC guidelines urge researchers to discuss and document how research to be conducted in Aboriginal communities will address issues of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity. The project will demonstrate each of these as outlined below:

Reciprocity

- The project will contribute to the advancement of health and well being of participants by providing a comprehensive screening interview for possible mental health problems. Commensurate with this interview, the project will arrange mental health follow-up for those participants concerned about their mental health. The broader Aboriginal community will derive benefits in advancing health and well being via the training of local Aboriginal mental health workers participating in the project.

- The project links with the NSW and Commonwealth government's strategies for improving the health of Aboriginal people. This research is in line with SESIAHS initiatives to improve mental health service delivery to the local community. Furthermore this project responds to the needs outlined by the local Aboriginal community and articulated through the HMAMHWP. These needs include improved identification of Aboriginal youth at-risk of mental illness and improved mental health service delivery to this group.

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School of Psychology (F12)
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- This research has the potential to improve identification of Aboriginal youth at-risk for psychosis and as such is likely to be of benefit to all Aboriginal and Torres Strait Islander communities. Clear and truthful discussion of the potential benefit of the research to the local community and other communities has evoked support for this research from the HMAMHWP, the SESIAHS Aboriginal Health Unit, and the Aboriginal mental health professionals working within SESIAHS.

- The project in discussion with the HMAMHWP has demonstrated a willingness to modify research in accordance with community values and aspirations. This willingness will continue throughout the life of the project.

- The research will enhance capacity of the local community via the advanced training of Aboriginal mental health professionals in detecting putative psychosis. Furthermore conducting research in the community raises the awareness of mental health issues in community members who have contact with young Aboriginal people. Results from the project will also be fed back to Aboriginal mental health professionals. In this way the community will draw on-going benefit beyond participation in the project.

Respect

- The research has responded to the diversity of Aboriginal and Torres Strait Islander communities by design in consultation with a number of Aboriginal communities and leading Aboriginal mental health professionals. The project recognises the way decisions are made in the local Aboriginal community and has sought HMAMHWP approval concerning all aspects of the research.

- The research acknowledges individual contributions by Aboriginal mental Health professionals and community members via establishing roles for Aboriginal co-researchers. These co-researchers are fully acknowledged as cultural experts. Furthermore, the opportunity exists for these researchers to become involved in analysis of data and publication of results. Collective community contribution is formally acknowledged by the project via the naming of the community in all reports and publications.

- Aboriginal people's knowledge and experience is engaged by the project via Aboriginal co-researchers role as 'cultural experts' in delineating symptoms and cultural experiences. In addition community members' advice will be sought and followed in approaching and recruiting young Aboriginal people for the study.

- Discussions held with the SESIAHS Aboriginal Health Unit, Aboriginal mental health professionals and the HMAMHWP indicate satisfaction with the projects: intentions regarding ownership and access to: Aboriginal intellectual property; research agreements and decision making processes; management of data; publication; and protection of individual and community identity.

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Equality

- The research project has in design valued the Aboriginal community's participation and expertise. This value will continue in conducting the research via the inclusion of Aboriginal co-researchers as cultural experts. This inclusion demonstrates the projects commitment to equality.

- The amount of support for the project obtained from the HMAMHWP, SESIAHS Aboriginal health unit, and the Aboriginal mental health professionals and the thorough nature of the research agreements reached, indicate the necessary strength to sustain equality.

- Across several discussions at HMAMHWP meetings and in negotiations with the Aboriginal health unit, and Aboriginal mental health professionals, the community and SESIAHS have expressed satisfaction with the proposed research, its potential benefits and their distribution. Throughout the above process, the project has provided information that is understood and usable for decision making.

Responsibility

- The project has provided all information requested by the HMAMHWP and has conducted negotiations in an open and transparent way. The purpose, methodology, and procedure are available to all parities for scrutiny. Aboriginal co-researchers and the HMAMHWP will also act as scrutinisers in conducting the research. Results will be discussed openly and provided to the HMAMHWP and other interested parties in the form of a summary of results.

- The HMAMHWP will act as reviewers of the project, and its ethics standards, for the time it is conducted in the community. Aboriginal co-researchers in addition to project investigators will provide reposts of project progress to the HMAMHWP. The HMAMHWP in conjunction with SESIAHS will address any unintended consequences from the research.

- The project undertakes to provide timely feedback to the community (via the HMAMHWP) and feed back an interpretation of the results that is likely to be of benefit to the community. In this way the project will provide information relevant to the expressed concerns and values of the community expressed through the HMAMHWP.

- The project undertakes to acknowledge the contribution of the community via the HMAMHWP in all publications and to protect the privacy and confidentiality of all participants involved in the project. The community will only be named in publications with the agreement of the HMAMHWP and Aboriginal co-researchers roles, and contributions will be fully acknowledged. Where Aboriginal co-researchers have aided in the research process to a significant amount they will be offered co-authorship on publications.

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- The agreement between the HMAMHWP, SESIAHS Aboriginal health unit, SESIAHS Aboriginal mental health professionals, and the research project, in conducting the research, is that the research will be fully supported by the above named parties and reasonable assistance will be given to researchers in conducting the research. The project undertakes to make every effort to conduct the research in line with the values and express wishes of the communities. The project undertakes not to place undue burden on any of the above named parties in conducting the research.

Survival and Protection

- The HMAMHWP was established by the La Perouse and districts Aboriginal community in recognition of the importance of improving the mental health of the community. Mental health problems have the potential to erode social bonds and by result erode cultural bonds. The support of this project by the HMAMHWP, SESIAHS Aboriginal health unit, and Aboriginal mental health professionals demonstrates a belief by Aboriginal people that this research is necessary to assist in stemming the erosion of social and cultural bonds via mental health and subsequent problems.

- Scrutiny of the conduct of the project by the HMAMHWP, the SESIAHS Aboriginal health unit, SESIAHS Aboriginal mental health professionals and Aboriginal co-researchers, are safeguards ensuring the research does not contribute to discrimination of Aboriginal individuals or culture.

- This research attempts to better understand Aboriginal mental health, beliefs and values about Aboriginal mental heath. The project respects the intrinsic values based expectations and has safeguarded this respect via the inclusion of Aboriginal co-researchers as experts and cultural advisers, and by inviting scrutiny of the HMAMHWP.

- This research is an investigation into whether young Aboriginal people can be assessed for possible mental health problems using established methods from the non-Aboriginal community. This research will highlight the ways in which Aboriginal culture must be considered in assessing mental health symptoms. Participating Aboriginal co-researchers will gain experience in utlising non-Aboriginal assessment methods, and making these culturally applicable to young Aboriginal people. This process provides a platform for highlighting and examining cultural distinctiveness.

- The inclusion of Aboriginal co-researchers in the research is a safeguard to identify and eliminate threats to Aboriginal people's cultural distinctiveness.

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Spirit and Integrity

- The HMAMHWP and SESIAHS Aboriginal health unit have identified the improvement of mental health and access to mental health services as a priority area for the local community. This priority exists on the belief that such an improvement would aid the community's cultural, spiritual, and social cohesion. In this way the project accepts a responsibility to aid the community in this cohesion via the training of Aboriginal mental health workers and promoting good mental health to community members throughout conducting this research.

- The project recognises the diversity of Aboriginal people's culture including the mechanisms through which communities make decisions. To this end the project is guided by the HMAMHWP, SESIAHS Aboriginal health unit, and Aboriginal co-researchers in all aspects of research conduct and reporting.

- The chief investigator of the research project is a professor of psychology and head of medical psychology at Westmead hospital. The student investigator is a registered psychologist and in training to become a clinical psychologist. The title of psychologist is granted to those who can demonstrate to the psychologists' registration board that they are of good character and have demonstrated both personal and professional integrity.

- This research aims to contribute to knowledge about Aboriginal mental health and specifically psychosis in young Aboriginal people. Furthermore the project works within the spirit and integrity of the Aboriginal community by highlighting cultural differences in the experience of mental illness, and by offering training to further the skills of Aboriginal co-researchers and Aboriginal mental health professionals. The above fall within the mandates outlined by the HMAMHWP to improve the mental health of the community and increase access to mental health services.

National Health & Medical Research Council. (2003). *Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research.* Canberra: Commonwealth of Australia.

The undersigned, representing the HMAMHWP, SESIAHS Aboriginal health unit, and research project, agree to the above outline as fulfilling the requirements of the NH&MRC values and ethics guidelines.

Barbara Caine
Aboriginal mental health professional & HMAMHWP member

Gail Daylight
Manager, SESIAHS Aboriginal health unit

Professor Alex Blaszczynski
Chief Investigator
Chair in Psychology

Blake Hamilton
Student investigator
DCP/MSc Student

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Appendix J

Medical record audit form

DARMSPA Medical Record Audit

Subject No: _____ MRN: _____ Date:_____ Loc:_____

Date of birth: _____ Aboriginality Noted: Yes ☐ No ☐

Other Medical Condition/Organic Illness:_____

Sex: Male ☐ Female ☐

Diagnosis:

Diagnosis at Intake;

Date:

Axis I:
Axis II:
Axis III:
Axis IV:
Axis V:

Diagnosis made by:

Most Recent or D/C Diagnosis;

Date:

Axis I:
Axis II:
Axis III:
Axis IV:
Axis V:

Diagnosis made by:

Other Diagnoses:

Axis I:
Axis II:
Axis III:
Axis IV:
Axis V:

Date:

Diagnosis made by:

Number of psychotic episodes: _____

Symptoms:

Primary Symptoms: _____

Secondary Symptoms: _____

Symptom pattern? _____

Substance Use:

Substance use recorded: Yes ☐ No ☐

Substance use: Use ☐ Abuse ☐ Dependence ☐

Substances used: _____

Substance use pattern: _____

History of substance use: _____

Pattern established between substance use and symptoms? _____

Office Use Only

Code: _____ Group: _____

Appendix K

Pilot Study Interview Questions

School of Psychology
University of Sydney

Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees.

Discussion questions for pilot study

The pilot study involves discussion with small groups of 5 young Aboriginal people around mental health in Aboriginal people's mental health, psychosis, and participating in research. The aim of these groups is to understand what these young people understand about mental health and what factors would encourage and discourage them from participating in the proposed research.
As the format for the Pilot study is a group discussion there is no formal questionnaire but rather prompts for the discussion. The prompts to be used include:

- Introductions: Blake, Camilla
- **What do you understand about mental health?** – What makes for good mental health, bad mental health? What do you think about that makes up your own mental health?
- **What do you understand about mental illness?** -What makes something a mental illness? When do mental health *problems* become so bad that they require treatment?
- **What experiences have you had with mental health or mental illness?** Do you know anyone with mental health problems? What kind of problems? Is it al illness- or something else?
- **How is Aboriginal people's mental health different to non-Aboriginal people?** -- Do Aboriginal people experience mental health in a different way? Do different things affect Aboriginal people's mental health? Do they have different symptoms? Show problems differently? Are there things that are not mental health that might look like it?
- **What do you know about schizophrenia and psychosis?** –What do you think these are? Do you know anyone with these problems? What might someone with these problems do or say?

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- **How would an Aboriginal person with psychosis appear differently than a non-Aboriginal person with psychosis?** -Do you think Aboriginal people have different symptoms? Do they think differently about these illnesses? What might they think caused them? Do they react differently to non-Aboriginal people? Do families act differently?
- **How should we ask Aboriginal people about mental health problems?** –Do we need to ask different questions? Do we need to check-out different things? Are there things we need to be sensitive or careful about?
- **How should we ask young Aboriginal people about some of the earliest changes that might be the first stages of psychosis?** – What would you ask if you suspected one of your friends was at-risk of psychosis or mental illness? Are some questions better than others?
- **Is it important to do research into mental health in Aboriginal people? Why/Why not?** –What is the most important thing to research?
- **Why is it important to do research into about how to ask Aboriginal people about their mental health?** -Are some things more important to research about Aboriginal people than mental health?
- **What would make you want to participate in that type of research?** –What encourages you to be in a research project? Money, community, knowledge?
- **What would make you not want to participate in that type of research?** –What would make you say no or not be interested?

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Appendix L

Pilot study interview transcript

School of Psychology
University of Sydney

Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees.

Discussion questions for pilot study- Results

Pilot Study Discussion: 30th October 2007

- **What do you understand about mental health?** – What makes for good mental health, bad mental health? What do you think about that makes up your own mental health?

"It's things like drugs and alcohol, suicide, depression (all the different types pre-natal post-natal)- all the bad things. I don't assoc mental health with people being healthy minded".

"It's an illness affecting people e.g. depression, like a physical illness –I think about the illness and the end of it."
"Also could be a grief-problem, sometimes depression. Psychosis etc- illnesses (but ongoing, not just a single event)."

"My own mental health?- drug and alcohol. PTSD, domestic violence, assault Grief, depression (but everyone gets that), healthy side- enjoying things, times with family, cultural stuff, community work- makes up own mental health".

"Make up of my own mental health? - don't really think about it. Feels like a wave, always up and down like a rollercoaster. One week could be all happy and the next could want to kill someone. If I'm OK I go to work all the time, if I'm not I couldn't care less, I have a week off. Take it out on the kids a bit, don't go and see them as much. Drink for a couple of days. If I'm training and eating right and things like that I can usually stay away from everything and be level headed. As soon as it changes I might have an argument with the missus or something... A while ago, I was at the stage where I'd look in the mirror talk to myself, act out like it really was happening- but I know that was an illness- smoking dope and drinking a lot of alcohol, on the party drugs as well. I used to be a very aggressive person. As soon as I cut everything out it went away".

- **What do you understand about mental illness?** -What makes something a mental illness? When do mental health *problems* become so bad that they require treatment?

"Mental illness- is maybe when you don't have control over your thoughts e.g. having a conversation in your head and not realising what you're doing. When you do realise it's a positive way of coming out of it."

Is self-esteem seen as a mental health problem?
"In this community that is the way of life, low self-esteem isn't seen as a mental illness really. When you see someone with scrubby clothes, no shoes, walking with his head down, you can tell he doesn't feel good about himself. It's low self-esteem and that's just normal in the community."

" I knew this bloke who suicided- and from talking to his family members, around that time about before he died- lots of people said he wasn't happy about where he was in life- so that's low self-esteem and depression. He didn't make his goals. He was a good footballer but he didn't make it professionally, and wanted a good house. These sorts of things can snowball into other things."

"When it snowballs- starts small, could start when you're young, then one thing after another happens. Death is so common in the community, it usually comes in threes. There are times when you can handle it and others when you can't, you don't know what to do, especially if they're so close to you, that's when you start to feel depressed, like- I've got nothing going for me. Hits you at the ankles, and you have no feet, then keeps going up, hitting you in the knees, and on top of that and on top of that, until you're down and you can't get up."

Do you think that's how people in the community feel?
"It's a cycle, people can cope with it because they're used to it. Lots of other people do drink, because it takes that pain/difficulty away. My uncle died when I was 17, I drank for 5 years, from 17-22 to take the pain away, then I woke up and snapped out of it. Drug addicts, in gaol, see them walking around with it."

- **What experiences have you had with mental health or mental illness?** Do you know anyone with mental health problems? What kind of problems? Is it al illness- or something else?

"I have known people with mental health problems- my cousin, she's not mental but a shadow of the person she was 10 years ago. You can see there's something wrong, there have been problems from when she was young. It's out in the open, she's just a young girl with kids, no father around, everything's got to her and she's just losing it a bit. It's just not feeling good, she's put on a lot of weight, feels uncomfortable with herself."

"Grief's a big thing in the community. I have a schizophrenic uncle from smoking yarndi, he's quick to go off, has irrational moods, and mood swings. In the community lots of alcohol covers a lot of things in this community. It's a coping strategy, first it's depressed cause of low self esteem then it's one thing after another. That would be that snowball effect. But if you take away

the alcohol, underneath the drunkenness is other problems- like mental health."

- **How is Aboriginal people's mental health different to non-Aboriginal people?** --Do Aboriginal people experience mental health in a different way? Do different things affect Aboriginal people's mental health? Do they have different symptoms? Show problems differently? Are there things that are not mental health that might look like it?

"I'd have to think about that, there'd be a few things. I don't really sit there and think about it."

"I guess Aboriginal people- have beliefs and religions, culture and a spiritual system different from non-aboriginal population."

What sort of things do Aboriginal people do, that might be different?
"With Aboriginal people it's a bit more deeper than with non-indigenous work, where they pretty much see their clients and then send their clients out. We have to take them shopping, cleaning up, take them to appointments etc 'cause they couldn't do it, it's more of a life skills thing. "

Is there an expectation that you would help them in more ways than just straight mental health?
"Yes. Non-aboriginal people with mental illness are pretty much the same as well, like they need to go shopping etc. But, with the Aboriginal community- It's an expectation, you're used as a service."

"The community would say that aboriginal mental health is different to non-aboriginal mental health. Just a feeling? Yeah."

"There was this bloke from the north coast down here admitted to Kiloh. They were saying he was psychotic, 'cause he was saying that the spirits were coming for him. What he was telling me was pretty much exactly what was actually happening. His grandfather did something bad and there's been a curse put on him and his family that will happen from generation to generation. I told the guy I understood- and then them (the staff)- it looked like the staff were going to lock me up as well, I couldn't believe it! People from where he was from would think the same things about the curse, which pretty much wiped out his whole family. So you do have examples like that the way they found him- coppers found him, and he tells them so and so's after him and going to come to get him. It didn't help him that he was half-drunk, just an example of how beliefs change things."

"What young guys who might have grown up in the city and not know about this stuff? The effect does go as long as how many generations that curse was put on, doesn't matter whether they believe it or not. Through stories we see it happen, there have documented cases although not published. Also a curse where a lady, her grandmother did wrong so they cursed every generation, so 5 husbands would die. The curse was put on in the 1850s, she was born in the 1930s, it happened to her. Now she's alcoholic, but there's

things like that that have become well known, It still effects even if you don't believe in the old ways."

"Stuff has been drummed into you as a kid, you've been told and seen things. If they (Aboriginal people) do have a mental attack it's sort of might be a bit harder to break through to them for something in the system because the system's been against them the whole life. Going to hospital to visit someone, that person dies. The stolen generation still has effects because the older people remember cops taking kids away, So as soon as someone tries to help they (Aboriginal people) back away."

- **What do you know about schizophrenia and psychosis?** –What do you think these are? Do you know anyone with these problems? What might someone with these problems do or say?

"Psychosis- go into another world, like another reality, or not reality but don't come out of it."

"Schizophrenia- don't really have control over being aggressive and things like that. Also get twitches and stuff like that."

- **How would an Aboriginal person with psychosis appear differently than a non-Aboriginal person with psychosis?** -Do you think Aboriginal people have different symptoms? Do they think differently about these illnesses? What might they think caused them? Do they react differently to non-Aboriginal people? Do families act differently?

"Depending on the person. You get kooris who are white anyway, urbanised. But then you can get urban kooris still caught in between (Aboriginal and non-Aboriginal culture). Basically I think there is a difference."
"What If the koori person was closer to the old ways? Yeah, would have an effect on the outcome

- **How should we ask Aboriginal people about mental health problems?** –Do we need to ask different questions? Do we need to check-out different things? Are there things we need to be sensitive or careful about?

"I Haven't seen the questions *(the question that would normally be asked).* No, I grew up in a white family and a black family. Father's family went to church, Sunday roast, strict. Mum's family, were, how can I say it, less organised more all over the place."

"Because I'm mixed in both worlds, I could answer in both ways. Could give it in both perspectives."

"From aboriginal perspective? The way you say it, more emotion involved, like to think I'm a bit more sensitive. The other way (non-Aboriginal)- is more forward and direct. You wouldn't say it straight out, you'd have to weave your

way through it. Build trust. There's been a lot of mistrust in the past. Just the way they've built up. The Stolen generation- effects still on these generations. Aunt walks down the street, Police come towards us, she crosses the street; so they don't take the kid. What does the kid think? Gets mistrust too even if those policies are now gone. Even if I ask my own Nan a question, and I know she knows answer, but she says I don't know, you don't ask those things (in the Aboriginal community). They give you answers that get you nowhere. You never ask- Why's that?"

Like...I've never met first cousins of my mother's family, but my dad's family...I know my 4th or 5th cousins- here we're pretty much like brothers even though we are 4th cousins are something."

"Measure it in western society-different." *(symptoms? Mental health problems?)*

"They think differently sometimes too- lots to do with education, they think they're being hoodwinked with all these questions in the hospital. I teach at the school and at school, as soon as there's too many questions at once, they (Aboriginal kids) start acting up and carrying on. Just the way they ask the question and, also the amount of info they're trying to push on them straight away."

- **How should we ask young Aboriginal people about some of the earliest changes that might be the first stages of psychosis?** – What would you ask if you suspected one of your friends was at-risk of psychosis or mental illness? Are some questions better than others?

"How would you find out about others? Shared experiences, give them something (about yourself), then they can give you something (about themselves). building trust, a relationship they feel comfortable with."

- **Is it important to do research into mental health in Aboriginal people? Why/Why not?** –What is the most important thing to research?

"It's a need."
Why?
"Every time I sit round with my mates or whoever, all of a sudden it comes out, they want to get it out of them but it will take a few drinks, they won't sit round and talk about it sober. Could have happened 10 years ago and not have come out."

"Also is important from as soon as we get aboriginal people as academics in mental health it can be done from both points of view."

"I had a client I knew well, and I went away, when I came back, I was up at the hospital and I was walking through the ED and I saw him there and asked him what he was doing there- He was psychotic but 'cause he was drunk they had just thought –just let him sober up and he'll be alright. The client had told

the staff to contact people. He was psychotic, but 'cause he was drunk, and picked up by police, took to hospital, they didn't look into history or anything cause he was aboriginal. Even though he had a huge file and had been in Kiloh before. Need to have awareness." *(about Aboriginal diff's and similarities?)*

- **Why is it important to do research into about how to ask Aboriginal people about their mental health?** -Are some things more important to research about Aboriginal people than mental health?

"Trust, the best thing. And just our ways, research into how we would ask questions, get them to be comfortable."

- **What would make you want to participate in that type of research?** –What encourages you to be in a research project? Money, community, knowledge?

"If a family person was affected. Comes with education, once people understand about mental illness. " (better education = more encouraged about research)

"Personal experience in mental health. I just like to get involved in things, know what's going on, general love for my people. There's not really a feeling of big responsibility to community in young people, except for the educated ones."

- **What would make you not want to participate in that type of research?** –What would make you say no or not be interested?

"Life experience, they might have had something similar that was bad before, will put them off."

"Also too much research, what do they want to know now?"

"Idea that they're coming in and rustling around. People came to do a study, door-knock around the mission- and Nan said she was sick of the research, they've studied us for 200 years, what else do they want from us?."

"That effect, the Jehovah's effect, well not the Jehovahs but you know what I mean- always knocking on the door."

"Perception for all age groups- and some people don't want to talk, lucky to talk to their closest relative let alone someone they've never met."

"There's a minister in the community and he has to junior ministers. When it's the one guy people will talk to, but if his two off-siders are there they won't talk- it's trust."

Appendix M

Project correspondence

Aboriginal Health & Medical Research Council
of New South Wales

AH&MRC ETHICS COMMITTEE

Mr Blake Hamilton
Research Fellow
NSW Institute of Psychiatry
School of Psychiatry (F12)
University of Sydney
NSW 2006

Dear Mr. Blake

Re: Project - Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol services attendees

Concerning your request for our ethics committee to evaluate and support the above-mentioned health research project the Committee responds as follows:

In all matters requiring ethical evaluation the Ethics Committee is committed to professional projects in essential epidemiological and medical research that increase scientific knowledge, demonstrate benefit to Aboriginal communities and provide transfer of skills to the Aboriginal health workforce.

Included in the criteria used by the Committee to evaluate applications for proposed research and publications of statistical data on Aboriginal health are the following principles which are contained within the AH&MRC publication *Guidelines for Research into Aboriginal Health.* (www.ahmrc.org.au/Publications.htm)

(i) that in accordance with the priorities set out in the *National Aboriginal Health Strategy* and the *Report of the National Workshop on Ethics of Research in Aboriginal Health*, research proposals must advance scientific knowledge to result in demonstrated additional benefit to Aboriginal communities.

(ii) that there be Aboriginal community control over all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings.

(iii) that the research to be conducted in a manner sensitive to the cultural principles of Aboriginal society.

(iv) that Aboriginal communities and organisations be reimbursed for all costs arising from their participation in the research process.

(v) that Aboriginal communities and organisations should be able to benefit from the transfer of skills and knowledge arising from the research project.

Furthermore, the Committee assumes that applicants of research proposals and epidemiological publications of Aboriginal health are conversant with relevant provisions within the following documents.

Funded by NSW Health Department

1. *Report of the National Workshop on Ethics of Research in Aboriginal Health* (NAIHO) [1987]
2. *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research* (NH&MRC) [1991]
3. *National Statement on Ethical Conduct in Research Concerning Humans*, (NH&MRC) [2000]
4. *NSW Aboriginal Health – Information Guidelines* (NSW Aboriginal Health Partnership, NSW Health Department/AH&MRC) [1998]
5. *Guidelines for Research into Aboriginal Health* (AH&MRC Ethics Committee) [1999]

The Committee has examined the proposal and with specific reference to your project the Committee responds as follows:

- Has any provision been made to involve Aboriginal researchers in the project?
- Do the researchers have extensive experience in Aboriginal Health as clinicians?
- What links do the researchers have with the Indigenous Chapter of the Royal Australasian College of Psychiatry?
- Do the researchers have evidence of support or consent agreements for undertaking the research at the Daruk AMS, Tharwal AMS and Redfern AMS cited as research sites for the proposed project?

The Committee apologises for the inordinate delay in responding to your application. Regrettably, we have encountered serious backlog of work resulting from an office fire which has compounded the onerous workload of the Committee. Mindful of your tight schedule the Committee will provide a prompt response upon receipt of the above requested information.

On behalf of the AH&MRC Ethic Committee,

Yours sincerely

Kaye Mundine
Chairperson

12th May 2005

KM/jw/490-00

Dear Blake,

Thank you for sending me your research proposal. I have just read it and I have a number of serious concerns. I can see your problem about the circularity in getting approval from an AMS and the AH&MRC. To have a chance of breaking the deadlock your project will have to meet certain criteria. At present, it does not do so. There are some relatively minor matters that I raise in the next paragraph and then there is the matter of meeting ethical guidelines. That is the most important issue.

As a psychiatrist working in Aboriginal mental health I have doubts that such an ambitious project can be completed with the resources you have available to you. When you came to see me last year, I suggested to you that you should attempt a more tightly focussed study but you have chosen to tackle the whole thing. I also wonder about whether some of your intended research methods are practical. For example, you propose to test your subjects with six different scales. I wonder how you will get young Aboriginal people, particularly those with drug and alcohol or mental health problems, to sit down and cooperate with you for so many scales. If you exclude those who don't or can't, you will seriously distort your results. However, I suppose that is your problem, not mine.

1. *Whilst the project may be ambitious it is not, we think, unachievable. The biggest resource I have available to me has been people's enthusiasm and willingness to support the project. It is unlikely that I will be able to complete the prospective study of Drug and Alcohol patients due to time constraints. This leaves the pilot study and phase 1 (the structured interviews). We anticipate that the interviews will take between 1 and 1.5 hrs. 2 of these scales are clinician rated global measure (0-100; GARF and SOFAS) based upon standardised short questions and the two D&A measures were both selected due to their short length and ease of completion. The CAARMS and the BPRS are of course longer and the intention is to complete these first. You are right that asking young Aboriginal people to attend for this period of time remains a challenge for the research. We will of course give participants breaks within the interviews if required. The project is not seeking people who are actively psychotic and one half of the sample will have had a history of psychosis, and of these people, half will be Aboriginal. Despite this the interview process may be difficult for people with mental health and drug and alcohol problems. We cannot control for those choose not to participate; however we can be flexible for those who find it difficult. The project has as an objective to examine the way in which we assess young Aboriginal people for psychosis. If young Aboriginal people cannot or will not answer questions from an established measure then this speaks to the shortcomings of current best-practice assessment techniques when applied to young Aboriginal people.*

On a much more serious note, I do not think that your project meets the requirements of the National Health and Medical Research Council's Guidelines for Ethical Conduct in Aboriginal and Torres Straits Islander Medical Research. I have made a few notes about

where your proposal appears to fall short of the guidelines, but my critique is far from complete. You really need to sit down with your supervisor and work through the whole matter in detail. Just writing a few more paragraphs into the proposal will not solve the problem; you will have to actually make formal arrangements with Aboriginal community organizations for the research to be acceptable. I have attached a pdf copy of the guidelines for you to review.

Here are the notes I made.

Reciprocity
I see no mention of reciprocity in the proposal. While a version of CAARMS might be useful and valid for young Aboriginal people and for clinical Aboriginal mental health work, this is not a foregone conclusion. The potential value of your project to the Aboriginal community can only be judged by the members of the community, guided by Aboriginal mental health professionals; probably with some input from non-Aboriginal mental health professionals who have experience working in the Aboriginal community. It is not enough to simply assume that a modified version of CAARMS would be of value to the Aboriginal Community.

2. *Reciprocity: We see the value of the research in both raising awareness of at-risk mental states for psychosis in AMS's and other services that deal with young Aboriginal people, and in providing some experience of both research and formal assessment to Aboriginal co-researchers. This is not to say that the CAARMS will not be of value to Aboriginal people. However, as you have raised a long structured interview is not ideal for young Aboriginal people. The question remains, what is? In order to answer this question we are forced to begin with the current best-practice technique for identifying those at highest risk of a psychosis. The CAARMS no doubt has many shortcomings in use with Aboriginal people, but there is nothing yet developed that has established validity for assessing for the risk of psychosis in Aboriginal people. The project has been endorsed by the Aboriginal Mental Health Workers Forum, and the HOPE-Moodgee Aboriginal Mental Health Working Party (SESAHS). In addition both Juvenile Justice and Corrections Health are interested in the project pending full AH&MRC ethics approval. The Aboriginal MH workers I have spoken to as well as staff from the forensic system want to be better able to assess young Aboriginal people's mental health including for psychosis or possible prodrome. The members of communities, including elders (La Perouse and Tharawal), whom I have spoken to are concerned about young people's mental health and are supportive of research that aims to highlight better idnetification and assessment methods. In this way we feel we have the support of the community and the Aboriginal MH workers who provide services to communities. There is a scientific value in answering whether the CAARMS is valid for use with young Aboriginal people, however the broader use of the project is to raise awareness, and provide training and experience to those who participate as co-researchers in assessing for possible psychosis.*

The possibility that such a scale might cause harm to Aboriginal people also needs to be considered. One of the most basic building blocks for useful social and emotional wellbeing and mental health work in Aboriginal communities is the principle that such work must be holistic. Aboriginal people frequently experience phenomena, such as hallucinations, that are an expression of spirituality and have nothing to do with psychopathology and are best understood in a holistic context. However, if an Aboriginal person is unfortunate enough to have a psychotic illness, he or she is likely have hallucinations generated by the illness. It is inherently difficult to distinguish between the two types of hallucination and this is likely to be a real stumbling block for any scale purporting to measure prepsychotic or psychotic symptoms.

3. *I agree that in the Aboriginal community mental health work must be holistic. However, this is a research project aiming to answer a research question. I appreciate that Aboriginal people experience cultural phenomena which may be perceived as psychopathology. This is an important aspect of the project, to tease apart these phenomena from cultural or pathological. As such Aboriginal co-researchers will be included in interviews to advise on whether phenomena described are cultural or pathological. If the CAARMS is unable to distinguish between cultural and pathological phenomena then this is a finding suggesting that a specific formal assessment tool for psychosis in Aboriginal people is warranted. I would argue that an individual suffering from non-cultural delusions has moved beyond pre-psychotic. I do not forsee how the structured interview has the potential to cause harm any more than a standard clinical interview. There is a low chance of distress from discussing mental health issues that is equal to that associated with any clinical research. If a participant becomes distressed during the course of the research they will be offered referral to the local mental health team (or AMS if this is their local MHT). Similarly we have stated in our ethics application that should anybody participating in the research who has a mental health problem and would like assistance for this will be referred to their normal treating clinician or local MHT.*

Scales of any type are inherently reductionist, but some scales may be so useful that such a non-holistic approach is justified. However, scales are also used to judge people; in this case, whether or not someone is psychotic or likely to become psychotic and such a judgement might have serious consequences. Misused, such a scale has the potential to harm young Aboriginal people.

4. *I would argue that far from being reductionist the CAARMS is expansionist in the depth and range of symptoms it assesses. The CAARMS derives specificity and predictive validity from assessing a broader range of symptoms in more depth than would be assessed in standard clinical interview. This scale will be used only for research purposes and in no way to judge people. As stated above a participant with mental health concerns will be referred to their local MHT. The instruent is not being used to judge whether people are likely to develop psychosis. Phase one aims to validate the instrument for use with young*

Aboriginal people by comparing the CAARMS to the BPRS across the 4 groups of Aboriginal versus non-Aboriginal and psychotic versus non-psychotic. Phase 2 (unlikely to be completed due to hold ups) uses the instrument to examine whether an at-risk mental state for psychosis can be detected in a high-risk group (D&A Pts.) who are Aboriginal and non-Aboriginal.

Inclusion

I can find nothing in your proposal to demonstrate that your research proposal was constructed by a process of consultation with Aboriginal people and communities. I know you went to the AH&MRC as I suggested but their input and opinion is not mentioned in the proposal. There is also no mention that there will be Aboriginal individuals or partners in this research project. I found no mention of any agreement with an Aboriginal person or community about co-authorship, ownership of the data and eventual publication of the research results.

5. *Yes I went to the AH&MRC. I went to Andrew Webster, Hope-Moodgee Aboriginal MH Working Party, SESAHS; the Aboriginal Mental Health Workers Forum, Elders, community members. The full list of people consulted appears in the full ethics application. As I have said, students from the Charles Sturt Degree Course in Aboriginal MH as well as Aboriginal MH workers have been invited to be co-researchers in the project. There has been no discussion around co-authorship as without full AH&MRC approval there has been no grounds for co-researchers to sign on. Moreover, as you know, co-authorship requires a significant input into conducting or writing up the research. If there are co-researchers interested in doing this work then they would of course be offered co-authorship. The data remains the property of the Aboriginal community from which it is collected and they are entitled to a copy of the research materials collected provided they can assure the storage of the data in a de-identified form. As you know I am bound ethically and scientifically to store the original data for 7 years, after which it will be returned to the community from which it is collected. The data belongs to the community but I am bound to hold the record of the data for the above period. I have agreed to the prescriptions placed on the research by the AH&MRC as to publishing results and have assured them results will be discussed before publication.*

Consent

Attention needs to be paid to the question of informed consent by the subjects. How are you going to explain to your young Aboriginal subjects the nature of the research and your need for them to answer a very large number of questions? There is also the matter of relying on clinicians working in Aboriginal mental health and drug and alcohol services for referrals. Your research must fully meet the NH&MRC guidelines before clinicians will be willing to make such referrals. As a psychiatrist at an AMS, I would not be willing to participate, even indirectly, in a project that did not meet those guidelines.

6. *The project meets the current USYD HREC requirements for informed consent via the provision of a participant information sheet. This outlines the project and the*

participant's option of withdrawing from the research at any time without penalty. The project does not rely on referrals only that clinicians be willing to give potential participants the information sheet and asked for permission for myself to phone them and explain further the project and seek their participation. During this phone call the research will be explained more thoroughly including the number of questions and why they are being asked. Clinicians will be asked to identify 20 potential participants (across all AMS's and the Justice system) who are Aboriginal and have had a diagnosis of psychosis. The project has been designed to meet both NH&MRC and AH&MRC research guidelines.

Accountability

I cannot see anything in the proposal that demonstrates that there will be accountability to the Aboriginal community or individual subjects. Will the subjects be told the results of the tests administered (all the tests, not just the CAARMS)? Will family be involved in sharing such information with young and potentially disturbed people? Will you refer those that are judged to be prepsychotic? What provision has been made for follow-up and support in the even of a bad reaction to test results?

7. *Accountability by the project is demonstrated by an ongoing advisory relationship between the AH&MRC and the project and via working relationships with the AMS's and their boards. This includes project updates and feedback on results of the project disseminated via a project report and feedback presentation to AMS's. Subjects will not ordinarily be told the results of the research interviews. Should they wish to know the outcome of their results they will be offered a follow-up appointment with the researchers who will give feedback. If concerns arise from the feedback they will be offered a referral to local MHS's for more comprehensive assessment. Family will not be involved in line with stipulations surrounding privacy and confidentiality. People who meet criteria for an at-risk mental state for psychosis will be offered an appointment with local MHS's if they are concerned about their mental health. If a person participating in the research has concerns about their mental health they will be referred to their treating clinician or local MHS. Similarly those with a bad reaction will be offered referral and should researchers have concerns warranting further action the local crisis team or police may be informed in extreme cases. For those who accept referral and are assessed as warranting treatment then treatment by the local MHS is indicated.*

I am sorry if these comments disappoint you or cause difficulties with your project, but you really need to prepare things properly if you are going to start, let alone complete, your research.

Yours sincerely,

Neil Phillips

1 June 2005

The University of Sydney

Department of Psychology
Clinical Psychology Unit

Faculty of Science

NSW 2006 AUSTRALIA

Professor Alex Blaszczynski
PhD
Professor of Psychology &
Head, Department of Medical Psychology,
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8 March 2006

Mr. Ken White
Director, Aboriginal Health Branch
NSW Department of Health
Locked Bag 961
North Sydney NSW 2059

Strictly confidential

Dear Mr. Ken White,

RE: Application to AH&MRC for ethics approval for University of Sydney research project into Aboriginal mental health

I refer to our recent telephone conversation regarding the difficulties we are experiencing in obtaining ethics approval for a research project into the early identification of psychosis among Aboriginal substance users.

Following preliminary discussions with John Williams (AH&MRC Ethics secretary) on the 13 April 2004, Blake Hamilton and I submitted a research proposal to the University of Sydney Human Research Ethics Committee. Blake Hamilton is a Doctorate of Psychology Student under my supervision who is keenly interested in the topic of early intervention for psychosis among Aboriginal youth. The project's aim is described in the title of the project: *Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohols service attendees.*

This project gained University of Sydney HREC approval on the 15th October 2004. In compliance with NSW Department of Health partnership agreements in respect to research involving Aboriginal community members, and HREC requirements, we submitted the protocol to the AH&MRC on 30th October 2004 for approval.

We attach a brief summary describing the timeline associated with the project. We also attach the following documents for your information:

- University of Sydney HREC letter of approval dated 5th October 2004
- Ethics application detailing the project and study design
- Letters to John Williams dated 30th October 2004, 17th February 2005, 18th May 2005, 18th August 2005

- Email responses from John Williams dated 12th September 2005 and 16th September 2005
- Letter from Kay Mundine dated 12 May 2005
- Letter from Professor Blaszczynski to Kay Mundine dated 15th February 2006

Our concerns are expressed at the excessive and unacceptable difficulties and delays we have experienced in our communication with the AH&MRC. Despite acting diligently to address the matters raised by the AH&MRC in a timely fashion, we continue to struggle with our attempts to obtain approval or knowledge of its current status. Following a telephone conversation with John Williams in November 2005, we were informed that the protocol was only now being sent for scientific evaluation. However, we remain uncertain as to what is transpiring with the review process.

On the 15th February 2006 I sent a letter to Kay Mundine expressing our concerns regarding the process and problems with effective communication with the AH&MRC but to date, have not received any response.

Given the delays and uncertainties experienced, the project is potentially compromised in NSW and this fact has imposed on us the necessity to contact interstate Aboriginal and Government health agencies to explore the option of shifting our research to other locations.

We believe our research will assist in the early identification of psychosis among at-risk Aboriginal community members and ultimately to the reduction in the severity and burden of mental health morbidity.

Naturally, we prefer to conduct this research for the benefit of members of the New South Wales Aboriginal community members. Accordingly, we are writing to you with a request for your guidance and advice in how to manage this difficulty. We are keen to collaborate with the Aboriginal community and adhere to the partnership guidelines in obtaining the necessary ethics approval. Is there any procedure whereby we can meet with the relevant parties and discuss options on how to advance this project?

We look forward to your support and assistance in this matter,

Yours sincerely,

Alex Blaszczynski & Blake Hamilton

AH&MRC ETHICS COMMITTEE

Mr Blake Hamilton
Research Fellow
NSW Institute of Psychiatry
School of Psychiatry (F12)
University of Sydney
NSW 2006

Dear Mr. Hamilton

Re: Project - Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol services attendees

Applicant Mr Blake Hamilton, Research Fellow, NSW Institute of Psychiatry, School of Psychiatry, University of Sydney,

Supervising Professor Professor Alex Blaszczynski, Professor Psychology, Head, Department of Medical Psychology, Westmead Hospital.

The Committee notes the correspondence from Professor Blaszczynski dated 15th February concerning the project to detect at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol services attendees and responds accordingly.

Concerning the above application the Committee, following liaison with Communities concerned, examined the proposal and responded to the applicant on the 12th May 2005 itemising the following matters with specific reference to the project:

- Has any provision been made to involve Aboriginal researchers in the project?
- Do the researchers have extensive experience in Aboriginal Health as clinicians?
- What links do the researchers have with the Indigenous Chapter of the Royal Australasian College of Psychiatry?
- Do the researchers have evidence of support or consent agreements for undertaking the research at the Daruk AMS, Tharawal AMS and Redfern AMS cited as research sites for the proposed project?

The Committee's letter acknowledged the tight schedule and offered to provide a prompt response upon receipt of the above requested information.

On the 18th May the applicant and the Project Supervisor replied

Funded by NSW Health Department

- The first dot point was responded to by mentioning that Aboriginal students from Charles Sturt University would be involved in the project and to be present and assist in any cultural sensitive communication issue during clinical interviews.
- The second dot point indicated that additional expertise in Aboriginal mental health had been incorporated into the project through the inclusion of Professor Ernest Hunter as associate supervisor. The principle investigator, the applicant as a 3rd year Doctor of Psychology student, has completed a year in association with an Aboriginal Mental Health Worker and was advised by Neil Phillips, psychiatrist from Daruk AMS.
- The third point is responded to by mentioning the advisory involvement of Drs Neil Phillips and Ernst Hunter who are assumed to be members of the Indigenous Chapter within the Royal Australasian College of Psychiatry.
- On the issue of approval from AMSs it was stated that it is a catch twenty two situation as approval from the ethics committee is required first from all participating AMSs.

The matter was again reviewed at subsequent Ethics Committee Meetings and the following matters were raised:

With regards to the detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees, the Committee noted documentation and expressed serious concerns regarding the following matters that required clarification:

- issues raised in points 2 and 4 of the Ethics Committee's letter have not been adequately addressed;
- demonstrated experience of the researcher, still an undergraduate, to singularly carry out, albeit with advice, such a comprehensive and complex study, especially when the applicant is in fact the principal researcher;
- use of confusing wording in the proposal;
- the method how the researcher will validate the diagnosis of psychosis;
- the use of Aboriginal university students of mental health course as cultural advisors;
- the testing of instruments to determine psychosis in clients with comorbidity is considered problematical and complicated.
- The original application indicated that participants for the research were to come from three Aboriginal Medical Services within the Sydney region, including Daruk AMS, Tharawal AMS and the Aboriginal Medical Service in Redfern, in addition to other participants from unidentified Public Mental Health Services and Drug and Alcohol centres.
- The question in the Ethics Committee's original response to the applicant specifically asked whether the researchers have evidence of support or consent agreements for undertaking the research at the Daruk AMS, Tharawal AMS and the Aboriginal Medical Service in Redfern, which were identified as research sites for the proposed project?

- The Committee anticipated consent being obtained from all participating AMSs to enable evaluation of the research to proceed.
- the level of scientific scholarship undertaking the project must be of the highest standard in light of the potential cultural sensitivity of the research and, furthermore, the demonstrated experience to extrapolate data responsibly from a cultural perspective due to the proposed dichotomy of data between Aboriginal and non-Aboriginal participants.
- The ambiguity in the response to Question 4.6 of the application where it states that consultation for this research had occurred with the AH&MRC, several ACCHS, Dr Andrew Webster and Robyn Shields, yet without any written documentation of these consultations or their endorsement of the research.

The Committee considered the project required the expert advice of specialists working in the field of psychiatry with Aboriginal patients. However, the Committee held this request in abeyance until all Agreements were received or until plausible explanations were given for eliminating certain AMSs from the study.

In response to several telephone calls from the applicant, the secretary of the Ethics Committee did communicate an anticipated Committee response but this was clearly contingent upon receipt of consent agreements from the Boards of each participating Aboriginal Medical Service, as indicated above, for without these the project could not proceed further.

The failure to receive consent agreements from the Boards of two of the identified Services, especially in light of information about initial contacts having been made with these AMSs yet without any consent obtained, together with the serious amendment for the research to exclude the two AMSs originally identified in the application but where consent was not available, gave reason for concern to the Committee and the matter was deferred until tangible responses or plausible explanations were forthcoming.

The Committee will again discuss relevant issues with the identified ACCHS involved to ascertain their position and concerns and to ensure that there are sufficient resources to provide backup, referral and management as required by each individual research participant and whether unqualified consent has been given.

The recent letter from Professor Blaszczynski has raised the issue of proceeding with the project within one AMS without addressing the failure to provide writing reasons why the original research is not proceeding with the other identified AMSs and any reasons given for withholding consent.

This is still a matter of concern to the Committee but leaving the matter aside until the Committee again considers the application at its next Ethics Meeting, the Committee will be considering professional peer advice in light of pertinent issues raised.

It is anticipated that the Committee will be able to further consider the application upon further communication with Communities concerned; receipt of appropriate consent forms and upon evaluation of peer specialist advice. The Committee will correspond with the applicant as soon as practicable.

The Committee apologises the misunderstanding of expectations between applicant and the Committee with regard to outstanding Community consent and liaison with ACCHSs.

On behalf of the AH&MRC Ethic Committee,

Yours sincerely

Kaye Mundine
Chairperson

7th April 2006

KM/jw/490b-06

cc Professor Alex Blaszczynski

School of Psychology
University of Sydney

Ms. Kay Mundine
Chairperson
Research Ethics Committee
Aboriginal Health and Medical Research Council
PO Box 1565
Strawberry Hills
Sydney, NSW 2012.

April 26th, 2006

Dear Ms. Mundine,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

We thank you for your letter dated 07/04/06 in which you outline your Committee's response to our correspondence of the 15/02/06.

We note our application was reviewed at subsequent AH&MRC Ethics Committee meetings after we received your correspondence of the 12/05/05. However, we wish to impress upon the Committee that the concerns expressed by the Committee as outlined in your letter were not communicated to us. Accordingly, we were not placed in a position where we knew of, and therefore could address, the matters described in your correspondence of the 07/04/06.

Our records reveal that we were diligent in responding to all correspondence received from your Committee. We note that our letter dated 18/05/05 (enclosed) responded to the Committee's initial concerns as listed in the points 1 through 4 contained in that correspondence. We emphasis at this point that our letter was not acknowledged, and that no further guidance was received advising us as to what further matters needed to be addressed to satisfy the Committees concerns such that approval for the project to proceed could be given.

Our letter of 18/08/05, (enclosed with agreements) requested ethics approval for those services where *in-principle* agreements had been obtained (SESIAHS and Tharawal AMS). Again, receipt of this letter was not acknowledged nor were we notified of any concerns that an insufficient number of services had provided support.

With respect to the further concerns outlined in your letter (07/04/06), we would like to respond with the following information. We reiterate that we received no prior correspondence from the AH&MRC HREC regarding the responses supplied in letters of the 18/05/05 and 18/08/05 (enclosed) to point 2 (expertise) and point 4 (in-principle agreements) of the Committee's 12/05/05 letter. We seek the guidance from the Committee as to how to

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best satisfy their concerns.

- With respect to expertise. The researcher identified (Blake Hamilton) is a postgraduate Doctor of Clinical Psychology and Master of Science student (not an undergraduate as imputed). He is a registered psychologist with demonstrated skills in psychological assessment and treatment gained through a variety of placements including contact with Aboriginal services. He is not working in isolation in carrying out the research project but is guided by the Principal investigator, a Professor of Clinical Psychology, and the associate project supervisor, Professor Ernest Hunter, a recognised expert in the field of Aboriginal mental health. In addition to standard clinical training the he has completed one year training with SESIAHS Aboriginal mental health including presenting the research to the Sydney Aboriginal Mental Health Workers' Forum. The researcher has extensive psychiatric clinical research and mental health service development experience. Most importantly, he has expressed and acted on a keen interest in the field of aboriginal mental health and supporting services with the intent of pursuing this further in his career. Regrettably, this interest is showing a tendency to diminish in light of his experiences with the AH&MRC.

- Reference is made to the use of confusing wording in the proposal. However, the nature or location of the confusing wording is not specified. We would be very pleased and grateful if the Committee could clarify the source of confusion so that we may clarify it.

- As outlined in section 7.1 (page 15) of the University of Sydney Ethics Protocol, subjects with psychosis do provide agreement as part of the process of giving informed consent for the researchers to access their medical record. The diagnosis of psychosis thus will be confirmed by the diagnosis recorded in the medical record by their treating psychiatrist or clinical psychologist.

- The AH&MRC Guidelines for research into Aboriginal health (AH&MRC, 1999) Section H: *Aboriginal Islander Health: Goals and targets* page 11, point 8 refers to: "The training and development of indigenous research workers wherever possible." In compliance with this directive, we sought and received interest from Charles Sturt University's Bachelor of Aboriginal Mental Health students, and Aboriginal mental health workers, to participate as Aboriginal co-researchers in accordance with the above principle. We have always acknowledged and actively sought the support and development of indigenous research and health workers. We firmly believe that participation in this project will foster cultural propriety and sensitivity. Furthermore we believe that participation by Charles Sturt students or Aboriginal mental health workers will further training in both clinical research and assessment for at-risk mental states for psychosis by these individuals. We actively seek guidance from the Committee as to who the Committee considers are appropriate co-researchers and we welcome the opportunity for collaborative work to foster common goals of improving the mental health of at-risk community members.

- The committee considers the testing of instruments to determine psychosis in clients with co-morbidity to be problematic and complicated. We agree with the Committee's view. However, to clarify the matter, attention is drawn to the design of the study. The project will, in Phase 1, use instruments on community members who are assumed to be healthy, and with those who have a prior diagnosis of psychosis. If the primary instrument (CAARMS) proves to be valid for use with young Aboriginal people, Phase 2 of the project will not test the instrument to determine psychosis, but use it to detect those individuals who may be at risk of psychosis. It is emphasised

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that at no time will the project instruments be used to make or determine a diagnosis of psychosis.

- Following the Committee's letter of 12/05/05 we endeavoured to obtain *in-principle* support from three nominated Aboriginal Medical Services (Redfern, Tharawal, and Daruk) and from SESIAHS Aboriginal Health Unit. This process was undertaken at the suggestion of Mr. John Williams, AH&MRC Ethics secretary. The project informed the Committee, in a letter dated 18/05/05, that full consent to participate could not be obtained from AMS's without Ethics approval from AH&MRC. *In-principle support* (pending full ethics approval from the Committee) was obtained from Tharawal AMS's Board, and the SESAHS Aboriginal Health Unit and forwarded to the committee on 18/08/05. Negotiations for project participation continued with Daruk AMS Aboriginal mental health workers, CEO Frank Vincent, and Dr. Neil Philips until November 2005. A meeting was scheduled on 3rd of November with Leanne, Emotional and Social Wellbeing officer, at Daruk. Leanne unfortunately did not attend that meeting. Leanne subsequently left her position and Daruk did not indicate any further interest in the project.

  We requested Redfern AMS be removed from the application in the letter dated 18/08/05. This was due to the failure of a response to a letter we sent to Redfern AMS CEO, Dr. Naomi Mayers, on 18/05/05, requesting a meeting to discuss the project and elicit their possible participation. This letter was subsequently re-sent via e-mail several weeks later. Numerous attempts were made by phone to contact Dr. Mayers who repeatedly declined to accept the calls from us. The letter of the 18/05/05 was subsequently e-mailed to Peter Fernando (2nd in charge) on his request after we contacted him by telephone. Despite several assurances of a response from Mr. Fernando, none were actually forthcoming. We had no option but to set aside Redfern as a potential supporting partner with no explanation from the Centre as to why they would or would not support the project.

- We received no reply to the request of the 18/08/05 to proceed with the project in the two services where *in-principle* agreements were obtained. Despite several assurances from Mr. John Williams, ethics secretary, we received no response from AH&MRC. In a telephone call to Mr. Williams in November 2005, Blake Hamilton was informed that the project was being sent by the Committee for scientific review and that a letter outlining this would be forthcoming. No letter was subsequently received as to which scientific committee would review the project, or of any feedback about the scientific merits of the study and its design.

- It is drawn to your attention that the scientific merit of the project was reviewed by the University of Sydney HREC and granted ethics approval on 05/10/04. Furthermore the NSW institute of Psychiatry granted Blake Hamilton a research fellowship on 26/11/04 based upon the scientific merit of the project. The project has also been granted ethics approval from NSCCAHS and is supported by the NCCAHS and SESIAHS directors of mental health, and A/Prof Micheal Levy, Head of Research, Justice Health. The scientific merit of the project has never been questioned outside of the AH&MRC.

- We have taken steps to improve the level of expertise in Aboriginal mental health, an underdeveloped field, including direct training and expert advice. We have continually acknowledged the importance of being guided by, and working collaboratively with, the AH&MRC and other community members with respect to cultural sensitivity and responsible data collection. We have continually

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demonstrated willingness to be guided by the AH&MRC to ensure the project proceeds in a culturally sensitive and acceptable manner to Aboriginal people.

- Consultation. No formal written records of consultation have been kept by the project beyond notes made as to suggestions to improve the project and assist with ethics, which have been incorporated. We can however, provide a list of people with whom we have discussed the project.

In light of the interest in the project shown by interstate agencies, it is regrettable that we are unable to progress this important project in New South Wales. We are aware of the cultural sensitivities and the concern that the Aboriginal community has in outsiders conducting research that does not benefit the Aboriginal community or draws attention to and magnifies problems in that community. In being cognisant of these issues, we would like to emphasise that we believe that this project is directed toward providing assistance to at-risk members of the Aboriginal community by identifying early signs of distress and symptomatology so that early intervention programs offered by relevant Aboriginal health professionals can prevent more serious problems and distress. To this objective, we wish to work in close collaboration with Aboriginal health professionals and the AH&MRC. We would be more that delighted to have the opportunity to meet with the AH&MRC and bridge any gaps in communication and understanding. We look forward to your response.

Yours sincerely,

Professor Alex Blaszczynski
Chair in Psychology
Head of Medical Psychology, WSAHS

Blake Hamilton
MSc Student and Clinical Psychologist
University of Sydney

Cc Ken White, Director of Aboriginal Health, NSW Health Department.

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University of Sydney

Associate Professor Stewart Kellie
Chairman
Human Research Ethics Committee
University of Sydney

29th June, 2006

Dear Associate Professor Kellie,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

Ref No. 7642

I write regarding the above named project granted ethics approval on 27/09/04 and until September, 2006. Ethics approval for this project was granted by the committee for inclusion of Aboriginal participants subject to ethics approval by the Aboriginal Health and Medical Research Council (AH&MRC).

The project submitted an ethics application to the AH&MRC on 30/10/04. Regretfully, the project team has not yet received an indication from the AH&MRC as to whether the project will receive ethics approval. This situation has been brought to the attention of Ken Wyatt, director of Aboriginal Affairs, NSW Department of Health. I include this correspondence and all correspondence between the project team and the AH&MRC. A summary of this correspondence is outlined in the enclosed document titled 'Timeline of project communication with the AH&MRC'.

The completion of the present project is compromised due to the unacceptable delay imposed by the failure of the AH&MRC to provide approval of the project despite approval being obtained from all other ethics bodies. Accordingly I am writing to the HREC Committee with a request to seek permission to proceed with the inclusion of Aboriginal participants in the research without the requisite ethics approval from the AH&MRC. This is an unfortunate predicament we find ourselves in and have in all instances attempted to collaborate actively with the Aboriginal community. Therefore I believe we have met our ethical responsibilities and undertake to comply with the fundamental principles as outlined in the AH&MRC Guidelines into Aboriginal Health Research submitted to the NH&MRC.I look forward the HREC's response and support in this matter.

Yours sincerely,

Alex Blaszczynski
Chair in Psychology

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Professor Carol Armour
Acting Pro-Vice-Chancellor Research
Rm L3.11, Quadrangle Bldg
University of Sydney

22nd November, 2006

Dear Deputy Vice Chancellor,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

Ref No. 7642

Following from our recent conversation regarding ethics for the above named Aboriginal health research project, I enclose the relevant letter of support from the Aboriginal community as discussed. I have also enclosed an agreement between the researchers and the Aboriginal community. This agreement outlines how the project will satisfy the requirements for research with Aboriginal communities set out in the recent NH&MRC guidelines. Furthermore I have enclosed a recent communication from the Aboriginal unit manager at the Department of Juvenile Justice outlining the importance of the project to juvenile justice and her support for the research.

I believe the project has satisfied the requirements and obligations for research in Aboriginal health. I have actively endeavoured to meet the fundamental requirements of working with the Aboriginal community, both in intent and spirit, but have been thwarted by the lack of appropriate responses, not to mention the lack of basic courtesy shown by the AH&MRC in failing to respond to our correspondence. In light of the enclosed documents I request permission for the study to proceed in collecting data from Aboriginal participants in the absence of formal approval from the AH&MRC.

Should you have any questions, or require any additional information, please do not hesitate to contact me on 9845 6686, or via **alexb@psych.usyd.edu.au**

Yours sincerely,

A Blaszczynski

Alex Blaszczynski

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for file

COPY

School of Psychology
University of Sydney

Ms. Pat Delaney
Chairperson
Research Ethics Committee
Aboriginal Health and Medical Research Council
PO Box 1565
Strawberry Hills
Sydney, NSW 2012.

17th January, 2007

Dear Ms. Delaney,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

Please find enclosed the ethics protocol and documentation relating to the above named research project. This project was approved by the University of Sydney HREC on 05/10/04 (encl.) and submitted for AH&MRC ethics approval on 30/10/04 (encl.). We also enclose copies of all correspondence between the project and the AH&MRC to date.

Despite our diligent correspondence we are still struggling in communicating with the AH&MRC ethics committee to gain some level of indication of approval. We have not yet received a reply to our last correspondence with the committee, addressed to Ms. Mundine, of the 26/04/06. In this letter we offered to meet with the AH&MRC to bridge any gaps in communication and understanding. We would still be delighted to do so.

In seeking approval for this important research we reiterate that we have attempted at all times to work within the spirit of the AH&MRC guidelines for research into Aboriginal health and have demonstrated a willingness to be guided by the AH&MRC in conducting this research. This project is directed at providing assistance to at-risk members of the Aboriginal community by identifying early signs of mental health problems. From this early intervention programs may be developed by relevant Aboriginal health professionals to prevent distress and more serious mental health problems. We re-state our desire to work in close collaboration with the Aboriginal community, Aboriginal health professionals, and the AH&MRC in conducting this research.

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Currently the project has access to research participants from the NSW department of juvenile justice and the NSW department of corrective services. As such we are currently seeking approval from the AH&MRC research ethics committee to include participants from the South Eastern Sydney and Illawarra Area Health Service (SESIAHS). We enclose a signed agreement between the project and SESIAHS Aboriginal health Unit outlining how the project will fulfil the NH&MRC ethical considerations for Aboriginal research. The project has been approved by the HOPE-Moodgee Aboriginal mental health working party representing the La Perouse and districts Aboriginal community and SESIAHS mental health management.

This project has received wide support from Aboriginal mental health workers and the Aboriginal community and we believe the research to be important to young Aboriginal people's mental health. We ask for your urgent attention to this matter and would be very pleased to answer any questions you may have or discuss any aspects of the research.

Yours sincerely,

Blake Hamilton
Co-investigator
Clinical Psychology Unit
University of Sydney

for

Professor Alex Blaszczynski
Chair in Psychology
Head of Medical Psychology, WSAHS &
University of Sydney

The University of Sydney

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ABN 15 211 513 464

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A/Prof Sandra Egger
Chair
Justice Health Human Research Ethics Committee
Centre for Health Research in Criminal Justice
PO Box 150
Matraville
Sydney, NSW 2036.

30th March, 2007

Dear A/Prof Egger,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees
GEN80/05

Following from your letter of the 3rd of May I am pleased to inform you that the above named research project has now obtained the requisite Aboriginal Health and Medical Research Council (AH&MRC) ethics approval. In compliance with the committee's request I have included the following:

1. AH&MRC ethics approval letter
2. A letter of approval from Justice Health agreeing to co-ordinate the accessing of files and inmates between the University of Sydney, DCS, and Justice Health.
3. A letter of project approval from the Department of Juvenile Justice
4. A letter of approval from the Department of Juvenile Justice to survey 16-18 year old clients of Juvenile Justice without parental consent.

In view of the obtained AH&MRC approval and approvals from Justice Health and the Department of Juvenile Justice, I request the committee grant out of session approval so that the project may proceed.

Should you have any questions, or require any further information please do not hesitate to contact us on 9036 5037 or via blakeh@psych.usyd.edu.au.

Yours sincerely,

Professor Alex Blaszczynski
Chair in Psychology

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Professor Carol Armour
Acting Pro-Vice-Chancellor Research
Rm L3.11
Quadrangle Bldg
University of Sydney

19th, July 2007.

Dear Pro-Vice Chancellor,

Re: Detection of at-risk mental states for psychosis in young Aboriginal and non-Aboriginal drug and alcohol service attendees

Ref No. 7642

Following from my letter of the 22/11/06 and your subsequent correspondence, I am pleased to enclose the requisite Aboriginal Health and Medical Research Council (AH&MRC) ethics committee approval for the above named project. This project is now proceeding with data collection in-line with the conditions imposed upon the research by the AH&MRC and other relevant ethic committees approvals.

Should you have any questions, or require any additional information, please do not hesitate to contact me on 9845 6686, or via alexb@psych.usyd.edu.au

Yours sincerely,

Alex Blaszczynski
Chair in Psychology

CC University of Sydney HREC