The At-Risk Mental State (ARMS) for Psychosis in Children and Adolescents.

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Abstract

Introduction

In the last decade it has been proposed that individuals who are at an elevated future risk of developing psychosis compared to the general population can be identified using operationalised criteria. Those who fulfil these criteria are labelled as having an At-Risk Mental State (ARMS) for psychosis. Research in working-age adults has reported a lowering of the short-term rate of transition of such individuals to psychosis over successive cohorts. Nevertheless, such individuals report poor psychosocial functioning and high distress levels. To date, there has been a dearth of research specifically focussed on the concept of the ARMS in adolescents. Thus it is not established how these young people present to mental health services, what mental health diagnostic categories, if any, they would fulfil and what their short-term outcomes are in terms of mental health and psychosocial functioning. Moreover, it is unknown how this group may experience the label of being 'at-risk' and whether these individuals would benefit from the ARMS criteria being made an official diagnostic category. The aim of this study was to investigate how young people fulfilling the ARMS criteria present to services, to characterise them and report the short-term outcomes, in terms of mental health and functioning. The views and experiences of young people with the ARMS label and mental health professionals potentially working with this client group were also explored.

Methods

Two separate projects were completed: Project 1; The Follow-up of the At-Risk Mental State (FARMS) project and Project 2; The Professional Attitudes towards the At-Risk Mental State (PAARMS) project. Study 1 of the FARMS project involved a prospective longitudinal cohort study and investigated how adolescents categorised as having an ARMS initially present to mental health services and fared over a six month follow-up period. Study 2 involved recruiting a purposive sample of participants fulfilling the ARMS criteria from Study 1, into a qualitative study. An Interpretative Phenomenological Analysis (IPA) framework was then used to

explore the personal understanding and experiences of these young people in relation to the ARMS concept. The PAARMS project used a mixed methods approach in order to evaluate the attitudes and experience of Child and Adolescent Mental Health Service (CAMHS) professionals in relation to the ARMS concept. Firstly, in-depth interviews were conducted with a purposive sample of six CAMHS clinicians who work in Early Intervention in Psychosis (EIP) services regarding their experience and attitudes in relation to working with young mental health service-users who have the ARMS label. Secondly, a survey involving 180 CAMHS clinicians was conducted.

Results

Study 1 of the FARMS project confirmed that adolescents fulfilling the ARMS criteria present to services with significant levels of reported psychopathology and functional impairment. Auditory perceptual disturbance was the most frequently reported 'positive' symptom whilst 70% of participants met the threshold for at least one current ICD-10 Axis I psychiatric diagnosis. In terms of short term outcomes, transition rates to psychosis were low (1/29; 3%) with a handful of individuals (7/29; 24%) demonstrating significant remission of symptoms and/or significant improvements in psychosocial functioning.

The findings from Study 2 indicate that young people wish to be told about their condition upon identification and do not report experiencing significantly negative or distressing instances of stigma, though this was a voiced initial concern. Talking to mental health professionals and possibly peers, who also experience similar symptoms, are perceived as the most beneficial elements of support offered by services.

Finally, CAMHS professionals participating in the PAARMS project reported being reluctant to recommend medication as a first-line treatment strategy. However, monitoring, psycho-education and psychological therapies were widely endorsed. Identification and management of adolescents with the ARMS label was viewed as challenging and complicated by a variety of factors including maturational process and a lack of official guidelines and protocols.

Discussion

The results of this study not only characterise how adolescents fulfilling the ARMS criteria present to services but also inform future debates regarding the ARMS concept as a distinct diagnosis. These findings should therefore facilitate the development of new policies for the identification and management of the condition in young people and address areas of clinical practice that require immediate attention. Future research is required to establish whether these initial findings are generalisable to services elsewhere and to evaluate plausible interventional approaches that target distressing symptoms and functioning.

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Publications from this thesis

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1 Overview of Thesis

1.1 Introduction

The project was initially conceived as a result of clinical observations and experiences. At the time the author was working with adolescents within an Early Intervention in Psychosis service and noted inconsistencies in relation to the assessment and management of adolescents that were likely to fulfil the criteria for an At-Risk Mental State for Psychosis (ARMS). This in turn led to discussions with clinical colleagues which confirmed the author's initial belief that clear professional guidance and an adequate associated evidence base for this adolescent age group were lacking.

This led to a review of the existing literature. The ARMS concept was, and still is, somewhat controversial. Indeed, critics of the construct highlight the potential for exposure to unnecessary psychiatric labelling and intervention. Despite these concerns there was a dearth of information relating to how young service-users of mental health services experienced being categorised as 'at-risk'. One paper in particular which struck a chord stated that '*no studies to date have systematically examined how any potential stigma induced by the label of psychosis risk might affect identified patients'* (1 [p43]). The emerging evidence suggested that the rate of transition to psychotic illness was declining to around 16% over the first year in working age adults. However, clinical experience and research reports indicated high rates of distressing psychological symptoms and poor functioning in this group. Despite this, little was known of the characteristics and short-term outcomes in adolescents labelled as having an ARMS.

Thus a commitment was made to prospectively identify and follow a cohort of adolescents fulfilling the ARMS criteria in order to create new knowledge about this interesting and complex group of young people. By assessing and observing such a cohort we hoped to improve identification and the overall care of patients accessing

our service. In order to understand the experience of these young people it was important to explore how young people perceived the care they were offered and the 'ARMS' label. However, it was also felt to be equally important to understand professional attitudes and knowledge in relation to this construct, which was identified as a further gap in the existing research literature.

1.2 Aims

The primary aim of this project was to describe how adolescents identified with an At-Risk Mental State for Psychosis (ARMS) present to mental health services and come to experience their condition over the short term.

The secondary aim of this project was to measure the short-term outcomes of those identified as having ARMS (in terms of psychological symptoms and psychosocial functioning). Together the primary and secondary aims were part of the Follow-up of the At-Risk Mental State or FARMS project.

A subsidiary (tertiary) aim of the project was to investigate the experiences and attitudes held by mental health professionals (from Early Intervention in Psychosis and Child and Adolescent Mental Health Services) in relation to the identification and management of adolescents suspected of having an At-Risk Mental State. The project designed to gather this information became known as the Professional Attitudes towards the At-Risk Mental State or PAARMS project.

1.3 Objectives

The objectives of the Follow-up of the At-Risk Mental State (FARMS) project were to:

1. Review the existing literature regarding the assessment, identification, management, personal experiences and short to medium term outcomes of individuals identified as having an ARMS.

2. To describe how adolescents identified as having an ARMS present to mental health services in terms of current symptomatology, psychosocial functioning and psychiatric co-morbidity.
3. To identify how many adolescents make the transition from an ARMS to a first psychotic episode over a six month follow up period.
4. To describe other short term outcomes of adolescents identified as having an ARMS, including whether they continued to fulfil the ARMS criteria at 6 month follow-up.
5. To explore the personal experiences of adolescents (aged 12-17 years old) identified as having an ARMS for psychosis in relation to identification, management and stigma.

The objectives of the Professional Attitudes towards the At-Risk Mental State (PAARMS) project were to:

1. Review the literature in relation to the attitudes and experiences of mental health professionals in relation to the assessment, identification and management of individuals identified as having an ARMS.
2. To explore the experience of mental health professionals working within an Early Intervention in Psychosis (EIP) service in relation to the assessment, identification and management of adolescents identified as having an ARMS.
3. To survey mental health professionals working within Child and Adolescent Mental Health Services (CAMHS) in relation to their contact, knowledge, ability and confidence in identifying adolescents with an ARMS.
4. To survey mental health professionals working within CAMHS in relation to their knowledge and attitudes regarding management, treatment and the clinical utility of the ARMS concept.

1.4 Identification of literature

Literature for this thesis was identified using a variety of methods. Predominantly, database searches were conducted in Pubmed, PsychINFO and Embase (on the advice of the Durham University, School for Medicine and Health librarian) by combining the following sets of keywords:

1. 'schizophreni*',' psychosis', 'psychotic';
2. 'prodro*', 'ultra high risk', 'at risk', 'at risk mental state', 'risk syndrome', 'attenuated symptoms';
3. 'adolescen*', 'child';
4. 'staff', 'clinician', 'professional', 'attitudes', 'knowledge'.

From these searchers, key (adolescent) papers were identified and citation alerts created for those deemed most relevant;

- Shin YM, Jung HY, Kim SW, Lee SH, Shin SE, Park JI, et al. A descriptive study of pathways to care of high risk for psychosis adolescents in Korea. Early Intervention in Psychiatry. 2010 May; 4(2):119-23.
- Meyer SE, Bearden CE, Lux S, Gordon J, Johnson J, O'Brien M, et al. The psychosis prodrome in adolescent patients viewed through the lens of DSM-IV. Journal of Child and Adolescent Psychopharmacology. 2005 Jun; 15(3):434-51.
- Mazzoni P, Kimhy D, Khan S, Posner K, Maayan L, Eilenberg M,, et al. Childhood Onset Diagnoses in a Case Series of Teens at Clinical High Risk for Psychosis. Journal of Child and Adolescent Psychopharmacology. 2009 Dec; 19(6):771-76.
- Correll C, Lencz T, Smith C, Auther A, Nakayama EY, Hovey L, et al. Prospective study of adolescents with subsyndromal psychosis: characteristics and outcome. Journal of Child and Adolescent Psychopharmacology. 2005; 15(3):418-33.

Citation alerts were also created on Pubmed using the following keyword search terms and limits "((Schizophreni*) AND (Adolescen*)) AND (prodro*) Limits: Adolescent: 13-18 years" to ensure the most recent literature was captured.

Supplemental searches were also conducted. One technique used snowballing principles and involved following up potentially relevant citations in already identified papers and book chapters. Other techniques involved searching websites and search engines (i.e. Google) using several of the aforementioned key terms or contacting experts within the field.

2 Introduction: Psychosis and the concept of early intervention

2.1 Definition, categorisation and associated symptomatology

Since ancient times, states of mind characterised by a loss of contact with reality and disturbances in perceptions, ideation and thought have been documented. In Ancient Greece, the poet Horace provides an intriguing description of a man who sits daily in an empty theatre, claiming to hear actors talking on an empty stage and applauding their nonexistent theatrical performances (2). Both the Old and New Testaments also contain vivid descriptions of episodes of disturbance and loss of normal mental functioning. For example, the Book of Daniel (3 ^{v28}) describes how King Nebuchadnezzar descends into a state of homeless disorientation after glorifying himself:

> *'All this happened to King Nebuchadnezzar. Twelve months later, as the king was walking on the roof of the royal palace of Babylon, he said, "Is not this the great Babylon I have built as the royal residence, by my mighty power and for the glory of my majesty?"'*
>
> *'Even as the words were on his lips, a voice came from heaven, "This is what is decreed for you, King Nebuchadnezzar. Your royal authority has been taken from you. You will be driven away from people and will live with the wild animals; you will eat grass like the ox. Seven times will pass by for you until you acknowledge that the Most High is sovereign over all kingdoms on earth and gives them to anyone he wishes."'*
>
> *'Immediately what had been said about Nebuchadnezzar was fulfilled. He was driven away from people and ate grass like the ox. His body was drenched with the dew of heaven until his hair grew like the feathers of an eagle and his nails like the claws of a bird.'*

Mark's gospel, likewise, gives an account of a man so disturbed he is chained to prevent him from harming himself and others (4 [v1]):

> *'They went across the lake to the region of the Gerasenes. When Jesus got out of the boat, a man with an impure spirit came from the tombs to meet him. This man lived in the tombs, and no one could bind him anymore, not even with a chain. For he had often been chained hand and foot, but he tore the chains apart and broke the irons on his feet. No one was strong enough to subdue him. Night and day among the tombs and in the hills he would cry out and cut himself with stones.'*

Thus it can be seen that this state has both intrigued and appalled writers for millennia.

The term psychosis derives from the Greek term 'psyche' meaning 'mind or soul' and uses the suffix '-osis' which means 'abnormal condition'. The word was first used by Ernst von Feuchtersleben in 1845 (5) to describe mental disorders as he believed they were diseases of personality not of the body or mind alone. The psychoses were diseases with a combination of causes that affected the personality as a whole. Just after Feuchtersleben in the late nineteenth century, credit is given to the psychiatrist Wernicke who used the term to describe an individual condition. Wernicke was also one of the first to use the adjective 'psychotic' (6). After Wernicke's initial attempts much effort was devoted to categorising the various manifestations of psychosis in the latter part of the 19th and early 20th century. One school, led by Emil Kraepelin (7), proposed that psychosis could be divided into 'Dementia Praecox' (equivalent to a modern diagnosis of Schizophrenia) and the 'Manic-Depressive' psychoses (equivalent to Bipolar Disorder and affective mood-related psychoses). Kraepelin's views were heavily influenced by the French Psychiatrist, Benedict Morel who, several years previously, believed clear diagnostic entities could be described based on cause, key symptoms and medium-term outcomes (6). At the same time as Kraepelin, Eugen Bleuler proposed the term 'schizophrenia' which roughly translated as 'splitting of the mind' and was intended to describe the separation of function between personality, thinking, memory, and

perception. Bleuler described the main symptoms as flattened affect, autism, impaired association of ideas and catatonia, whilst hallucinations and delusions were viewed as being secondary psychological reactions to the underlying illness (8, 9).

In later years Kurt Schneider attempted to differentiate schizophrenia from other forms of psychosis by listing the psychotic symptoms that he deemed to be pathognomonic for the condition (10). These symptoms became known as Schneiderian First-Rank symptoms and have heavily influenced the World Health Organizations diagnostic manual (ICD-10), widely used within European psychiatry today (11).

An alternative view was that all functional (i.e. 'non-organic') psychoses were manifestations of the same underlying disorder and that each formed part of a continuum or a series of stages representing a further level of deterioration. This perspective initially championed by Griesinger (12) became known as the unitary psychosis theory. However, Griesinger later recanted some of his claims stating that disorders of thought could occur without going through the stage of depression (13). The debate in relation to unitary psychosis continues today with the genetic evidence suggesting that a relatively small number of genes interact to give rise to the spectrum of functional psychoses from the primarily mood driven to those characterised by mainly schizophrenia-like symptoms (14). Kendell's research (15) however indicates that it is not always possible to distinguish between the two disorders on the basis of symptoms.

For the purposes of this thesis the term psychosis is used to describe functional psychoses that include the schizophrenias and related syndromes but also mania with psychotic symptoms (thus 'Bipolar II' is excluded). This terminology is in keeping with that generally used by the Early Intervention (EI) in psychosis movement. The principles and ideology of EI will be described in more detail later. When describing the modern day definition of psychosis we look to the current definition as proposed by the Oxford English dictionary (16):

> *'A severe mental illness, characterised by loss of contact with reality (in the form of delusions and hallucinations) and deterioration of intellectual and social functioning, occurring as a primary disorder or secondary to other diseases…'.*

And to the description of 'psychotic' as outlined in ICD-10 (11 [p10]):

> *'Psychotic – Its use does not involve assumptions about psychodynamic mechanisms, but simply indicates the presence of hallucinations, delusions, or a limited number of severe abnormalities of behaviour, such as gross excitement and over activity, marked psychomotor retardation, and catatonic behaviour.'*

The person most influential in creating these modern day descriptions is the German Psychiatrist Karl Jaspers. His book entitled Allgemeine Psychopathologie (General Psychopathology) published in 1913 is full of detailed descriptions of the lived experiences of those affected by psychotic illness (17). One of the key symptoms identified by Jaspers in his patients was the holding of often bizarre and erroneous beliefs usually involving a misinterpretation of perceptions and experiences. Delusions, as they became known, may include varying content ranging from persecutory ideas, somatic concerns, religious beliefs or those of a grandiose nature. Jaspers was the first to outline the three main criteria for a belief to be considered delusional. These stated that the belief must:

1. Be held with certainty (absolute conviction).
2. Have incorrigibility (not changeable by compelling counterargument or proof to the contrary).
3. Have aspects of impossibility or falsity of content (implausible, bizarre or patently untrue).

As well as delusions, patients also experienced perceptual disturbances or hallucinations often in a variety of sensory modalities (visual, auditory, olfactory, gustatory, tactile). In the broadest sense hallucinations are defined as perceptions

consciously experienced in the absence of stimuli. Of these, auditory hallucinations appear to be the most commonly experienced (18).

Communication, thought difficulties and catatonia were also observed. Incomprehensible language in either speech or writing were presumed to reflect thinking disturbances. Bleuler, in particular, believed this to be the single most important feature of the illness with these symptoms becoming known as 'formal thought disorder'. Patients with catatonia on the other hand experienced a loss or slowing of motor activity, sometimes interspersed by periods of hyperactivity leading to exhaustion. Catatonic patients were thus sometimes observed holding rigid poses for hours and ignoring external stimuli. More latterly Crowe (19) partitioned these phenomena into 'positive' and 'negative' symptoms that may co-occur or in some instances co-exist. Positive symptoms (such as delusions, hallucinations, disorganised speech and catatonic behaviour) were named based on the notion that they appear to reflect an excess or distortion of normal functioning. Other associated symptoms (such as reduced motivation, social withdrawal, poverty of speech and affective blunting) were termed 'negative' as they appear to reflect a diminution or loss of normal functions.

2.2 Psychosis: the case to intervene early

Although research findings vary according to the population studied and length of follow-up, often the outcomes of those affected by the condition are poor, both in terms of illness course and day-to-day functioning (20, 21). Intriguingly, outcomes may be worse in westernised compared to developing countries (22). The illness process may have significant detrimental effects on personal, social and occupational functioning (23-25) whilst outcomes may be especially poor for those who develop psychosis as adolescents (20, 26, 27). Patients with the condition also experience a higher than expected mortality rate due to several factors with suicide accounting for a large proportion (28).

The evidence of an association between the duration of untreated psychosis (DUP; the time between the onset of the first psychotic symptoms and the start of some form of intervention) and poor illness outcome is robust (29, 30). However the aetiological process driving this association and the definition of DUP are still debated. The observation that long durations of untreated illness were often associated with poor prognosis also gave rise to the *critical period* hypothesis. This concept postulates that the illness course of the first three years of an initial psychotic episode also predicts the longer term outcome (31). During the critical period repeated relapses occur, treatment resistant symptoms may develop, whilst social and occupational impairments have an opportunity to accumulate, giving rise to long term disability. These deficits accrued in these early years may then set a ceiling for long term recovery, justifying intensive intervention and support during the earliest stages of illness. Psychotic illness generates both direct (health care related) costs as well as indirect costs to society through unemployment and financial benefit provision. Indeed a significant proportion of health care expenditure (in terms of in-patient care and medication) is consumed annually in relation to psychosis (32, 33).

These implications provided the impetus to develop new mental health services that had the capacity to provide prompt, intensive and effective treatment and support for those affected by a first episode psychosis during the first three years of their condition. These new teams were as much a product of a mental health philosophy as the existing evidence base at the time and collectively represented the Early Intervention (EI) movement. The focus of this movement has primarily focussed on young people, who have recently experienced a first episode of psychosis. Within the UK, Early Intervention in Psychosis (EIP) Services have been commissioned by the Department of Health for England to provide care to young people (between the ages of 14 -35) with a first episode of psychosis for a period of up to three years (34). This represents a major shift from previous work which has concentrated therapeutic resources on those people who have already developed severe and chronic disabilities (35). Direct cost savings (mainly through reducing the use of in-patient services and the prescription of antipsychotic medication) and improved

outcomes were perceived to be possible if these services could significantly reduce DUP.

Since the establishment of these services, research suggests that they are making significant reductions in expenditure (36). These reductions seem to be the result of significantly reduced hospital bed utilisation and better engagement with services (37). Results from a randomised control trial comparing treatment from the Lambeth Early Onset Team (LEO) versus standard care, also demonstrated significantly improved outcomes. After 18 months of treatment, improvements were noted in social and vocational functioning, satisfaction, quality of life and medication adherence (38). Similar findings have been observed in a naturalistic evaluation of EIP services (39). Outside of the U.K, the benefits of establishing services based on these principles have been widely confirmed (40-43).

At present it is uncertain to what extent DUP has to be reduced before long term outcomes are positively influenced. In addition, clinicians working in EIP teams recognised a group of patients referred to their services that have psychotic-like symptoms but do not fulfil the full criteria for a psychotic disorder. Some of these patients quickly became ill whilst being monitored, whilst others did not. These questions and observations led to an increased interest in the possibility of intervening even earlier and before the onset of frank psychosis altogether.

2.3 The At-Risk Mental State for Psychosis (ARMS)

Attempts to identify the earliest possible stages of the illness can be traced back to Kraepelin and Bleuler who both regarded the onset of psychosis, to be gradual, slow (sometimes lasting for decades) and difficult to pinpoint. The term ‘Latent Schizophrenia’ was eventually coined by Bleuler to describe the earliest stages of the illness (a potentially pre-psychotic state; 44). Like Kraepelin and Bleuler before him Harry Stack Sullivan (45 ^{p135}) noted:

> '*The great number of our patients have shown for years before the break, clear signs of coming trouble'*

His sentiments were also shared by Ainslie Meares, who also called for the '*diagnosis of pre-psychotic schizophrenia*' (46 [p55]). Following on from the calls of Sullivan and Meares, Cameron (47) observed that a period of psychosis was initially preceded by a deterioration in functioning and a range of non-specific symptoms. In one of the first studies to retrospectively reconstruct a patient's symptoms and experiences before becoming psychotic, Cameron stated that the earliest observable symptoms (i.e. sleep disturbances, increased anxiety, reduced attention) were non-specific, since they could be found preceding the development of disorders other than psychosis. As time progressed more specific sub-threshold or attenuated psychotic symptoms became apparent and were less varied from patient to patient. Recent studies also confirm that first episode patients experience a wide variety of phenomena during the earliest stages of their illness (48).

Instead of the term pre-psychotic, this state or stage of psychosis came to be labelled the 'prodrome' (a term used in clinical medicine referring to the early symptoms and signs of a disease that occur before the obvious characteristic features become apparent; 49). The findings from retrospective reconstructions of the psychosis prodrome led to the first official description in the Diagnostic and Statistical Manual of Mental Disorders third edition revised (DSM-III-R; 50). However the description and concept were short lived as they were soon dropped by DSM-IV (51). Critics were concerned that many of the symptoms could have been the result of many other underlying mental states whilst experiential phenomena, frequently noted during the prodrome had also been omitted (49). Analyses of the diagnostic accuracy revealed a small positive predictive value which was regarded as insufficient to justify indicated prevention (52). Based on the aforementioned analyses the term (which literally translates as 'before the illness') was construed to be unreliable and deterministic since it implied that all individuals exhibiting such difficulties and symptoms would eventually develop psychosis which was clearly not the case (53).

Whilst the ‘prodrome’ concept, informed by retrospective observations struggled, research aimed at prospectively investigating the earliest stages of psychosis began. Attempts to do this focussed on observing individuals perceived to be ‘at risk’ of developing psychosis over the coming years. Research by Heinrichs and Carpenter (54) and Subotnik and Nuechterlein (55) although largely forgotten, focused on the prospective study and observations of individuals at risk of psychotic relapse. Other prospective attempts adopted genetic predisposition approaches whereby children and adolescents with a first and second degree relative with a psychotic illness were monitored for years and even decades at a time, as in the on going Edinburgh High Risk study (56).

Discontent with these approaches grew, given their expensive and fruitless nature, as many participants never became psychotic during monitoring periods of several decades (i.e. a high false-positive rate; 57). In order to increase predictive accuracy and shorten the likely follow-up period, Bell (58) suggested a ‘close in’ or ‘ultra high risk’ (UHR) strategy whereby focus was placed on the developmental period of peak onset. This combined with other risk factors such as behavioural difficulties in adolescence would make prospective studies in ‘at risk’ individuals more viable and move away from traditional screening paradigms by focusing on a help seeking population (59). Since such strategies would set high thresholds in an attempt to reduce the number of false positives, they would not be appropriate for predicting transition within the general population (53).

These ideas were first translated into practice by the Personal Assessment and Crisis Evaluation (PACE) clinic in Melbourne, Australia in 1994 (59). By combining the work of genetic predisposition and clinical features observed during the earliest stages of the illness, the PACE clinic constructed three groups that identified individuals seen as having an ‘At-Risk Mental State’ (60). This ‘At-Risk Mental State’ for psychosis or ‘ARMS’ was perceived to describe a state that confers a high but not inevitable risk of developing a psychotic disorder in the near future (61).

The Melbourne Criteria as it has become known consists of the following ARMS groups:

1. Trait and state risk factors (i.e. genetic vulnerability and poor or deteriorating functioning).
2. Attenuated or sub-threshold positive symptoms, present within the previous 12 months.
3. Brief Limited Intermittent Psychotic Symptoms (BLIPS) which spontaneously resolve, within the previous 12 months.

Since their original conception, the criteria have been recently modified to aid predictive power. In all groups (previously just the Trait and state group), chronic low functioning or deterioration in functioning must be present for an individual to identified as having an ARMS (62). In order to operationalise this criteria, the PACE clinic originally adopted the Brief Psychiatric Rating Scale (BPRS; 63) in combination with the Comprehensive Assessment of Symptoms and History (CASH; 64). Both measures lacked sensitivity when measuring developing psychotic symptoms (57) and therefore were replaced by the Comprehensive Assessment of At-Risk Mental States or CAARMS (65). The CAARMS is a semi-structured interview designed specifically for the assessment of help seeking individuals suspected of having ARMS. Despite criticisms for including individuals with diagnosable psychotic symptoms (BLIPS group; 66) and the validity of the CAARMS psychosis threshold (67) both the Melbourne criteria and the CAARMS are widely adopted within UK research and clinical practice (68-71).

As hoped, the adoption of a UHR strategy using the Melbourne criteria and the CAARMS led to a significant increase in the predictive ability to identify individuals destined to become psychotic. Figures have varied greatly between some of the initial studies conducted, with 10% to 50% of participants making the transition to psychosis within a 1-2 year period (60, 69).

Since the development of the Melbourne criteria other clinical research programs are now developing and modifying their own criteria in order to improve

identification. The PRIME clinic in America have developed the Criteria of Prodromal Syndromes (COPS; 72) which is a slight modification of the Melbourne criteria and again classifies UHR individuals into three categories. Like the Melbourne criteria, positive symptoms serve as the basis of inclusion in the symptom defined groups (73) although these criteria are operationalised using the Structured Interview for Prodromal Syndromes (SIPS; 74-76).

Whilst the Melbourne criteria and COPS focus on sub threshold positive symptoms, which are usually more proximal to the onset of psychosis (48), other research groups such as the Recovery and Prevention (RAP) program (77) and the Bonn group (78) have focused on identifying individuals postulated to be at an even earlier stage in the development of psychotic illness. Although the RAP program incorporates many aspects of the Melbourne and COPS criteria, such as a clinical high risk group characterized by attenuated positive symptoms (CHR+), some individuals are deemed to be at risk due to the presence of non-specific, attenuated negative symptoms without positive symptoms (CHR-). These Clinical High Risk (CHR) groups are believed to reflect phases of developing psychosis with the CHR- group representing the earlier prodromal state (79). In comparison the Bonn group have used what has become known as the 'Basic Symptoms' approach for almost two decades to define those they consider to be at high risk of developing psychosis (80). Basic symptoms, are subtle self-experienced deficits, including affective, cognitive and social disturbances, which are hypothesized to appear months or years prior to the onset of psychosis and earlier than attenuated positive symptoms (78). The Bonn Scale for the Assessment of Basic Symptoms (BSABS; 81) was originally used to rate basic symptoms, but more recently associated research clinics have utilised the much shorter Schizophrenia Prediction Instrument – Adult version (SPI-A; 82). Research by the Bonn group, assigning individuals into either an Early Initial Prodromal state (EIPS; defined by the presence of at least one cognitive-perceptive basic symptom) or a Late Initial Prodromal State (LIPS; defined by the presence of at least one attenuated positive symptom) is on-going (83-85).

Unlike the description of the prodrome proposed by DSM-III-R that lacked specific symptoms, diagnostic accuracy and predictive value it is unsurprising that a

'psychosis risk syndrome' is being considered for inclusion in DSM-V in 2012 (86, 87). Therefore the need for more ARMS related research has never been greater.

2.4 How do individuals initially present with an At-Risk Mental State?

Since ARMS individuals are drawn from a help-seeking population they are frequently observed to present to services with substantial functional impairments and/or reported distress, as might be expected (69, 88-90). Although reduced or chronic levels of poor functioning are now part of the Melbourne criteria, baseline assessments of overall psychosocial functioning in this patient group have found mean Global Assessment of Functioning (91) scores of 58 (60), 61 (92), 56 (93), 41 (94) and 42 (95) respectively. These scores equate to serious and substantial impairment in social, occupational and educational functioning and appear to be significantly worse than scores obtained by other psychiatric help seekers (96). Social functioning (as opposed to a measure of overall global functioning) at initial presentation also seems to be significantly impaired, with ARMS patient's exhibiting similar levels of impairment as first and multi-episode psychotic patients (97, 98). Understandably poor social, occupational and academic functioning impinges greatly upon on quality of life. Consequently individuals with an ARMS label report worse quality of life scores than healthy controls and less predictably, other psychiatric help seekers (99-101).

In terms of intake criteria, studies using the Melbourne criteria indicate that the majority of cases meet the attenuated or sub threshold positive symptoms group (60, 93). In one of the first studies undertaken by the PACE Clinic, 71% of participants met the 'attenuated' or Group 2 criterion, 24% met the 'BLIPS' criterion whilst 37% met the 'trait marker' or Group 1 criterion. It is important to note that the categories are not mutually exclusive and around 29% of participants were also found to fulfil the criteria of another ARMS group. Within the UK the Outreach and Support in South London Service (OASIS) found similar findings with 84% of participants meeting the attenuated positive symptoms criteria and only a handful fulfilling the

criteria for groups 1 and 3 (69). Again, several participants (19%) were found to meet the criteria for at least two of the ARMS categories.

As well as considering profiles of initial intake criteria, one study has attempted to record the prevalence of specific attenuated positive symptoms. Miller et al., discovered that suspiciousness (60%), perceptual abnormalities (50%), unusual though content (48%), speech disorganization (48%) and grandiosity (17%) were the most commonly reported symptoms (95). Attenuated positive symptoms were defined in this study as a symptom scoring between 3 (moderate) and 5 (severe but not psychotic) on the SOPS. In terms of measuring symptom frequency and severity using the CAARMS, data from a large intervention trial assessing the efficacy of CBT indicated that non-bizarre ideas (frequency mean = 3.61/severity mean =3.57), followed by perceptual abnormalities (frequency mean = 2.72 /severity mean = 3.02), and unusual thought content (frequency mean = 2.52 /severity mean = 2.66), were the most frequent and severe symptoms at baseline assessment (71).

Regarding distress associated with specific attenuated positive symptoms; findings from a community sample of non-help seeking adolescents (102) suggest that bizarre experiences and persecutory ideas are the most distressing symptoms. These findings are interesting but may not generalise to those with an ARMS and therefore two attempts have been made to measure distress using 10 and 100 point analogue scales. Data from one study suggested that distress was worse for thought content problems (mean = 6.92) as opposed to perceptual abnormalities (mean = 4.21) and disorganised speech (mean = 2.92; 103). Data from another study however indicates that non-bizarre idea (mean = 65.99) and perceptual abnormalities (mean = 44.86) appear to be the most distressing attenuated symptoms (71). Despite specifically measuring attenuated positive symptoms and utilising them to identify an ARMS, it appears that in several studies negative symptoms are more frequent and severe in this patient group (60, 92, 95). For example data from an ARMS assessment clinic in Spain found mean scores of 13.4, 15.8 and 35.6 for the positive, negative and general subscales of the Positive and Negative Syndrome Scale (104).

As for demographic factors relating to an ARMS, gender, ethnicity, education, age and social class are regularly recorded by studies. In terms of the proportion of males and females within ARMS studies, findings have been mixed with some samples demonstrating relatively equal proportions (60, 62, 93) whilst others report a much greater representation of males (65%; 69, 95). Gender differences in symptoms at baseline measurement may exist. One study reported that males (95) present with worse motor, conceptual disorganisation, mannerism, abstraction, blunted affect and overall negative symptoms compared to females, who had higher scores for dysphoria, depression, sadness, tension and sleep disturbance. These findings however were not replicated by another ARMS study (105) despite a similar methodology and sampling framework to the former study.

The majority of studies report no significant ethnic trends in those presenting and fulfilling ARMS criteria. However, the reports so far concern samples where most participants describe themselves as white Caucasian and therefore would have limited power to detect inter-ethnic differences should they exist. Only one study demonstrates a high proportion (>40%) of black British, Caribbean or African participants and simply reflects the catchment area of the recruiting clinic (69). This study from the OASIS team also presents some data on social-economic status, recording levels of those who were employed (38%), students (31%) or unemployed (31%) at the time of presentation. Findings from another study indicated that only 12.5% of participants were employed whilst 58% were students (106). Other methods of measuring social-economic status in order to characterise those presenting to services do not appear to have been adopted.

As previously outlined, risk factors associated with psychosis have been incorporated into the ARMS criteria in order to potentially increase predictive power. Therefore the majority of studies restrict inclusion to individuals usually aged between 12-35 years old (i.e. the age span when onset of psychosis peaks). Findings from some of the largest studies report mean ages of 19.1 (60), 18.1 (62), 17.3 (93), 24.1 (69), 21.0 years (107) indicating that those in their late teens and early twenties seem to be the most prevalent age groups presenting to services.

Attempts to record the time between symptom onset and first contact with services (sometimes referred to as Duration of Untreated Illness or DUI) have been problematic given difficulties relating to patient and clinician recall (48) and the varying definitions for DUI (60). Phillips et al., (108) report an average time of 127 weeks from first onset of symptoms to contact with the PACE Clinic. There may be many reasons why individuals with an ARMS take so long to present to the PACE clinic. These could include patients rationalising and concealing their symptoms rather than seeking help earlier (109) or the newly established nature of PACE services when the study was conducted. More recent estimates from the PACE clinic show that although there is still much variability in time taken to make contact with the service (3 days to 7286 days) the median time between onset and receiving help is now just over 1 year (60). Other services have still chosen to report DUI as a mean and have reported time frames between 13 and 22 months (103, 110, 111).

The concept of DUI could be compared to that of DUP and potentially could be associated with long-term outcomes and recovery. Therefore is it clearly worthy of measurement and study given that a significant duration may potentially prolong distress, lead to poor social functioning and increased symptom severity and place individuals at a greater risk of making a transition to psychosis. Initial findings from one study support a link between longer symptom duration and a more severe picture of psychopathology (103). In this study those with a longer DUI (>1 year) demonstrated significantly greater levels of distress and social impairment at baseline assessment.

Regarding pathways to care, ARMS clinics have shown that referrals arise from a variety of services, including other psychiatric facilities, schools and colleges, GPs, accident and emergency departments as well as families and self referrals (49, 112). Pathways to care studies have shown that in the UK, GPs are important gatekeepers in identifying mental health problems and facilitating appropriate and prompt treatment whereas in countries without a GP system, family members, teachers and the internet have important roles in the identification of psychosis (110). It is important that feeder services refer appropriate cases so as not to inundate early intervention services with assessments characterised by high rates of ‘false

positives'. It is here that services need to engage in community education for other professionals and the public. In the first 20 months of operation, 73% of individuals assessed at the PACE clinic were identified as having an ARMS (49) compared to only 32% at OASIS (69). At least half of those found not to have an ARMS at OASIS were already psychotic upon referral (69) with some sceptics claiming these figures could be even higher given that many patients conceal their symptoms upon first contact with services (113, 114).

Individuals with psychosis experience a wide range of co-morbid psychiatric syndromes (115) and the same appears to be true for those with ARMS. Co-morbidity is an important topic within the ARMS concept given that individuals with an Axis I co-morbidity appear to demonstrate a higher risk of transition to psychosis and worse symptom scores at baseline (116). In one of the first studies to consider co-morbidity, retrospective accounts and medical records were scrutinised in individuals presenting with an ARMS. Ninety percent of patients were found to have had a previous contact with mental health practitioners with at least half having been previously prescribed psychotropic medication. Sixty percent of patients in this study had received a previous psychiatric diagnosis with the most common diagnoses being either affective (23%) or an attention deficit disorder (17%). The authors of this study concluded that the overlap of symptoms between a possible prodrome and other disorders could easily lead to the under diagnosis of ARMS (117).

Since then several prospective studies of co-morbidity have taken place. Rosen et al., (88) using the Structured Clinical Interview for DSM-IV (118) discovered that 48% of their sample met the criteria for one or more current Axis I diagnoses. Other studies have suggested much higher figures ranging from 60-80% (69, 103, 119). Baseline characteristics of those entering the North American Prodromal Longitudinal Study (NAPLS) found that 35% had a current mood disorder (major depression, dysthymia or bipolar disorder), 30% an anxiety disorder (panic, agoraphobia, social or simple phobia, obsessive compulsive or generalised anxiety) whilst 20% had a substance dependence syndrome (89). Findings are similar elsewhere with 28% of participants in one study meeting the criteria for an affective

disorder, 24% were judged to have an anxiety disorder and 24% were diagnosed with substance abuse disorders (88). Chung et al., (103) discovered that depressive disorders were the most prevalent upon initial presentation with 29% meeting DSM criteria for a depressive episode NOS or a major depressive episode. Around 7% of individuals in this study were deemed to have more than one co-morbid DSM diagnosis.

These and a handful of other smaller studies seem to confirm that mood, anxiety and substance abuse are the most common Axis I co-morbidities in those presenting with an ARMS (69, 88, 89, 103, 116). Indeed studies that measure affective symptomatology at baseline using tools such as the Hamilton Rating Scale for Depression (120) demonstrate particularly high mean symptom scores (17.25 and 18.24; 93, 103). The high rates of depressive and anxiety disorders raise questions as to whether these disorders play a significant role in the development and maintenance of psychotic symptoms (88).

Despite the high level of co-morbid mood and anxiety disorders, only cannabis dependence (88) and general substance abuse (89) have been found to be significantly more prevalent in ARMS samples as opposed to other groups of psychiatric help seekers. Since co-morbidity profiles are remarkably similar it could be argued that this makes it more challenging for clinicians to distinguish between individuals who are and are not ‘at risk’ of future psychosis.

The high prevalence of substance, and especially cannabis, use in ARMS samples are unsurprising given that this is risk factor for the development of psychosis (121, 122). For example forty-one percent of ARMS individuals in one study were found to have a baseline history of cannabis abuse (123). ARMS substance users are also significantly more likely to be male (124), older, have a higher IQ and less likely to have a family history of psychosis than nonusers (123). Research into the motives for substance abuse seem to indicate that young people use drugs to cope or deal with negative emotions and symptoms, to socialize with peers and to enhance mood (125).

Identifying co-morbidity in this patient group is by no means easy and therefore there is considerable debate as to whether these figures from previous studies are misleading. For example Hafner et al., (126) claim that the schizophrenia prodrome is at times indistinguishable from that of major depression (127). Pervasive developmental disorder is another disorder which historically has been conflated with very early onset psychosis in children (128, 129). Alternatively, individuals who start to develop psychotic-like symptoms often hide underlying struggles with abuse, bulimia, identity, suicidal ideation, depression and substance abuse (130). It is therefore unclear whether co-morbidity figures for ARMS samples are under or over reported at this time.

Research suggests that risk of suicide is particularly higher during the early phases of psychosis (131). Similarly, according to one study of working-age adult study around 9% of those with ARMS had attempted suicide sometime before study enrolment. The authors of this study also found that the frequency of suicide attempts was comparable to that of first episode psychotic patients (132). Another related study suggests 14% of patients who go on to develop a first episode of psychosis report attempting suicide during an initial untreated stage of psychosis (131).

Numerous studies also point to an association between trauma and the development of psychosis and this could also be observed within the ARMS population. Two studies report that 97% (133) and 70% (134) of ARMS patients reported at least one general trauma in their lifetime. Total trauma exposure in the first of these two studies was positively associated with severity of attenuated positive symptoms. The experience of bullying has also been recorded elsewhere with 32% of those with ARMS reporting significant experiences (103). The reliability and validity of trauma reports in those who have altered mental states is controversial however since psychotic symptoms and the delusional systems at work may significantly influence and distort recall, memory and the willingness to disclose information (135).

Other interesting phenomena identified in ARMS patients is that these individuals tend to use more maladaptive and unhelpful metacognitive beliefs when compared

to samples of non psychiatric help seekers. Studies show that these beliefs may be in part responsible for the development and/or maintenance of psychotic experiences. (136). Levels of family functioning especially expressed emotion also appear to be significantly impaired in families of those with ARMS (137-139) whilst a family history of depression and other psychiatric illnesses is particularly common (21%; 103).

Despite the empirical literature it is important to consider the underlying bias that exists within the ARMS field. Data presented in these studies appears only to represent those individuals who have presented to or have been referred to mental health services. It is likely that many other patients may have been seen had they not hidden their symptoms or assimilated their experiences into the self rather than recognising their problems as a mental health issue (140). Such patients may therefore only present after the onset of frank psychotic illness.

2.5 Follow up studies and predictors

Longitudinal studies of individuals with ARMS usually focus on how many individuals make the transition to psychosis and which factors seem to predict that transition. Studies using the Melbourne Ultra High Risk criteria have shown declining transition rates despite the use of larger cohorts of around 300 participants that are now followed up for several years as opposed to several months (60, 62, 92). In Australia, transition rates of around 40-50% within a twelve month follow up (60, 93) have gradually declined in latter studies to 16% after two years (62) and most recently to 5% after a six month follow up period (141). The authors cite various reasons for this decline including earlier detection of high risk individuals (because of improvements in the knowledge of referrers), poor follow up rates, more effective intervention or a higher rate of 'false positive' cases within the sample (i.e. those who were never at risk of psychosis). Assessment practices in these studies have been extremely vigorous with the majority of individuals undergoing regular review and re-assessment at monthly intervals. The latter figures of transition appear

to be much closer to the 10% transition rate observed within the OASIS service for individuals receiving monitoring and treatment as usual within an NHS setting (69).

Possibly because of declining transition rates, a recent trend in follow up studies has been to record the number of individuals with a sustained ARMS status at review. Simon and Umbricht (106) found that 13.5% of their sample had converted to psychosis within one year whilst only 27.3% remained 'at risk' (i.e. they still presented with symptoms that would meet the ARMS criteria). The authors note that the high remission rates within this study (around 60% of patients no longer fulfilled the baseline inclusion criteria for this study) which used the Structured Interview for Prodromal Symptoms to identify caseness, are concerning given the possibility of stigmatisation and the anxiety provoked in mislabelled individuals. Findings from another recent longitudinal study using the SIPS found transition rates of 18% at one year follow up but remarkably low remission rate of around 15% (111).

What is apparent in longitudinal follow up studies (60, 62) and intervention studies utilising control groups (107, 142) is that the period of maximum risk of transition is usually within the first six months. Survival curve analysis for two studies indicates a transition rate of around 29% (60) and 36% (142) after a six month period of monitoring. However, some sceptics claim that the majority of those making the transition are already psychotic at baseline assessment. Researchers and clinicians are unable to detect symptoms because they are insufficiently expressed, possibly because of suspiciousness or concerns about the response of health services by the patient (113, 114). The authors of one study (111) suggest that 3 out of 11 patients making a transition to psychosis were already psychotic at baseline with information only coming to light in posterior phases of treatment due to concealment or difficulty in describing symptoms. On occasions when it has become apparent that an individual was actually psychotic at baseline, studies that have removed such individuals from data analysis have been heavily criticised. Critics for one intervention study point to the removal of such cases in order to present more favourable data (143). For those individuals who do become psychotic, studies have shown that the majority receive a label of Schizophrenia or Schizoaffective disorder

(60, 93, 144). A much smaller number of young adults in these studies go on to develop affective psychosis or major depression with psychotic features.

Despite the fact that many ARMS individuals do not go on to develop psychosis at follow up, many are later diagnosed with another mental health problem. Two studies found that more than half of those who did not become psychotic over a 12 month period were diagnosed with a mood or anxiety disorder instead (60, 145). Although it could be argued that these individuals were wrongly identified as being at risk of developing psychosis, it is impossible to know whether identification and treatment interrupted and prevented a path to psychosis (i.e. such cases could be 'false' false positives; 60). It may be possible to assume that 'wrongful' identification for some of these individuals had some benefits with much earlier engagement with mental health services and having the time and support to shed light on their 'prodromal' like problems (146).

With dwindling transition rates, studies are also focussing upon improvements in symptomatology and functioning at follow up. In one study after an average follow up period of 8 months and controlling for treatment effects, 50% demonstrated improvements in social and role functioning suggesting that ARMS individuals are not all predestined to a path of cognitive and functional decline (147). Mean follow up functioning scores for these improvers using the Global Assessment of Functioning were significantly higher than those obtained at baseline (53.57 vs 42.43).

In terms of which factors predict transition to psychosis, numerous areas are being investigated. Functioning at intake is one factor, with several studies having shown that poorer functioning at baseline predicts onset of psychosis (60, 92, 93, 148, 149). It has been postulated that those with poorer functioning may be less able to cope with psychotic experiences, more susceptible to depression, anxiety and substance misuse and have fewer social supports. This leads to a cycle in which psychotic experiences worsen and quickly become a full episode of psychosis (150). Demographic factors such as sex, ethnicity and socio-economic status do not seem to be predictors of transition to psychosis per se (92, 151) but Amminger et al.,

(152) found that female gender was a predictor for developing affective psychosis. Age at baseline also appears predictive with adolescents (15-19 year olds) and older at-risk cases appearing to be at a considerably higher risk (111, 145, 153).

Fulfilment of specific ARMS criterion groups in two studies has been found to be a predictor with those with a first degree relative being more likely to become psychotic in one study (145). Amminger et al., (152) found that those with a family history and attenuated or brief limited psychotic symptoms were the most likely to make a transition.

As previously mentioned, individuals with an Axis I co-morbidity demonstrate a higher risk of transition to psychosis (116). In terms of specific co-morbidities, a history of substance abuse has been predictive of transition to psychosis in several ARMS samples (145, 151). More specifically a history of cannabis and/or nicotine abuse/dependence has also been found to be predictive (124). It is surprising that other co-morbidities such as depression are not associated with transition risk given that severity of depressive symptoms as measured by the Hamilton Rating Scale for Depression is a highly significant predictor (60, 92). Speculation here may suggest that a substantial proportion of those with a co-morbid depressive illness are in fact false positives given that the prodrome is at times indistinguishable from that of major depression (126). In terms of specific positive symptoms, magical thinking and auditory hallucinations have been found to be predictive (93). Elevated scores on measures of unusual thought content, suspiciousness, perceptual disturbance and conceptual disorganisation (as measured by the Brief Psychiatric Rating Scale positive symptoms scale) have also been found to predict the development of psychosis (60, 145). This could be because some sub-threshold positive symptoms are more likely to progress whilst others may be more likely to be associated with functional decline and poor outcome (154). In terms of negative symptoms, blunted and inappropriate affect, anhedonia, withdrawal, concentration, attention and impaired energy have been shown to be significantly associated with the development of psychosis (65, 93, 149). Other interesting factors which have predicted transition have included movement abnormalities (155), neuroanatomical abnormalities (156), neurocognitive deficits (such as working memory, verbal

memory and olfactory identification; (157, 158) and schizotypal personality features (93).

As with any follow up study, dropout rates are a challenge to interpreting and generalising findings. Drop-out rates vary greatly in these studies and are obviously related to the length of the follow up period. Large studies report drop-out rates of 32% (106) and 26% (111, 144) for follow up periods ranging from 1 to 3 years. Some studies have tried to deal with missing data and drop out by checking state medical records in order to ascertain if participants were attending psychiatric services elsewhere (62).

2.6 Potential Intervention Strategies

By improving the identification of individuals who are at risk of developing psychosis, attention has been turned to the exploration of several interventions. The hope is that these treatments may target current symptoms but most importantly delay or even prevent a transition to psychosis altogether (159). Both the early pioneers, Sullivan and Meares believed that this was indeed possible:

> *'The great number of our patients have shown for years before the break, clear signs of coming trouble…I feel certain that many incipient cases might be arrested before the efficient contact with reality is completely suspended, and a long stay in institutions made necessary.'(45 [p135])*

> *'The thought must come to all of us – if only the patient had been brought to consultation earlier, we might have been able, by judicious psychotherapy and perhaps with adequate dosage of chlorpromazine, to ward off the illness…' (46 [p55])*

In terms of potential treatments being considered today, neuroprotective agents such as certain atypical antipsychotics, antidepressants and omega-3 fatty acids have all been considered based upon the notion that brain maturation is disturbed in those with emerging psychosis (156). These agents could potentially protect or limit the

potential decline in brain maturation (160) and significantly alter and improve the long term trajectory of an individual's psychosis by potentially limiting its progression and preserving a person's ability to respond to future treatments (29). Psychological therapies have also been seen as a viable alternative or a potential addition to such treatments. Psychological therapies have already demonstrated some efficacy as an adjunct treatment in acute and first episode psychosis (107) and perhaps most importantly, do not have the stigmatizing and harmful side effects of medication. These proposals have given rise to several randomized control trials (RCTs) and open label trials in the hope of evaluating the efficacy and appropriateness of these treatments.

In the first RCT of its kind, patients receiving a combination of low dose risperidone and Cognitive Behavioural Therapy (CBT) were initially found to have significantly lower transition rates after a 6 month treatment phase when compared to those receiving monitoring alone. However this inter-group difference had disappeared by the one and three year follow up stage (161).The authors concluded that specific preventive intervention demonstrates the potential to delay onset of psychosis, although participants may have been treated too briefly given that the risk of developing psychosis clearly continued after the treatment phase. In order to assess the efficacy of medication and psychological therapies separately, other trials soon followed. Findings from the Early Detection and Intervention Evaluation (EDIE) trial (an RCT comparing cognitive therapy versus treatment as usual) have been more positive. Over a 12 month follow up period, six months of cognitive therapy demonstrated significant reductions in progression to psychosis, significant reductions in the likelihood of being prescribed antipsychotic medication and significantly improved positive symptoms (107). However, a three year follow up once again suggested that transition rates between the two groups were no longer statistically significant (162). Because of its initial success a much larger and methodologically robust study (EDIE-2) has been undertaken (71). The first placebo controlled trial of an antipsychotic medication (olanzapine) was conducted in North America by the PRIME clinic (163) and so far has demonstrated significant reductions in 'positive symptoms' but led to very significant weight gain and high study drop out.

Other RCTs or open labelled trials have investigated the use of supportive counselling versus CBT (85), clinical management versus amisulpride medication (164), eicosapentaenoic acid (an omega 3 fatty acid) versus placebo (165), low dose lithium (160) and low dose anti-depressants medication (166). As for psychological therapies, pilot studies of psycho educational multi-family group (PMFG) treatment have shown improvements in symptomatology and functioning alongside acceptable levels of user satisfaction and adherence (167). Psycho-educational programmes have also been piloted with significant reductions in symptomatology and improvements in quality of life being demonstrated (168). Psycho-education proved to have an unburdening effect rather than a disturbing effect for participants with many endorsing a better understanding and ability to handle symptoms, reduced anxiety and the wish to recommend the treatment to others. Finally, although less intensive and evidence based, stress management and supportive interpersonal therapy have important roles to play and appear to be offered frequently by several ARMS clinics (159).

In the absence of any official treatment guidelines (apart from limited guidance issued by the International Early Psychosis Association; 169), the consensus from this literature appears to be the use of more benign interventions such as psychological therapies or omega 3 fatty acids as a first option strategy for ARMS. These therapies may prove more acceptable to many patients because of their less controversial nature as compared to low dose medication. Drug therapy could be a second option for patients who seem to deteriorate or are perceived to be on the verge of transition. Despite encouraging findings, psychiatrists still need to consider the initiation of medication, since without infallible prediction, many young people who will never develop psychosis could be treated with potentially harmful agents (170).

In this absence of guidelines and a lack of research conducted outside of clinical treatment trials it is often unclear what treatment and support is routinely offered by Early Intervention in Psychosis services. A wide variety of treatments, as previously discussed, are available and what is currently offered to patients and their families in such clinics around the world appears high variable (159). In the literature that does

exist for well-established Early Intervention services in the UK, psychological therapies appear to be offered, sometimes in combination with low-dose medication (69).

Data from a well-established Early Intervention service (OASIS) indicates that around 10% of ARMS clients agreed to monitoring on a monthly basis, around 34% received CBT as a stand-alone treatment, around 23% received CBT in combination with antipsychotic medication, around 10% received CBT and antidepressants, 7% chose antipsychotic medication and monitoring whilst around 2% preferred antidepressant medication and monitoring (69).

For adolescents in one Early Intervention in Psychosis service young people and their families are first offered written and verbal psycho-educational material about ARMS. In collaboration with the young person and the treating clinician, CBT, relaxation training and in some cases family therapy may be offered. If psychological work appears ineffective or refused young people are usually offered a choice of low dose quetiapine (25-50mg twice daily) or risperidone (0.5-1mg twice daily). Antidepressants are rarely prescribed at this service because of their belief that such medication may precipitate psychosis in this age group (70).

Patient satisfaction with at-risk clinics and the treatments offered is not well understood although preliminary research suggests that some individuals within UK Early Intervention services spoke positively about their experiences of therapy. These comments were related to being able to rationalize their negative thinking patterns and normalising their experiences (undoubtedly these individuals had been offered some form of cognitive therapy). In terms of the monitoring and reassurance provided by services, participants in this study acknowledged how their psychological needs were met and how this meant they were better able to deal with their personal difficulties (171). If treatment and the Early Intervention service had not existed all service users predicted that their outcomes would have been a lot worse.

A qualitative study examining interpersonal relationships and communication difficulties during an ARMS suggests that cognitive therapy and contact with early intervention services is highly beneficial. Those involved with services appreciated the value of being able to communicate their psychological distress which reduced levels of anxiety and confusion, improved their ability to cope with symptoms and enhanced mood and social ability. Cognitive Behavioural Therapy was highly valued because it was perceived to be collaborative and promoted interpersonal interactions with clinicians (172).

Feedback from service users at the OASIS Clinic found that most were happy to receive treatment but many were reluctant to take medication, often because they wanted to see if they could manage without it (69). Patients' experiences of antipsychotic medication are often strongly polarised into positive and negative views depending on their current level of wellbeing, distress and the drugs' side effects (173). The medical model and associated interventions are therefore often experienced as disempowering because affected individuals come to believe they have no control over their illness and there is nothing they can do themselves to get better except take medication (174). Being involved in treatment decisions has been outlined by service users of Early Intervention services as a key aspect of recovery and patient satisfaction (175) and the same appears to be true when prescribed and treated by antipsychotic medication (173).

2.7 The lived experience of the At-Risk Mental State

The use of the ARMS label and how the term is understood is in need of investigation, given the potential to create anxiety and stigmatization (170, 176). Research from genetic testing for conditions such as Huntington's disease and breast cancer show that people are not always keen to know one's own risk status (177). When individuals do learn their risk status for these conditions it can often have a powerful impact with patients and family members experiencing acute anxiety, depression and interpersonal strain (170). Many individuals then go on to report examples of discrimination and hostility from life insurers, employers, family members and health care professionals (1).

Obtaining a diagnosis of psychosis is often perceived as detrimental with many individuals feeling as if others perceive them to be different or unacceptable (178). Some researchers have mused that the ARMS label, rather than increasing apprehension as is the case with psychosis, may open the door for new optimism that outweighs any anxiety as symptomatic patients know that some form of treatment is forthcoming (177). However for those who never make the transition to psychosis they may experience a lasting sense of fragility which may alter their future life goals. Others have postulated that 'false positive' ARMS individuals are by no means asymptomatic and that engagement with services helps to shed light on what is actually wrong and what contributed to the development of their prodromal like symptoms (146). Initial reports from the PACE clinic suggest that young people and their families experience a range of feelings and emotions when presented with this term. Some experience relief and tend to feel 'better', possibly because they are not currently psychotic (179). Others demonstrate concern, scepticism and denial to the news (159) which does not seem surprising given many young people's tendency to ignore psychotic symptoms in order to cope with their difficulties (180).

Adolescents who are diagnosed with depression seem to react in similar ways. Wisdom & Green (181) found that about a third of their sample reported relief when hearing about the diagnosis as it validated their distress and reassured them that they were not the only person to experience these symptoms. It helped them make sense of their distress and seek information to reduce their symptoms. A similar proportion of adolescents saw the diagnosis as confirming they had a mental illness which required some form of treatment. These teens tended to be distressed and became reliant on their treating clinicians seeing them as responsible for 'curing' their condition. The final group of adolescents perceived the diagnosis as confirming a part of their identity or self-image (thus, they agreed with the diagnosis). Receiving a diagnosis was not associated with distress but confirmed that depression was a personality characteristic that could not be changed. The prognosis for this group was understandably poor. Although adolescents with depression did not demonstrate denial, the reaction of denial to a diagnosis of psychosis has been observed and is usually caused by poor information giving

(182). Wisdom and Green's findings demonstrate that diagnosis giving and persons subsequent reactions can influence willingness to engage with services and recovery. Labelling is potentially harmful but in many cases helpful and important. By not providing an ARMS label for a person's symptoms and an adequate explanation, individuals may tend to stay in a state of denial (thus letting their condition worsen) or they may never experience the sense of relief a label can provide.

With the possible inclusion of a psychosis risk syndrome in DSM-V researchers have started to debate to a greater extent the affect any ARMS label may have especially in terms of stigmatisation. As previously demonstrated some people experience relief when a psychiatric label is given as it seems to explain and validate their experiences (181). An ARMS label may result in prompt and effective treatment reducing symptoms thereby decreasing stigma (1) as symptoms and behaviour usually shape community rejection rather than labels. Drake (183) argues that any DSM definition must recognise that many individuals experience psychotic like symptoms who are not particularly distressed or help seeking and that these individuals are unlikely to benefit from any label. Other proponents of a more formalised ARMS label point to the fact that those presenting to services are already ill (have reduced functioning, quality of life and other co-morbidities) and have a need and a right to be offered treatment (184).

Opponents of the psychosis risk syndrome suggest that any use of a 'psychosis' label would interfere with a patient's ability to communicate with others, making them withdraw or limit social contact to those accepting of their condition. For adolescents, anticipated peer rejection is probably a major concern given that many people endorse the view that children who obtain mental health treatment are likely to be outsiders at school. Adolescents' perceptions of peers with psychosis are also extremely negative with the majority endorsing attitudes that suggest those with the condition are more violent, suicidal and academically poor (1). Adolescence is a time when young people are rapidly negotiating developmental goals and obtaining their own self-concept. Consequently a mental illness label may interfere with these processes. There is also a risk that the illness role becomes central to the young

person's identity and threatens a future sense of normality. This is something that has been observed for other conditions with about 20% of adolescents identifying a mental illness label as a core aspect of themselves (1). Labelling seems to have a greater impact (in terms of self-stigma and secrecy) among adolescents who are younger with less well formed identities. Prior literature has also shown that labelling-induced stigma can be devastating in terms of reduced self-esteem, greater feelings of depression and demoralisation, poor treatment adherence and reduced social contact making a relapse more likely (1).

Most qualitative research to date has focused upon how patients, friends and family members experienced the psychosis prodrome in terms of emerging symptomatology (185) and the neglect of research to examine the potential effects of labelling and stigmatisation within this population is visible. Opponents of the inclusion of the psychosis risk syndrome in DSM-V rightly state that '*no studies to date have systematically examined how any potential stigma induced by the label of psychosis risk might affect identified patients'* (1 ^{p43}). Parnas (186) supports this view stating that there is an alarming ignorance of the subjective perspectives of 'pre-schizophrenic' patients. How an ARMS diagnosis or label comes to affect the attitudes and beliefs held by the young person and their family could be important in the early stages of this condition given its potential to shape family dynamics (a factor significantly associated with positive short term outcomes; 137, 138). Indeed, conversely there is evidence that young people at risk of psychosis living in a critical family environment have significantly worse positive symptoms at six month follow up (187), highlighting the potentially important role that parents play in the course of the syndrome. Family members and partners of those with psychosis are seen to influence the explanations and beliefs held by the young person and therefore come to reinforce either a helpful or unhelpful explanation (188). Parents of those with 22q11 deletion syndrome (these individuals have a 25-30% risk of developing psychosis sometime during their lives) report the strain of living with uncertainty and the struggle to differentiate between normal changes in behaviour and those that are cause for alarm (i.e. 'over vigilance'; 189). Parents of individuals with psychosis, however, suggest the label of a mental illness offered them a way to

deal with the negative feelings they had experienced towards their child and a diagnosis gave them hope of potential treatments (190).

Qualitative research exploring the experiences of siblings of individuals with psychosis indicate that brothers or sisters also act as a valuable resource in engaging in recovery, normalisation activities and providing opportunities for socialising (191). Many of those surveyed in this study reported feelings of being overwhelmed, resentful, ashamed and embarrassed when initially faced with their sibling's condition, finding it difficult to disclose to friends and teachers about their circumstances. Despite this many went on to develop a closer relationship and involved their brother and sister as much as possible in their own circle of friends and social engagements. Many identified a lack of information giving by services about their sibling's condition. Despite all of this, their viewpoint and education is often ignored by mental health services.

Attitudes held outside the family by friends, schools and future employers may exert great influences on the young person, subtly affecting the individual's relationships, opportunities and aspirations (177). Friendship is an important factor in an individual's recovery from psychosis (192) and because of the impact a label might exert its use must be carefully considered. Perceived negative attitudes of others have been shown to be an early indicator to patients that they might be developing psychosis (193) and the ARMS label may just serve to fuel these beliefs.

A lack of information in this situation may be critical and may heighten patients and their families' anxieties forcing them to turn to unreliable sources of information for guidance, support and confirmation. This is something which is common for patient with 22q11 deletion syndrome (a chromosome disorder caused by the deletion of a small piece of chromosome 22). Many do not received adequate information from a variety of different health professionals leading them to use un-vetted non-medical sources of information particularly on the internet (189). Although individuals with 22q11 are often at risk for other medical conditions, families indicate that the risk of psychosis causes them the greatest anxiety for whatever reason. Providing sufficient time for adolescents and their families to ask questions and supplying appropriate

psycho-educational material may or may not be adequate in resolving any anxieties and concerns. Practices linked to lowering anxiety in cancer patients when communicating a diagnosis may provide helpful indicators of best practice. These show that preparing the individual for a possible diagnosis, having the people wanted by the patient present, giving the patient as much written and verbal information as desired and talking about how the cancer might affect other aspects of life are all important (194). This approach to care may also be effective for those with an ARMS given that feelings of confusion and worthlessness are often replaced with relief when service users affected by psychosis are provided with accurate meaningful information (195, 196). Coping, engagement, medication adherence and long term outcome also appear to be much improved when people are more informed about their diagnosis of psychosis (197).

Comparing the experiences of individuals with an ARMS and those with a first episode psychosis is of interest and maybe valid given those recovering from psychosis have similar problems to those with ARMS. Research suggests that many individuals with psychosis experience a loss of social roles, hopes and aspirations often leading to stigmatisation and trauma. The sufferer changes the way in which they see themselves, their ability to achieve goals and how they are perceived by others (135, 140). Parents of those with psychosis go through a variety of feelings and stages with many feeling anger, grief and loss for all the hopes and dreams they had for their child. In time these feelings are replaced by increased knowledge and understanding, finding ways to cope, stability and possibly a sense of recovery and growth (190). Other qualitative research conducted with those recovering from psychosis has shown that participants clearly discriminate between safe and unsafe people in terms of talking and disclosing information about their condition (188). Beliefs and explanations about symptoms were also found to be more important than the symptoms themselves in how a person reacts and acts in response to their condition. Understanding one's experiences and working through them is an area that many people recovering from psychosis find important (192).

As stated previously, social relationships and friendships are an essential part in the recovery process but for those who experience psychosis many experience a loss of

contact with friends they had prior to their illness (198). Many service users come to value the support from family members more and develop friendships with people who understand and have experienced the condition themselves as they assume that peers will not understand or be accepting of their condition. People in this study believed that others, even old friends perceived them differently because of the way people now interacted and behaved towards them. This study highlights that psychosocial engagement programmes that encourage activities typical of young adults but also allow opportunities to meet with people who have similar experiences are essential to the recovery process. Interviews conducted with a group of young men who had experienced psychosis suggest that many try to avoid their psychotic experiences and symptoms by any means possible. This group also observed a sense of loss in terms of their age related goals being thwarted or modified because of their condition in the initial stages of the recovery process. Participants felt that they had missed out on normative age related social roles such as having qualifications, jobs and partners and found themselves more reliant on their parents. Despite reporting this sense of loss many participants' difficulties appeared to predate their illness possibly indicating that their targets were initially too high (199). It is clear that people regularly reflect upon their lives before, during and after psychosis.

As previously mentioned one study has investigated how individuals experience an ARMS during their journey through services. Findings suggest that those who have contact with at risk services demonstrated positive experiences of therapy and clinical contact (171). Orientation to the future was also a commonly identified theme in the research with individuals expressing hopes and concerns regarding their future, most notably in the areas of employment and whether their mental health problems would return. All participants recognised that their basic needs had to be addressed before psychological issues could be tackled. However, it has been questioned that the self-selected sample for this study may have included those who were most happy with the service thus leading to a possible positive bias in responses and reported experiences (171). Future research might benefit from attempting to recruit participants who haven't engaged well with services. Despite these concerns the reported experiences seem to be significantly more positive than

those experienced by individuals who never obtained help until they were fully psychotic (200).

2.8 Adolescent specific research

Studies specifically focussing on adolescents with ARMS are currently very few in number, despite the importance of this stage in the development and course of psychosis. Firstly, adolescents who develop psychosis have much worse long term outcomes when compared to individuals with a later adult onset (26, 27, 201, 202) possibly because they have a longer duration of untreated psychosis and significantly more depressive symptoms and suicidal intentions (203). Secondly, given that a prodrome may last several years and the chances of developing psychosis peaks between the ages of 15-24 (154), young people in their early and mid-teens should represent a substantial proportion of the ARMS population. This however does not seem to be recognised within current studies since recruitment practices have traditionally focussed upon a range anywhere between 14-30 years of age (60). Thirdly, adolescents may be more sensitive to the negative effects of misidentification and consequent inappropriate medical treatment. Moreover, they may experience more intense stigma and social isolation than their adult counterparts. Young people are more prone to neuroleptic side effects such as extrapyramidal symptoms, prolactin elevations and weight gain compared to working age adults (204).

The lack of research for this age group may be the result of difficulties in accurate identification. There is definitely the potential for studies to include a substantial proportion of false positives, given the non-specific nature of prodromal symptoms (48), the potential masking of prodromal symptoms by co-morbid conditions and the neuro-maturational and psychological changes that naturally occur during adolescence (73, 174). Certain characteristics typical of 'normal' adolescence such as conflicted family relationships, grandiosity, egocentrism and magical ideation bear a close resemblance to psychotic features and could easily be mistaken for a psychosis prodrome. Genuine symptoms on the other hand may therefore be dismissed as normal adolescent development by others. Prodromal symptoms in

teenagers at times are highly associated with normal psychological development given that more psychologically mature teenagers who demonstrate greater parental autonomy report more frequent symptoms (174). Screening programmes in the general adolescent population further demonstrate just how difficult it is to identify potential cases given that a high proportion of non-help seekers report unusual psychotic like experiences (205). In the overall adolescent psychiatric help-seeking population, perceptual disturbance (not meeting the definitions for 'true' hallucinations) are common but are often masked because they are not seen as distressing, are not the main reason for a mental health referral or because they remit very quickly (206).

Identification and potential studies may also be hampered by the fact that within the UK and across the world, the core business of child psychiatry has traditionally focused on developmental disorders such as autism and ADHD, meaning that child and adolescent clinicians may have limited experience and are ill equipped to assess and treat an adult type disorder such as psychosis (207). It maybe that Child and Adolescent Mental Health Services (CAMHS) already have several young people fulfilling the criteria for ARMS on their caseload but as yet have not been recognised as such. Perhaps such patients would be labelled as having depression or emerging personality disorder, if self-harming behaviour was prominent. A survey comparing the attitudes of child versus adult psychiatrists found that child psychiatrists were less likely to refer a suspected case of psychosis onto their local Early Intervention in Psychosis service (208). Even if these cases are identified and referred correctly to Early Intervention services, the number of overall ARMS cases is difficult to obtain given that these individuals are not currently included in nationally set caseload targets.

Although there is limited evidence, it is possible that an adolescent with ARMS will demonstrate similarities to their adult counterparts. ARMS individuals for example present with a wide array of co-morbid psychiatric syndromes along with substantial functional impairments when presenting to services (69, 88-90). At the time of writing only four studies have specifically looked at the initial and lifetime

presentation (in relation to functioning, demographics and co-morbidity) of high risk adolescents (110, 209-211).

The first of these studies sampled twenty four ARMS individuals aged between 12-19 years of a age (209). They were identified using the SIPS and were part of a much larger longitudinal study. Baseline demographics indicated that the mean age of this sample was 15.75 years, predominantly male (70.8%) with individuals coming from a diverse range of socio-economic backgrounds. In terms of family history, 33% had a first, second or third degree relative with psychosis. The mean Global Assessment of Functioning score was 44.37 (range 20-60) indicating significant functional impairment. Although the study did not adopt the Melbourne Ultra High Risk criteria individuals were allocated to similar criterion groups. Ninety-six percent were found to fulfil the attenuated positive symptoms syndrome which equates to Group 2 of the Melbourne Ultra High Risk criteria. In terms of the frequency of attenuated positive symptoms perceptual abnormalities and hallucinations were the most common (83%) followed by unusual thought content (75%), suspiciousness/persecutory ideas (54%), disorganised communication (38%) and grandiose ideas (17%).

In order to assess current co-morbidity, individuals were either assessed by the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS; 212) or the Structured Clinical Interview for DSM-IV. Analysis of the data produced by these screening tools found that 50% of adolescents met DSM criteria for a major depressive disorder which represents a much higher proportion than those found in ARMS studies mainly sampling young adults. The next most common diagnoses were anxiety disorder NOS and social phobia both with a frequency of 17%. Other co-morbidities included generalised anxiety disorder, post-traumatic stress disorder and eating disorders (although these only represented one or two cases at most). Although no individuals were found at baseline to meet the criteria for attention deficit disorders, the authors of this study noted that many of the participants (25%) had received a diagnosis in the recent past (209). The observation that attention deficit disorders are a prevalent lifetime co-morbidity has been identified elsewhere with around 30% of patients in one study meeting a lifetime ever diagnosis (90).

The authors also confirm the great difficulty in identifying and assessing adolescents with a potential ARMS given that the majority of participants meet actual and sub-threshold criteria for around 3-4 different disorders. Based on clinical experience, literature from areas of childhood-onset schizophrenia (213, 214), genetic high risk studies (215) and assessment of co-morbidity in adults with ARMS (90, 100) it is surprising that none of the adolescent participants in this study presented with a current co-morbid developmental disorder (i.e. Attention Deficit or Pervasive Developmental Disorder). Research further highlighting this point found that 78% of adolescents with a diagnosis of PDD-NOS met criteria for an ARMS (216).

The second identified study involved a case series of 9 teenagers aged between 13-17 years old and again used the SIPS and K-SADS to estimate current and lifetime diagnosis (210). In terms of demographics the sample was predominately male (78%) and had a mean age of 14.7 years. In terms of functioning the mean GAF score was 46.3. In terms of current and lifetime co-morbidity all individuals bar one met criteria for a co-morbid diagnosis. Attention deficit hyperactivity disorder was found to be the most common diagnosis (56%), followed by oppositional defiant disorder (56%), enuresis or encopresis (44%) conduct disorder (22%), separation anxiety (33%) and transient tic disorder (22%). Sub threshold diagnoses were also reported in this study and indicate that adolescents at risk for psychosis experience several psychiatric symptoms and difficulties at one time.

A separate study claiming to prospectively study adolescents with sub-syndromal psychosis is more controversial given its questionable adolescent age range (12-22 years old) and its inclusion of adolescents diagnosed with psychotic disorder NOS and brief psychotic disorder (211). Compared to other studies these individuals are likely to have been excluded because they already would have been deemed to have made the transition to psychosis. In this study 29 adolescents were recruited with a mean age of 16.2 years. The majority of participants were male (65.5%). In terms of baseline DSM-IV co-morbid disorders frequencies indicated that many fulfilled the criteria for a depressive disorder (52%) or a personality disorder (45%). Less common co-morbidities included anxiety disorders (35%), oppositional defiant/conduct disorder (35%) or attention deficit hyperactivity disorders (31%).

One individual was diagnosed as having Asperger's syndrome. Given the unusual method of categorising individuals for inclusion it is hard to interpret the subsequent six month follow up data. The authors report a 27% transition rate to schizophrenia or schizoaffective disorder but report that 38% of their sample showed considerable improvement in terms of positive symptomatology.

Finally, in a descriptive study of pathways to care in Korea, 18 adolescents aged between 15-18 years old were identified with ARMS using the Melbourne Ultra High Risk criteria (110). Demographic details indicated a mean age of 15.78 years and a predominately male cohort (72%). The mean duration of untreated illness was 13 months with a range of 2 weeks to 36 months. No data was presented in relation to baseline functioning or co-morbidity.

Looking instead to the psychosis literature, findings from a comparison between adolescent and adult onset demonstrated that the emerging clinical profile of an adolescent appears to be more affective (perhaps confused with the stereotypic 'moody teenager' which potentially delays assessment and referral). The study also discovered that adolescents experienced fewer positive symptoms and have higher functioning scores compared to working-age adults (203).

Although there are concerns that adolescents with ARMS are not always identified, some authors have commented about the degree of youth within generic ARMS samples and have speculated that this could be because of family concern and intervention (95). Adolescents who still live with their parents may find it more difficult to conceal their symptoms, whereas those who have left home may have a tendency to withdraw from others and inhibit their need to seek help. These factors may mean that at-risk adolescents present earlier than their adult counterparts (thus reducing treatment delay which in turn may influence symptomatology and transition). This does not seem to be the case however when duration of untreated illness data is presented for adolescents with ARMS (110). Another study by Amminger et al., (152) found that individuals who experience the onset of attenuated psychotic symptoms before their 18th birthdays had significantly fewer

depressive symptoms at baseline assessment but they also had a significantly longer duration between symptom onset and initial help seeking presentation.

Transition rates and predictors of outcome within the ARMS population vary widely between research centres using UHR criteria (79, 150, 154) but very little is known about how these relate to adolescents with ARMS. Transition rates have been studied prospectively in one adolescent study of structural brain changes, with the authors concluding that a transition rate of 14% after 18 months was low (217). An explanation by the authors for the low conversion rate suggested a lack of exposure to environmental risk factors associated with psychosis such as unemployment and social isolation since all participants were still receiving some type of formal education and/or were living with at least one parent/carer at the time.

This finding appears to be at odds with other research where age has been found as a potential predictor of transition. In one study adolescents (15-19 year olds) were found to be at a considerably higher risk (153) whilst Amminger et al., (152) demonstrated that individuals who experience the onset of attenuated psychotic symptoms before their 18th birthdays are significantly more likely to develop non-affective psychosis. This has led to the authors of this study to suggest that studies wishing to investigate the biology of transition should consider oversampling individuals with an age onset of symptoms before their 18th birthday to inflate the conversion rate in their samples. Several reasons why adolescents may be more likely to make the transition have been proposed including biological mechanisms, changes to peer dynamics, initial exposure to substances and parent-child conflict.

One area that might prove fruitful is the association between childhood trauma and the development of psychosis (218, 219). Emerging research suggests that a substantial proportion of ARMS individuals experience traumatic events and exposure is significantly associated with symptom severity (133). It may be that difficulty coping with stress and trauma alongside poor social skills may precipitate the transition from non-distressing positive symptoms to actual psychotic disorder (65). Despite these findings initial research suggests that trauma exposure does not predict transition to psychosis in ARMS individuals (220). This study does not rule

out the possibility that trauma is a potential predictor within an adolescent ARMS sample however.

Another potential predictor which appears to be worthy of investigation in this population is family functioning. Initial research into this area demonstrated that there was a positive association been adolescents' conflict communication skills at baseline assessment and an increase in positive symptoms six months later. Conversely, adolescents who had constructive skills and were more able to reduce tension between themselves and their parents, had better social functioning scores six months later (221). Similar findings have shown that parents positive remarks and warmth predict a decrease in at risk adolescents negative symptoms and a significant increase in social functioning at follow up. Supportive attitudes and behaviours may therefore buffer stress and enhance coping (137).

In regard to how adolescents subjectively experience and come to understand the At-Risk Mental State, limited primary research is available. As previously mentioned it is highly likely that individuals will react in several ways. Some may experience relief and tend to feel 'better', possibly because they are not currently psychotic (179) whilst others may demonstrate concern, scepticism and denial to the news (159).

In spite of an absence of official treatment guidelines, it is probably safe to say that some form of treatment is indeed warranted in adolescents fulfilling the ARMS criteria (given the likelihood they will demonstrate significant impairment and distress). One study has demonstrated that services specifically designed for ARMS adolescents based on the principles of stress reduction care are having a significant impact (222). Findings from the Jorvi service in Finland have shown that ARMS adolescents have experienced significant improvements in functioning, quality of life, anxiety and depression after around 6 months of care. Although a couple of studies can be identified in the literature which outline and describe the processes of routine NHS care for those with an ARMS (69, 70) little is known about the care and levels of user satisfaction experienced by at risk adolescents. Reports suggest there have been some concerns about the consistency of care for all 14-18 year olds

within EIP services, since dedicated input from CAMHS services is not always available (223). Another evaluation of services has shown that only 26% of EIP teams provided care for adolescent between the ages of 14-18 (224). What is routinely offered to these individuals within an NHS setting and its effects are largely unknown.

Pharmacological interventions have demonstrated some favourable results within an adolescent specific sample (166) but these interventions are problematic given that young people are believed to be prone to neuroleptic side effects (204). However little is known about the effect that antipsychotic medication may have on the developing adolescent brain (113) and without infallible prediction many of those treated this way will have been exposed to risk unnecessarily. Psychological therapies may therefore prove to be more acceptable for patients, families and clinicians in the clinical world (working outside of large scale research and treatment trials).

2.9 Professional attitudes towards ARMS

Understanding professional attitudes and experiences in relation to the ARMS concept is an important area of study as these factors could have practical implications for how such young people are dealt with by services.

One survey has compared the attitudes of 87 Singaporean psychiatrists versus primary healthcare physicians in the identification and management of ARMS (225). In terms of preferred treatment for the condition 79% of psychiatrists endorsed the use of atypical antipsychotics. Other treatments endorsed included psychological therapies (28%), watchful waiting (26%) or antidepressant medication (14%). The majority of psychiatrists believed duration of treatment should last between 6 months to 2 years or until the symptoms resolved. Sixty-four percent of psychiatrists surveyed believed that there was no clear consensus about the management of ARMS. Despite an overall consensus the authors conclude that the psychiatric community seems to acknowledge the clinical utility of the ARMS

concept given that many individuals have a preferred treatment choice whilst around half would advocate screening of ARMS in high risk groups (such as students).

Whether these treatment preferences will be replicated for child and adolescent mental health professionals is unclear. Many, for example, may not support the wide spread use of antipsychotic treatment since adolescents are shown to be more sensitive to the effects of this medication (204). Preference for antipsychotic treatment in adolescents may specifically relate to psychiatrists given that a recent survey of child psychiatrists demonstrated that all supported the use and efficacy of medication in the treatment of psychosis (208). This latter survey also found that child psychiatrists were less confident in dealing with the condition when compared to their adult counterparts. Again this may suggest that child and adolescent clinicians may potentially struggle in the management and identification of an ARMS given that they lack experience and are less well equipped to assess and treat an adult type disorder like psychosis (207). Identification of an ARMS may also be particularly challenging for clinicians working with adolescents given the frequency of psychotic like symptoms reported in the normal population (205). Some psychotic like symptoms are at times a normal part of adolescent development (174) or a part of another underlying condition (73).

It could be that some healthcare professionals may struggle to inform individuals about their condition when presenting the ARMS label. A recent survey suggests that healthcare workers are reluctant to inform a patient about a diagnosis of psychosis (226). Moreover, it may be that many clinicians may not endorse the clinical utility of the ARMS concept. After all, a separate survey of psychiatrists in Singapore found that many challenge the concept of the ARMS itself (103) whilst mental health professionals can often contribute to the negative stigma experienced by service users (172).

Apart from this study, literature in the area of ARMS and first episode psychosis as a whole appears to be particularly neglected given that a recent review of qualitative research highlighted only a handful of studies that included interviews, audits and focus group data involving clinicians (185).

2.10 Literature survey: Summary

Although the ARMS concept is highly controversial there is the potential to greatly improve the detection, outcomes and experiences of young people presenting with this condition. Despite the importance of adolescence in the developmental stages of psychosis only a handful of studies have specifically investigated the initial presentation (i.e. baseline symptomatology, functioning and co-morbidity) of adolescents identified as having an ARMS. To date none of these studies have prospectively followed up an adolescent only cohort over the short term in order to assess outcomes.

In addition, no studies have been identified that aim to qualitatively investigate how adolescents with ARMS come to understand and experience their condition and care. This is a particular concern given that this population is potentially more sensitive and vulnerable to the negative effects of misidentification and unnecessary treatment. By considering the views and attitudes held by mental health professionals as well, it will be possible to provide 'real world' insight into the clinical utility, assessment and treatment of adolescents with a suspected At-Risk Mental State.

The aim of this thesis will be to address these gaps in the academic literature. However before proceeding any further it is important to consider the ARMS criteria within the context of normal adolescent development. Given the proposed inclusion of a 'psychosis risk syndrome' in DSM-V it is also important to consider whether the attenuated symptoms essential to applying the ARMS criteria represent a genuine illness worthy of diagnostic categorisation. The following issues will be dealt with in Chapter 3.

3 A theoretical understanding of the At-Risk Mental State concept in adolescents

3.1 Key theories of 'normal' adolescent development

"Adolescence represents an inner emotional upheaval, a struggle between the eternal human wish to cling to the past and the equally powerful wish to get on with the future" (227 [p21])

The word adolescence comes from the Latin '*adolescere*' meaning *'to grow into maturity'*; 16). The period of adolescence has no strictly age-bound definition but is usually perceived as the period of transition between childhood and adulthood marked by various changes in physiology, cognition and behaviour (228). Before the modern era, philosophers such as Plato and Aristotle began to comment upon stages of development from childhood, to youth then to adulthood. However it was not until 1904 with G Stanley Hall's publication of '*Adolescence: Its psychology and its relation to physiology, anthropology, sociology, sex, crime, religion and education'* that adolescent development became an independent and theoretical discipline in its own right (229).

Hall considered development during adolescence to be suggestive of some ancient period of storm and stress (Sturm und Drang; 230). To Hall storm and stress was apparent in adolescent's tendency to question their parents, their mood fluctuations and their frequent engagement in risk taking behaviour. These behaviours represented an internal struggle or turmoil between self-interest and social good. Since Hall perceived this process of storm and stress to be biological it would naturally follow that this was indeed universal (231). In the 1920s and 1930s anthropologists, most notably Margaret Mead, began to challenge Hall's claims by suggesting that adolescent behaviours varied from culture to culture (232). Mead's extensive work on the pacific island of Samoa led to the theory of cultural relativism; the way adolescents behave and the problems they face are relative to the culture they live and develop in. Cultural relativism was based on Mead's

findings that Samoan adolescents experienced few problems and difficulties and in fact made an almost smooth transition to adulthood (232, 233).

Despite Mead's claims, her work has subsequently been subject to criticism most notably from the academic Derek Freeman (for an interesting critique of Freeman's claims see Cote; 234). Freeman claimed that Mead's view of Samoan life was skewed because of her inability to integrate into the culture and society of the island therefore obtaining a biased 'outsider' perspective. Freeman also points to crime figures and subsequent interviews with educated Samoans' that support a more turbulent period than that portrayed by Mead.

In order to synthesise the work of Hall and Mead theorists now support a modified view that adolescence is a time when various problems are more likely to arise than at other ages, although this is especially true for Western cultures (231). For example, Hall's work is largely supported by public perceptions of adolescence since the vast majority of the population endorse this time as a major period of storm and stress characterised by insecurity, depression, recklessness and impulsivity (235). Other support comes from numerous studies that have indirectly recorded the occurrence of adolescent storm and stress in terms of increased parental conflict, emotional volatility, negative effect and risk taking behaviour (231). Perspectives from a cultural relativism approach state that adolescents may experience something akin to storm and stress in Westernised cultures as these are characterised by rapid changes in social and technological change. Parents and teachers are unable to provide adolescents with the necessary skills required for adulthood because of the ever changing nature of society and its norms. There is also a sharp break between what one does as a child and the role suddenly thrust upon individuals when they become adults (236).

Although classical psychoanalytic theory initially outlined by Freud suggested that few personality changes occurred during adolescence, his daughter Anna later applied the underlying assumptions and framework to this period (231). According to this theory, personality emerges during five stages of psychosexual development. The genital stage was the beginning of adolescence and it is at this time that the Id

(the basic urges drive) re-energises. Sexual needs become dominant and must be counteracted and managed by the ego and superego. An imbalance during this period leads to stress, turmoil and emotional disturbance. Anna believed that this emotional turmoil was desirable and that *"to be normal during the adolescent period is by itself abnormal"* (237 [p267]). The absence of any storm and stress was a sign of reluctance to grow or to become autonomous and therefore maladaptive (although she also qualifies this by suggesting that too much turmoil can also be maladaptive). 'Intellectualization', as it became known was an important process during this time whereby personal problems and conflicts had to be resolved on an abstract philosophic plane. Successful mastery of abstract thinking and hypothesis generation during intellectualization leads to adaptive and advanced development (228).

Despite his psychoanalytic training Erik Erikson placed a greater influence on social environment and theorised that life represented a series of determined sequences of psychosocial stages. Each stage involved a struggle with two personality outcomes, one adaptive and one maladaptive. Erikson believed the major challenge in adolescence was to develop a strong sense of personal identity as during this time individuals would experience an identity crisis (a loss of personal identity). Failure to integrate perceptions of the self into a coherent whole would result in role confusion and maladaptive behaviours. Adolescents at this stage see themselves as products of their past experiences (238). In an extension of Erikson's work, Marcia proposed four stages of adolescent identity where a mature identity can only be achieved if an individual experiences several crises in exploring and choosing between life's alternatives. An adaptive identity was achieved when an individual had committed themselves to a set of clear life choices and goals (239). Coleman and Hendry later added that adolescents who must deal with more than one crisis at a time are most likely to experience great difficulty in life (240).

Piaget's theoretical perspective on cognitive development suggested that adolescents are actively trying to construct an understanding of the world they live in. Piaget viewed cognition and intellectual activity as means by which adolescents adapt to everyday life. By developing cognitive structures or schemas these may

effectively help solve problems and facilitate positive adaptation to change. When an adolescent is unable to use an existing structure to solve a problem an unpleasant state of cognitive conflict occurs. It is proposed that during adolescence formal operational thinking emerges which is focussed on describing and attempting to explain, rationally, why something occurs. The previous stage of concrete reasoning relies on description alone. Formal operational adolescents think about hypothetical possibilities and many possible outcomes (241). They must also think about the combined effects of multiple variables and consider and reflect on the influence of their own thinking process (metacognitions; 242). According to Elkind (243) a negative by-product of the development of formal reasoning is conceptual egocentrism where an individual is tied to one's own view point. Once formal operations are developed a person is able to think not only about their own thinking style but that of others as well. Since adolescents may be preoccupied with themselves they assume that the thoughts of others are preoccupied with them also. Therefore, a certain degree of self-consciousness may be anticipated in young people at this stage.

Biological theories of adolescent development consider several maturational processes within the brain and nervous system. A major belief is that biochemical changes are brought about by hormones secreted by the endocrine glands such as follicle stimulating hormone, luteinizing hormone and prolactin. These in turn lead to the development of the gonads (ovaries in females, testes in males) and secondary sexual characteristics. The production of sex hormones (oestrogen in females and testosterone in males) from these areas is believed to lead to behavioural changes in addition to physical growth (244). Buchanan et al., consider and explain 'typical' adolescent behaviour such as aggression, irritability and family relations as products of hormonal influences (245). In terms of brain maturation, investigators have observed a decrease in front-cortical grey matter but an increase in white matter (246). Biological theories have argued that normal adolescence follows a pattern of synaptic pruning (grey matter reduction; 247) and the gaining of increased levels of myelinated white matter (248). Such changes are believed to enhance more efficient sharing of information within the adolescent brain allowing for increased learning potential.

Although these theories emphasise different aspects of adolescent development (i.e. cultural, cognitive, psychosocial, biological etc.) no single theory can completely capture the notion of 'normal' adolescent development. However, they all highlight the state of flux in thinking, emotional regulation and behaviour that should, if adaptive, eventually result in the achievement of competencies necessary for adulthood.

3.2 'Abnormality' and illness

Defining abnormality is by no means an easy task given the dynamic processes involved in adolescent development outlined above. According to Rosenhan and Seligman (249) abnormality as a concept is dependent on several main features (although these features are not a prerequisite for the application of this label). Firstly, they suggest that an individual must be experiencing some form of suffering. However, critics may point to individuals who lack insight into their condition and do not necessarily feel distressed but create a great deal to those surrounding them. Secondly, abnormal behaviour should be maladaptive in that it prevents individuals from functioning and achieving life goals. The unpredictability and loss of control criterion suggests that it is abnormal to react to certain situations in a way that could not be predicted. Observer discomfort defines abnormality as behaviour that makes others surrounding the individual feel uncomfortable such as family members, friends or general members of the public. This criterion however is double edged as others' distress might help and identify individuals who lack insight into their own self destructive behaviour but pathologises individuals in order to reduce the observers own personal discomfort (228). Finally the breaking of residual social, moral and legal rules and norms is also a criterion of abnormality but some critics such as Becker (250) suggest that norms and rules are defined by educated middle class values. This criterion is therefore used to label and potentially control individuals who do not conform to this way of thinking.

Beyond Rosenhan and Seligman others have attempted to define abnormality using a statistical approach whereby abnormality is identified when something statistically rare is observed in the population. For example individuals with an IQ score below 70 represent the lowest 2% of the population and according to this criterion their intelligence is 'abnormally' low. However this definition is not adequate as it does not take into account whether deviations from the average are desirable or undesirable within society. Using the IQ example again individuals obtaining a score of 130 or above are by the statistical definition 'abnormal' but within western society such a score is seen as 'desirable' and the individual is often described as 'gifted' (a positive label; 251).

Within the psychiatric profession abnormality has been categorised (as is the case with physical illness) using various diagnostic categories for individuals who display various behaviours or symptoms. The dominant modern systems of classification stem from the work of Kraepelin who proposed that certain groups of behaviours or symptoms occur together sufficiently to merit the designation of 'diseases' or 'syndromes'. He in turn went on to try and describe the diagnostic indicators of these syndromes. The two current major classification systems are the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association and the International Classification of Diseases and Health related problems (ICD) published by the World Health Organisation. In defining abnormality the fourth edition of DSM proposes the following:

"A clinically significant behaviour or psychological syndrome or pattern that occurs in a person and that is associated with present distress or disability with a significantly increased risk of suffering death, pain, disability or an important loss of freedom. In addition this syndrome or pattern must not be merely an expectable response to a particular event" (51)

Advocates of the classification of mental illness suggest that grouping individuals together with similar symptoms facilitates our understanding of the causes of the problem and how it should be treated. They also help us simplify and provide a brief and straightforward means of describing complex difficulties (252). However,

critics point to many conceptual weaknesses of this system. Unlike physical illness, mental health problems have highly subjective diagnostic tests which are biased by information from patients and families and also the interpretations of the professional involved. Indeed research suggests that clinicians with similar information often disagree about the exact psychiatric diagnosis to be given (253). Since the dawn of categorisation, studies have shown that symptoms supposedly representative of psychosis result in differential diagnoses with these sometimes highly dependent on the country (UK vs. USA) or diagnostic manual used (DSM vs. ICD).

Another criticism is the validity of these diagnostic categories (are they meaningful and useful?). If a diagnosis is valid it could be argued that it should predict prognosis whilst specified treatments should be effective. For individuals with a diagnosis of schizophrenia the outcome is extremely variable (253, 254) whilst various interventions have had limited success. Pharmacological interventions have been reported to be more effective for treating specific symptoms rather than specific diagnoses (254). Diagnostic categories are also expected to represent illnesses with a known aetiology but in the vast majority of cases this is not the case. Co-morbid problems within mental health are the norm and potentially indicate that many diagnostic categories have some common cause or underlying mechanism. Such co-morbidity blurs the distinction between categories and makes the assessment of aetiological validity difficult. Finally, another way to explore the validity of diagnostic categories is by using statistical techniques to investigate whether symptoms cluster together in a way predicted by a diagnostic approach. For example the correlation amongst psychotic symptoms has been found to be negligible (255) whilst there is an extensive overlap in symptoms between those diagnosed with schizophrenia and those diagnosed with a major affective disorder (256). A novel way of assessing the validity of a diagnosis (by combining aetiology with symptomatology) is proposed by Craddock (257) who argues that if psychosis is a distinct illness with an underlying aetiology, then an affected individual will have several relatives with the same illness but few relatives suffering from any other kind of mental illness (See Bentall [258] for a fascinating critique of the categorisation approach).

Others have suggested that diagnostic categories and manuals are largely adopted for political and economic gain (in terms of controlling certain populations, insurance claims and pharmaceutical sales; 259, 260). A powerful argument against classification is that of labelling theory which according to Scheff (261) heavily stigmatises diagnosed individuals. As a result the person's behaviour is constantly interpreted and perceived within the light of a psychiatric label. However as described previously, diagnosis giving (labelling) can help reduce anxiety (181).

Instead of a categorical approach to mental illness others have advocated the development of a dimensional system of classification. Van Os and colleagues (262) found that symptom dimensions were better at predicting illness course and quality of life than diagnostic categories. Within the field of psychosis this type of approach has led to the psychosis continuum approach whereby more severe symptoms are perceived to be a more severe expression of traits that are present within the general population (263). The presence of psychotic traits in the normal population has been termed 'schizotypy' (264). Such an approach does not draw a clear dividing line between normality and abnormality, nor does it assume that symptoms are always pathological. Non-categorical clinical formulation approaches are commonly employed in clinical settings whereby specific complaints reported by an individual are taken on their own merits and are treated as a phenomenon with its own causes. Efforts are made to try and explain and understand the actual experiences and behaviours (252). Support for this continuum approach has pointed to the frequency of so called 'abnormal' experiences (e.g. hallucinations) within the healthy or functioning population (265) and that individuals who score highly on schizotypy scales resemble individuals with psychotic experiences in several different ways (266). However, the problem with entirely dimensional classifications is that they are said to be of limited practical value in clinical practice where yes/no specific categorization decisions often need to be made (in order to justify adherence to NICE treatment guidelines or in order to obtain funding from commissioners of mental health services; 252).

3.3 Explanations of psychosis: Medical versus cognitive models

In order to explain the development of mental health problems and symptoms of psychosis several models and theories have been proposed. Until recently the most dominant of these has been the medical model which in essence suggests that abnormal behaviours are the result of biological and physical pathologies within the brain and nervous system. These pathologies therefore require medical treatment (267). Within the field of psychosis, early research by Kraepelin focussed upon the use of post mortems to study the 'psychotic' brain. This method of study was limited by the fact that death itself, not even taking into account the cause of death, leads to matter decay and alterations (258). With the vast advancement in technologies, structural magnetic resonance imaging studies, have found significant brain volume reductions in both chronic and first-episode schizophrenia patients. Theories of ventricular enlargement in psychotic patients has seen mixed support (268) but these structures are not uniquely associated with psychosis. Such research and methods fail to take into account that brain abnormalities may be the result of past traumatic experiences rather than a psychotic illness *per se* (252).

In terms of biochemical approaches these initially developed through the accidental discovery that certain drugs not only mimic psychotic symptoms but also lead to reductions in their existence. Albert Hoffman's first synthesis of LSD and its observed effects led others to investigate whether psychosis was actually caused by endogenous hallucinogenic substances (269). Since then the *dopamine hypothesis* has become one of the dominant approaches whereby abnormalities in the dopamine system (uptake and blocking of receptors) are perceived to be responsible (see Toda & Abi-Dargham for a review of this theory; 270). Once again critics have argued that any dopamine abnormalities present in psychotic patients may represent the brains response to past emotional trauma rather than the supposed underlying illness of psychosis (271).

As well as biochemistry and neurology, decades of research have focussed on genetic influences in the development of psychosis based upon the initial observation that the condition runs in families. Various studies have shown that risk

of developing psychosis appears to rise if a parent or close relative is diagnosed (14) but these studies fail to take into account the role played by a shared family environment. If genetic factors do play a role can the gene or genes responsible be identified? Genetic markers on various chromosomes have been suggested but at the moment hold limited support (228).

When these medical approaches are applied to the At-Risk Mental State, studies have indicated grey matter loss in the left inferior frontal region, left medial and inferior temporal regions (156), reduced cortical thickness (272) and potentially greater brain contraction in the right prefrontal region (273). In terms of neuroendocrine explanations, levels of testosterone have been found to be significantly lower in adolescents with ARMS symptoms whilst serotonergic receptor density is also decreased (274). In terms of genetics, the Melbourne Ultra High Risk criteria itself acknowledges a genetic vulnerability criterion group (60).

One alternative to the medical model is the *cognitive model* developed mainly by Ellis (275) and Beck (276). The central notion of this framework is that individuals with a mental health difficulty have distorted or irrational thought processes. In many instances these individuals have a negative inner dialogue which maintains the maladaptive behaviour. In terms of understanding psychosis Garety and colleagues (277) have proposed a model in order to understand the development and maintenance of positive psychotic symptoms. In the first instance a triggering event (such as stress, an adverse life event or illicit drug use) gives rise in a predisposed vulnerable person (of potentially bio-psychological origin) to a disruption of cognitive processes. This cognitive disruption may take the form of impairment in the regulation of stored memories which leads to ambiguous sensory input and intrusion into consciousness of unintended material from memory. A second cognitive disruption within this model implies difficulties with the self-monitoring of intentions and actions which leads to the individual to experience these as alien. The model also argues that many of these processes emerge during a genuine psychotic prodrome whereby individuals at this time experience unfamiliar cognitions that feel external and threatening. However these experiences have not been transformed into full psychotic symptoms. It is emotional changes and social

isolation that also occur during this time because of the triggering event and in response to the anomalous experiences that facilitate this transformation. Social isolation, for example, contributes to the acceptance of psychotic appraisal by reducing access to normalizing explanations (278).

A review of the evidence for biases in cognitive processing in psychotic patients infers a cognitive style characterized by jumping to conclusions, externalizing attributional biases and deficits in understanding social situations and the intentions of others (279). Evidence of these cognitive impairments is also apparent in those who fulfil the ARMS. Broome et al, (280) found that ARMS individuals, when matched with a group of healthy volunteers, demonstrated significantly increased levels of a 'jumping to conclusions' style of thinking (as assessed by the beads task) as well as a significantly reduced working memory and a poorer ability to tolerate uncertainty. While the 'jumping to conclusions style of thinking' has received little further exploration within those with an ARMS label other studies in this population confirm deficits in working and episodic memory as well as executive functions (157, 255, 281). These studies seem to suggest that faulty appraisal of anomalous experiences play a fundamental part in the development of positive symptoms.

Predisposition and vulnerability to cognitive disruption in psychosis could be explained by childhood trauma and unsupportive and inconsistent family environments which may create enduring distorted thinking styles characterised by negative schematic models of the self and the world. Other instances of social adversity may also lead to the development of negative schemas particularly involving social humiliation and subordination that in turn fuel paranoia and negative voice experiences (277). The frequency of lifetime and childhood trauma and its potential causal role in the development of psychosis is well established (282, 283). In terms of the social and family context of psychotic vulnerability the early work of Bateson (284) suggested that parents who communicate with their children in inconsistent patterns may predispose their child to the condition ('the double-bind' hypothesis). In more recent years the concept of heightened expressed emotion (the tendency to express criticism, disapproval and hostility) within families and especially parents has been investigated with the likes of Laing (285)

expanding upon Bateson's initial ideas. Although the role of expressed emotion (EE) is no longer considered to be a significant causal factor, studies have consistently indicated that the presence of a high EE environment is a predictor of relapse in psychotic illness (286, 287). Associated to this research, family approaches, partly targeting EE, have been shown, to be effective in improving long term outcome in diagnosed Schizophrenia (288, 289). Within the ARMS literature two studies report high levels of general lifetime trauma (133, 134) whilst another reports high levels of traumatic bullying (103). Total trauma exposure in one of these studies has also been found to be positively associated with severity of attenuated positive symptoms (133). In terms of family functioning, studies suggest that this is indeed perceived as being impaired in families of those 'at-risk' (137-139). More specifically family functioning is also associated with symptom exacerbation and reduced social functioning in 'at-risk' adolescents (138). The cognitive model therefore proposes that current and past trauma and/or maladaptive family environments may create a predispotion for cognitive disruption or act as a stressor, representing a triggering event.

In terms of symptom maintenance, the cognitive model proposes that feelings of hopelessness, uncontrollability, worry and ruminative processes contribute to this process (290). Metacognitive beliefs are perceived by many to increase the anxiety and distress caused by psychotic symptoms as they are responsible for guiding attention, the execution of worry and ruminative processing as well as interpreting and controlling cognitive events such as unwanted thoughts (136). Two subtypes of beliefs are suggested to exist; positive beliefs (e.g. 'worrying helps me cope') and negative beliefs (e.g. 'worrying thoughts are dangerous'). For example in one study individuals who held negative beliefs about paranoia were found to experience more distress than those with positive beliefs (291). If these processes are indeed true then individuals with psychosis, ARMS or distressing psychotic symptoms should demonstrate heightened or maladaptive meta-cognitions compared to health controls. Evidence is already available to support the relationship between such beliefs and several psychiatric disorders (i.e. generalised anxiety, depression). Morrison et al (136) hypothesised that people with psychosis should have higher

levels of unhelpful metacognitive beliefs than people with ARMS who in turn should have higher levels than other controls. This could present as higher scores on one or both dimensions of beliefs (positive and/or negative). The findings of this study confirmed that psychotic individuals exhibited significantly higher levels of positive metacognitive beliefs about worry whilst psychotic and ARMS individuals exhibited higher levels of negative beliefs. These findings were confirmed in a smaller study whereby ARMS individuals demonstrated differences to non-patients on all negative dimensions of metacognitions but not in levels of positive beliefs about worry (292). The authors concluded that negative beliefs about thoughts may be initial causal factors whilst positive beliefs about worry contribute to escalation and persistence of symptoms leading to full psychosis. These studies are, however, limited by the inability to control for, or measure, the levels of anxiety and depression within their samples. Thus, these results may reflect concurrent emotional distress rather than characteristics of those with an ARMS. Given the heightened co-morbidity levels for those identified with an ARMS (69, 88, 89, 103, 116) this is an issue which would be worthy of further investigation.

The cognitive model, like the medical model, suggests the possibility of plausible psychological treatments for psychosis. For example, Cogntive-Behaviour Therapy (CBT) aims to change the appraisal bias and negative self-schemata that exist. Events previously appraised as externally caused are re-appraised as inner experiences, reflecting improved reality testing. Based on previous findings, Metacognitive beliefs should also be targeted and this is indeed how the investigators of the Early Detection and Intervention Evaluation (EDIE) trial developed their treatment manual (292). Family interventions may also have a role as they have been shown to improve social functioning. They may also work by reducing environmental stress and improving associated affect. Indeed a principal focus of family work is to replace critical behaviour that may increase anxiety and depression, with supportive relationships and perceptions, that would help reduce distress. A supportive family environment could also lead to a higher quality of communication and discussion of psychotic experiences leading to the exposure to normative explanations of experiences (277).

3.4 The At-Risk Mental State as abnormal behaviour requiring categorisation

In answering the question whether individuals fulfilling ARMS criteria should be labelled as being mentally ill, it is useful to revisit Rosenhan and Seligman's earlier descriptions (249). Indeed from the literature previously discussed there is little argument that ARMS individuals experience distressing psychotic-like experiences, reduced quality of life and psychosocial functioning (69, 88-90, 100, 101). Another criterion, observer discomfort, defines abnormality as behaviour that makes others surrounding the individual feel uncomfortable such as family members, friends or general members of the public. This criterion too is potentially supported by the observation that a high proportion of referrals to 'at-risk' services come from education providers and family members rather than being instigated by the individual themselves (49, 112). Finally the breaking of residual social, moral and legal rules and norms is also deemed to be a criterion of abnormality. In this regard self-harm, suicide attempts and antisocial behaviour could be behaviours perceived to lie outside the bounds of normality. Indeed, one study has reported a higher than average frequency of suicide attempts in those with ARMS (132) whilst another has observed increased rates of antisocial behaviour amongst adolescents who report psychotic like experiences (293). Illness, as defined by the medical model, assumes underlying irregularities in biochemistry and neuoranatomy. Within the ARMS literature there is already some evidence as previously discussed of neurological and biochemical abnormalities (156, 272, 273). As for the cognitive model, ARMS individuals have also been found to have 'abnormal' or maladaptive belief systems that appear to be beyond the 'normal' range when directly compared to healthy controls and other psychiatric help seekers (136, 157, 255, 280, 281).

However, it is possible to generate several counter-arguments to this suggestion of abnormality and illness. Although it has been suggested that individuals with ARMS demonstrate personal suffering, observations within some 'at-risk' clinics describe mixed findings. For example some young people presenting to the PACE clinic acknowledged elements of personal suffering and a potential illness, whilst others demonstrated concern, scepticism and denial to the news indicating that they

did not perceive themselves to be ill (159, 179). In terms of the unpredictability criterion it could be argued that attenuated psychotic-like experiences in those with ARMS could have been predicted given the high level of past and current trauma experienced.

In terms of the statistical norm, psychotic-like experiences could be part of normal adolescent development. In one study of 657 high school students, around 10-15% reported clinically significant prodromal symptoms as defined by DSM-III-R (205). In addition 51% of students reported experiencing brief symptoms of magical thinking whilst 46% reported unusual perceptual experiences. From a developmental prospective, attenuated symptoms in adolescents may not be indicative of risk for psychosis or illness but perhaps an alternative reaction to the normal stressors and transitions of adolescent life (storm and stress). Indeed Harrop and Trower (174) found that more psychologically mature adolescents (i.e. those demonstrating greater parental autonomy) displayed more prodromal symptoms. These quasi-psychotic experiences may therefore represent some kind of bereavement response to the natural process of gaining greater personal freedom and autonomy from one's parents (174).

Cognitively, adolescents naturally progress from concrete thinking styles to formal reasoning whereby they start to consider hypothetical and alternative possibilities. As previously stated a negative by-product of this is process is conceptual egocentrism whereby the young person is preoccupied with themselves and tied to a personal view point. It is easy to see how this normal developmental process, taken to the extreme, could be interpreted as attenuated ideas of reference or grandiose beliefs (174). Anatomically, although studies have demonstrated supposed brain abnormalities in those 'at-risk' (156) the observed grey matter reduction may not be pathological but, rather, developmental in nature since grey matter reduction and synaptic pruning is the norm within adolescent brain maturation (247).

Many individuals argue that the basis of a diagnosis requires an agreed aetiology, symptom profile, course of illness and treatment preference. Firstly, it is possible to see that the research into the possible aetiology of the ARMS is in its infancy and

medical and cognitive models are just some of the potential mechanisms currently being investigated and discussed. Both of these models have demonstrated potentially supportive findings but an agreed aetiology appears distant (although this is still the case with many other diagnoses including psychosis itself). In terms of what constitutes an ARMS and which criteria (Melbourne ultra-high risk, Basic symptoms approach, Criteria of Prodromal Syndromes) or assessment tools to utilise (CAARMS, SIPS/SOPS, SPI-A) is in itself contested and varies greatly between countries and research groups (60, 72, 77, 78). As for the natural course of an ARMS some studies suggest a high degree of symptom remission and improved functioning over the short term for many individuals (106) however earlier studies have indicated high conversion to psychosis and escalation of symptoms (60, 93). Finally the variety of interventions previously offered, the limited number of randomized controlled trials undertaken and the lack of clear national and international guidelines on treatment approaches indicate a far from clear treatment preference at this time.

The need to consider the ARMS as an illness worthy of diagnosis or an example of normal maturational processes is highlighted by the proposed inclusion of a Psychosis Risk Syndrome in DSM-V which may have profound affects for patients, clinicians, families and society in general. Based on the literature to hand and the author's clinical experience, it is the author's belief that the ARMS may probably represent a potentially useful diagnostic entity. As discussed previously, individuals identified thusly appear to have distressing psychotic and other psychiatric symptoms alongside significant impairments in psychosocial functioning. Therefore, this group of help-seeking individuals, who are not psychotic, but are indeed 'ill', warrant assessment, identification and some form of treatment or support. Within the literature, however, and the psychiatric field as a whole there has been no attempt to formally investigate the potentially stigmatising affects associated with the current ARMS label or any other subsequent diagnostic term. At this time the potential affects and arguments for and against labelling are purely speculative in nature and based on observations from other areas of medicine and psychiatry. It is therefore the aim of the studies embedded within this thesis not only to confirm the symtomatology and level of disability within an 'at-risk' adolescents

sample but also to investigate the positives and negatives associated with the application of the ARMS term from the perspective of affected young people and the mental health professionals working within the field.

4 Follow-up of the At Risk Mental State (FARMS) project: Study 1

4.1 Introduction and Aims

Individuals with an ARMS present to services with substantial impairments in functioning, symptomatology and quality of life (69, 88-90, 100, 101). The majority of these individuals usually experience distressing sub-threshold or attenuated symptoms of perceptual disturbances and ideational anomalies (60, 93, 95). Possible mechanisms explaining the development, maintenance and distress associated with these sub-threshold symptoms have been suggested and include maladaptive family relations (66-68) and metacognitive beliefs (136). Several studies confirm that a high proportion of those identified with ARMS also fulfil the criteria for another Axis I diagnosis. The most prevalent co-morbidities appear to be related to mood, anxiety and substance misuse (69, 88, 89, 103, 116). Given these difficulties it is not surprising that suicidal ideation is potentially common within this group (132).

In terms of following up individuals who have been identified as having an ARMS it appears that the majority of individuals do not become psychotic over the short term. For studies using the Melbourne criteria, rates appear to be declining (62) with one clinical service in the UK demonstration a transition rates of around 10% (69). Because of this decline, studies have started to record the number of individuals with a sustained ARMS status or even a full remission of symptoms (106, 111). One study controlling for treatment effects, has indicated that 50% of patients demonstrated significant improvements in social and role functioning after an 8 month follow up period (147). In terms of which factors significantly predict transition to psychosis, numerous areas are being investigated although poorer functioning at baseline appears to be an important factor (60, 92, 93, 148, 149). What is also apparent is that the period of maximum risk of transition is usually within the first six months after identification (60, 62).

In spite of this previous research, we do not understand how adolescents with ARMS present and experience their condition since relevant studies are generally small scale and adopt highly variable samples (110, 209-211). Obtaining detailed knowledge about this age group is extremely important given that they may be more sensitive to the effects of wrongful identification (1, 170). The following study is therefore required to investigate the presentation and the short term outcomes of adolescents identified as having an ARMS.

4.1.1 Research Aims

The two primary aims of this study were as follows:

a) To conceptualise how adolescents identified as having an ARMS present to mental health services in terms of symptomatology, psychosocial functioning and psychiatric co-morbidity.

b) To investigate and describe the short term (six month) outcomes of adolescents identified as having an At-Risk Mental State for psychosis.

4.1.2 Research Objectives

The principal objects of the study were:

a) To quantify the current levels of symptomatology, psychosocial functioning and psychiatric co-morbidity in adolescents identified as having an ARMS presenting to mental health services.

b) To evaluate the outcome for such young people at 6 months after identification in terms of symptomology, functioning and psychiatric disorder.

4.1.3 Research Hypotheses

Based upon analysis of the previous literature, the following hypotheses were generated for testing within this study:

1. Adolescents with an ARMS will have a significantly negative view of Family perceptions/functioning, compared to a normative sample of adolescents (as measured by the Family Perceptions Scale).

2. Negative perceptions of family functioning will be significantly associated with symptom distress and intensity (as measured by the Family Perceptions Scale and Comprehensive Assessment of At-Risk Mental States).

3. Adolescents with an ARMS will have significantly higher (maladaptive) Metacognitive scores when compared to an existing normative sample (as measured by the Metacognitions Questionnaire).

4. Metacognitive scores will be significantly associated with symptom distress and intensity (as measured by the Metacognitions Questionnaire and Comprehensive Assessment of At-Risk Mental States).

5. Transition to psychosis and maintenance of an ARMS at six month follow up will be associated with lower (maladaptive) psycho-social functioning scores at baseline assessment (as measured by the Children's Global Assessment Scale).

4.2 Methodology

Study Design

The following study adopted a prospective longitudinal repeated measures study design to conceptualise how adolescents initially present to services and progress over the short term. A flow chart conceptualising how adolescents were recruited and followed up throughout the study can be seen in Figure 1.

Recruitment

For the purposes of recruiting individuals into this longitudinal study, the author, with the help of several colleagues, established the Follow up of the At-Risk Mental State for Psychosis (FARMS) Clinic based within the Tees, Esk and Wear Valleys (TEWV) NHS Foundation trust. The trust provides a range of mental health, learning disability and substance misuse services for over 1.3 million people living in County Durham, Tees Valley and the Scarborough, Whitby and Ryedale areas of North Yorkshire. Services are delivered by working in partnership with seven local authorities and primary care trusts and are spread over a wide geographical area which includes coastal, rural and industrial areas. The FARMS clinic was served by one Assistant Psychologist (the author) who was employed by the trust's Early Intervention in Psychosis (EIP) service and a Consultant Psychiatrist working in Child and Adolescent Mental Health Services (CAMHS). The remit of the clinic was specifically for the assessment of adolescents suspected of fulfilling the ARMS criteria.

Recruitment was undertaken on a referral and assessment basis. Mental health professionals working within TEWV CAMHS and EIP services were asked to contact a member of the FARMS team if they suspected a young person in their care was currently displaying symptoms consistent with an ARMS. To aid identification and help clinicians decide whether to make a referral to the clinic, informal training and a short screening measure was offered to all CAMHS and EIP

teams before study commencement. An information booklet incorporating this screening tool and contact details about making a referral is included in Appendix 1. Before referrals were accepted and arrangements made to assess the young person in question, a telephone consultation took place between a member of the FARMS clinic and the referrer. This acted as an initial screening stage to ensure accepted referrals were likely to meet the study's inclusion criteria.

Inclusion Criteria

To be eligible for assessment at the FARMS clinic, and therefore possible study inclusion, young people had to be:

- Under the care of CAMHS or EIP services in TEWV NHS trust at the time of referral.
- Aged between 12 to 18 years of age at commencement of the initial assessment session.

Potential participants were excluded from study entry if they were known to have a significant learning disability (IQ<70). Individuals with a known history and/or on-going substance misuse were not excluded.

As well as meeting the above criteria, eligibility for study inclusion was eventually decided after conducting a full clinical assessment at the FARMS clinic. A typical assessment usually lasted two to three hours and spanned two to three clinical sessions. To be eligible, individuals had to be identified as having an At-Risk Mental State as defined by the Melbourne criteria. This decision was aided by the scores obtained during the administration of the Comprehensive Assessment of At-Risk Mental States (CAARMS; 65) assessment tool and other information collected during the assessment. The final decision however required an overall agreement from both members of the FARMS research team and the young person's CAMHS or EIP care co-ordinator.

Baseline Assessment Measures

All individuals accepted for initial assessment by the FARMS Clinic were asked to complete a battery of assessments (a summary table of all the assessments used can be seen in Table 2 whilst paper copies can be found in Appendix 2). Assessment measures were administered by the author with additional support at times from the FARMS Consultant Psychiatrist and/or the young person's CAMHS or EIP care co-ordinator. All assessments were completed within a one month time frame.

The Comprehensive Assessment of At Risk Mental States (CAARMS) is a semi-structured interview designed specifically for the assessment of help seeking individuals suspected of having ARMS (65). It measures a range of 'positive' psychotic like symptoms (under the sections of *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* and *Disorganised Speech*) as well as other general symptoms thought to be indicative of imminent psychotic disorder (i.e. negative, dissociative and 'basic' symptoms). During assessment the intensity, frequency, duration and distress related to the reported symptoms are rated on a likert scale to classify individuals via the Melbourne UHR criteria. For this study a modified version of the CAARMS was used to avoid repetition of assessments. This incorporated all questions from section one (Positive symptoms), section two (Cognitive change attention/concentration) and questions referring to mania (section seven, General psychopathology) from the original CAARMS interview. The decision to use the CAARMS as opposed to another measure was based on its reliability, validity and widespread use in UK clinical practice and research (68-71).

As previously discussed, the ratings obtained on the CAARMS were used as an aid to determine if the young person under assessment was currently presenting with an ARMS, a first episode of psychosis or neither of these conditions. Using the CAARMS, individuals scoring within the parameters described below were assigned into at least one of the following ARMS groups:

GROUP 1 (Vulnerability Group): Individuals were assigned to the vulnerability group if they were known to have a family history of psychosis in a first degree relative. In addition, the young person also had to demonstrate a recent decline in functioning or a sustained period of chronically poor functioning.

GROUP 2a (Attenuated Psychosis Group; Sub-threshold intensity): To be deemed as having psychotic-like symptoms of sub-threshold intensity individuals had to obtain; a CAARMS global rating scale score of 3-5 on the *Unusual Thought Content* subscale, 3-5 on the *Non-Bizarre Ideas* subscale, 3-4 on the *Perceptual Abnormalities* subscale AND/OR 4-5 on the *Disorganised Speech* subscale. In addition to this a frequency scale score of 3-6 on *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* and/or *Disorganised Speech* subscales for at least a week had to be reported. If reported symptoms were not as frequent, a frequency scale Score of 2 on *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* and *Disorganised Speech* subscales occurring on more than two occasions (experienced a minimum of four times in total) was accepted. The rated symptoms had to have been experienced in the past twelve months and again associated with a period of declining or chronic functioning.

GROUP 2b (Attenuated Psychosis Group; Sub-threshold frequency): To be deemed as having psychotic-like symptoms of sub-threshold frequency individuals had to obtain; a CAARMS global rating scale score of 6 on *Unusual Thought Content,* 6 on *Non-Bizarre Ideas*, 5-6 on *Perceptual Abnormalities* AND/OR 6 on the *Disorganised Speech* subscale. In addition to this, a frequency scale score of 3 on *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* and/or *Disorganised Speech* subscales had to be obtained. The rated symptoms had to have been experienced in the past twelve months and again associated with a period of declining or chronic functioning.

GROUP 3 (BLIPS Group): To be deemed as meeting the BLIPs criteria a CAARMS global rating scale score of 6 on *Unusual Thought Content* subscale, 6 on *Non-Bizarre Ideas,* 5 or 6 on *Perceptual Abnormalities* subscale AND/OR 6 on *Disorganised Speech* subscale had to be obtained. In addition, a frequency scale

score of 4-6 on *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* AND/OR *Disorganised Speech* subscales had to be apparent. These symptoms had to have occurred in the past twelve months, lasted no longer than a week in duration and spontaneously remitted. Again, these symptoms had to be associated with a period of declining or chronic functioning.

Thus, in all groups a period of chronically poor functioning or declining functioning had to be observed alongside positive symptoms or certain vulnerabilities. Deteriorating functioning was defined as a 30% drop from premorbid level in scores obtained on the Children's Global Assessment Scale (C-GAS, 294), sustained for a month, occurring within the past 12 months. Chronically low functioning was defined as a C-GAS score of 50 or less for the past 12 months or longer.

Individuals demonstrating chronic poor functioning and CAARMS scores above the parameters set were deemed to be potentially psychotic. However, the final decision regarding illness status was made via consensus between both members of the FARMS clinic and the young person's care co-ordinator. Individuals demonstrating high levels of functioning and/or scores below these parameters were deemed to be neither 'at risk' nor psychotic.

For the purposes of this study clinically significant positive symptoms were defined as those scoring a global rating score of 3 or more on the CAARMS. Duration of untreated illness was defined as the time between the onset of a clinically significant positive symptom and the date of baseline assessment. A symptom intensity score was calculated for the positive symptoms sections (*Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* and *Disorganised Speech*) by combining the global (severity) rating (0-6) score and the frequency and duration (0-6) score in the following manner: Global Rating x Frequency and Duration = Intensity (0-36).

The Children's Global Assessment Scale (C-GAS; 294) is an adaptation of the Global Assessment of Functioning Scale and is a reliable and valid global measure of functioning and disability for children under 18 years of age (294, 295). Levels

of functioning are assessed against a 100 point scale with lower scores denoting poorer functioning. The C-GAS was used as an overall measure of functioning which assisted with categorising the participants into the above listed ARMS groups. The decision to use the C-GAS as opposed to another measure of functioning was based on its readily available nature, it applicability to an adolescent population and its widespread use by mental health practitioners within the UK. Additional information collected in order to derive this score was obtained using a functioning matrix specifically designed to record adolescents' social (frequency of contact with peers, romantic relationships, general social skills) educational/occupational (performance and grades, attendance and conduct) and practical functioning (self-care, levels of independence and vulnerability) within the previous two years. Information for the matrix was gathered from the young person and/or their parents/significant other.

The Development and Well-Being Assessment (DAWBA; 296) is a package of questionnaires, interviews and rating techniques designed to generate International Classification of Diseases (ICD-10; 11) and Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV; 51) psychiatric diagnoses for children and adolescents aged between 5-18 years. Unlike other adult assessment instruments such as the Structured Clinical Interview for DSM-IV (SCID; 118) the DAWBA primarily focuses on the emotional, behavioural and hyperactivity disorders associated with childhood and adolescence. For the purposes of this study the DAWBA was administered on a face to face basis with the young person and on occasions with one of their carers. Although other adolescent specific diagnostic assessments exist such as the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS; 212, 297), the DAWBA was chosen because of its previous clinical and research applications in the UK (298). During a pilot administration before study commencement, the DAWBA demonstrated acceptable levels of engagement and generated sufficient data to make informed diagnostic decisions. The whole process was aided and facilitated by the ability to score and review the assessments online.

For the purposes of this study the DAWBA was utilised as a means of generating

current co-morbid mental health diagnoses using the ICD-10. Information was collected from several sources where possible since it has been reported that data derived from multiple informants if assimilated correctly can increase the accuracy of diagnostic estimates (299). Direct observations and information was obtained from the young person as well as reports from the young person's parent(s) and occasionally teachers/school counsellors (where possible). Historical information was obtained from the young person's medical notes (again where possible).

To ensure a rigorous methodological approach to diagnosis, principles of the best estimate procedure were adopted (299). In order to derive diagnoses using this method both members of the FARMS research clinic independently made diagnostic decisions based on the information to hand. Both were kept blind as to each other's decisions until a diagnostic review meeting was undertaken often involving the young person's care co-ordinator. Once at this meeting diagnoses were compared. In instances where there was disagreement, discussion took place between both researchers and the care co-ordinator in order to reach consensus and a final decision.

After generating final diagnoses a multi-axial framework based upon the ICD-10 classification system was utilised as a means of profiling the young person's difficulties (300). Multi-axial systems of classification according to Taylor and Rutter (301) are the norm in child and adolescent psychiatry as it ensures clinicians are not forced to choose between two diagnoses that do not constitute meaningful alternatives. Secondly multiple axes provide more complete and less ambiguous information. They also provide a more complete clinical picture informing clinicians about possible causal factors or factors likely to influence prognosis or treatment efficacy. The ICD-10 Multi-axial framework is outlined in Table 1.

Table 1. Summary of ICD-10 Multi-axial framework

Axis	Description
Axis I: clinical psychiatric syndromes.	Criteria for particular diagnoses were applied as described in ICD-10. In order to handle multiple diagnoses this axis was further divided into 1a and 1b with the former representing the primary diagnosis (the most significant psychiatric complaint) and the latter a secondary diagnosis.
Axis II: Specific disorders of development	These included speech and language, reading, spelling and motor developmental problems such as dyslexia and dyspraxia.
Axis III: Intellectual level.	This categorises generalised learning disability into mild (IQs between 70 and 50) and severe (IQs below 50).
Axis IV: Associated medical conditions	All potentially relevant medical conditions outlined during the assessment and obtain from the young persons medical notes were included.
Axis V: Associated abnormal psychosocial conditions	These included a range of psychosocial hazards, acute life events and chronic interpersonal distress. Examples of conditions coded included marital breakdown, past physical or sexual abuse, mental health problems in close family members and significant bullying.

The Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) is an outcome measurement tool that assesses behaviours, impairments, symptoms and social functioning of children and adolescents with mental health problems. Thirteen clinical features are rated on a five point severity scale using information obtained from the young person and/or their parent/carer. The HoNOSCA has demonstrated good acceptability for use in clinical settings

(302) and good reliability and validity (303-305). The HoNOSCA was adopted for this study since it is the most commonly used outcome measure for Children and Adolescents accessing mental health services in the UK.

The Young Mania Rating Scale (YMRS; 306) is a diagnostic questionnaire used to measure the severity of manic symptomatology in children and adolescents between the ages of 5 and 17. Eleven items are rated and scored based upon the patient's reported and observed symptoms over the past 48 hours. Higher scores indicate more severe symptoms with scores of 12 or more indicating a significant clinical profile of mania. For the purposes of this study the YMRS was only administered when individuals were rated as scoring a severity score of 2 or more on the Mania section within the CAARMS or elevated or persistently irritable mood had been previously reported in the person's medical notes or mentioned by their treating clinician. In the instances where these conditions were not met and therefore the YMRS was not administered, the young person was assigned an arbitrary score of zero on the scale.

The Hamilton Depression Rating Scale (HDRS/HAM-D; 120) is the most widely used clinician administered assessment of the severity of depressive symptoms (307). Seventeen items relating to symptoms of depression are rated and scored based upon the patient's reported and observed symptoms over the past 48 hours. Higher scores indicate more severe symptoms with scores of 7 or below generally accepted to be within the normal range. Scores of 8-17 indicate mild depressive symptoms whilst scores of 18-24 indicate at least a moderate severity. The reliability and validity of the HAM-D have been extensively investigated. The instrument was selected for this study partly due to the focus on biological symptoms which may be more characteristic of the depression associated with psychosis. Other measures of depressive symptomatology were considered such as the Mood and Feelings Questionnaire although the tool is not validated for older adolescents (308). For the purposes of this study the HDRS was only administered when individuals answered 'yes' to the initial depression screening questions of the DAWBA or when symptoms of low mood had been previously reported in the person medical notes or mentioned by their treating clinician. In the instances where

the HDRS was not administered for the aforementioned reasons the young person score was assigned a score of zero.

The Family Perceptions Scale (FPS; 309) is a 29 item self-report questionnaire used to assess a young person's perceptions of their family functioning. Scores are obtained in relation to *Overall Family Functioning* and for the subscales of *Nurture, Problem Solving, Expressed Emotion, Behavioural Boundaries* and *Responsibility*. The FPS demonstrated high levels of internal consistency, high test-retest reliability and has concurrent validity with other widely used self-report measures of family functioning.

The Substance Use Record (created for this study) was a clinically administered schedule used to record information relating to patterns of alcohol, cigarette and other illicit substance consumption. Information is recorded both for current and past (previous six months).

The Metacognitions Questionnaire short form (MCQ-30; 310) is an instrument for assessing maladaptive metacognitions, composed of five dimensions: *cognitive confidence, positive beliefs about worry, cognitive self-consciousness, negative beliefs about worry* and *need to control thoughts*. The psychometric properties of the MCQ-30 have been previously reported, suggesting that it is a valid instrument for evaluating metacognitive style in clinical research.

The Social & Communication Disorder Checklist (SCDC) is a brief and effective screening measure for pervasive developmental disorders completed by a parent, carer or another significant family member. Ratings are obtained in relation to the young person's observed behaviours around the time of their tenth birthday. Twelve questions are scored on a three point likert scale with higher scores indicating symptoms worthy of further assessment (311). The SCDC does not provide a clinical diagnosis but aids the decision making process as to whether a more in depth assessment is required. The SCDC demonstrates good test-retest reliability over a two year period and high internal consistency (Cronbach's α coefficient 0.93). Content validity was assessed against items used in standardised interviews such as

the Autism Diagnostic Interview and 3di. Discriminant validity between pervasive developmental disorder and other clinical groups was good, although discrimination from non-clinical samples was better (Sensitivity 0.90; Specificity 0.69; 312).

Table 2. Summary table of baseline assessment measures

Assessment Measure (acronym; reference)	**Format**	**Symptom Measurement**	**Scale**	**Reliability/Validity**
Comprehensive Assessment of At-Risk Mental States (CAARMS; 65)	Semi-structured interview	Severity and frequency of positive psychotic symptoms & negative, dissociative and 'basic' symptoms.	Likert scale for all items: Global Rating (0-6) Frequency (0-6) Distress (0-100)	Inter-rater reliability (rho =0.62-0.93). Sensitivity (0.83), Specificity (0.74), Positive Predictive Value (0.12), Negative Predictive Value (0.99).
Children's Global Assessment Scale (C-GAS; 294)	Rating scale (information obtained via overall clinical assessment)	Global measure of psycho-social functioning	Likert scale (0-100) with lower scores denoting poorer functioning.	Inter-rater reliability (rho =0.84), test retest reliability (rho =0.85). Concurrent validity (rho =0.58, $p < 0.001$; Achenbach Child behaviour Checklist).
The Development and Well-Being Assessment (DAWBA; 296)	Semi-structured diagnostic interview	Severity and frequency of common childhood psychiatric diagnoses (International Classification of Diseases; ICD-10)	Use of various nominal scales/questions & inclusion/exclusion criteria.	Inter-rater reliability (κ =0.70). Sensitivity (0.92), Specificity (0.95), Positive Predictive Value (0.83).
Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA; 303-305)	Questionnaire (completed by young person and/or Parent)	Global assessment of behaviours, impairments and symptoms associated with childhood mental health problems	Likert scale for all items (0-4). Higher scores denote more severe symptoms. Total score (0-52).	Inter-rater reliability (rho =0.63-0.98), test retest reliability (rho =0.69). Concurrent validity (rho =0.32-0.51, $p < 0.001$;Strength & Difficulties questionnaire & C-GAS).

Young Mania Rating Scale (YMRS; 306)	Semi-structured interview	Severity of manic symptomatology	Total score (0-60). Score of ≥12 indicate a significant clinical profile of mania	Inter-rater reliability (rho =0.93). Concurrent validity (rho =0.71-0.89, $p < 0.001$; Beigel Scale and Petterson Scale)
The Hamilton Depression Rating Scale (HDRS/HAM-D; 120)	Semi-structured interview	Severity of depressive symptoms	Total score (0-53). Score of ≥8 indicates at least a mild depressive episode	Internal consistency (Cronbach's α =0.48-0.92), test retest reliability (rho =0.81-0.98). Convergent validity (rho =0.27-0.89, $p < 0.05$; Beck Depression Inventory). Sensitivity (0.45-0.88), Specificity (0.75-0.99), Positive Predictive Value (0.37-0.99).
Family Perceptions Scale (FPS; 309)	Questionnaire (completed by patient)	Global assessment of family functioning	Likert scale for all items (0-4). Lower scores indicate poorer family functioning.	Internal consistency (Cronbach's α =0.70-0.81), test retest reliability (rho =0.70-0.82). Concurrent validity (χ^2= 27.2-196.4, $p < 0.0001$; McMaster Family Assessment Device)
Substance Use Record	Semi-structured interview	Current and past levels of alcohol, cigarette and other illicit substance consumption.	Use of various nominal scales/questions.	Not validated at this time (i.e. bespoke for this study)

Metacognitions Questionnaire short form (MCQ-30; 310)	Questionnaire (completed by young person only)	Assessment of Metacognitive thinking styles	Likert scale for all items (0-4). Total score (30-120). Higher scores indicate more maladaptive thinking styles.	Internal consistency (Cronbach's α =0.93), test retest reliability (rho =0.75). Convergent validity (rho =0.19-0.54, $p < 0.05$; Padua Inventory & Penn State Worry Questionnaire).
Social & Communication Disorder Checklist (SCDC; 312).	Questionnaire (completed by parent only)	Screening measure for pervasive developmental disorders	Likert scale for all items (0-2). Total score (0-24) with higher scores indicating more severe symptoms requiring further assessment.	Internal consistency (Cronbach's α =0.93), test retest reliability (rho =0.81). Sensitivity (0.90), Specificity (0.69), Positive Predictive Value (0.75).

Follow-up Assessment measures

At six month follow up, individuals agreeing to a face to face psychiatric assessment were assessed using the CAARMS (Positive symptoms scale only), the C-GAS or GAF (depending upon age at follow up) and the HoNOSCA (in order to capture other symptom dimensions). Medical notes and information obtained from the young person's CAMHS or EIP care co-ordinator were also reviewed to see if the young person had made a transition to a first episode of psychosis before this time point. After assessment, a review process (conducted by both members of the FARMS clinic and the young person's care co-ordinator) was undertaken whereby individuals were then judged to meet one of three categories:

1. ARMS – Individuals were still deemed to fulfil the ARMS criteria if they reported significantly poor functioning (C-GAS/GAF ≤ 75) present for at least the previous two months. In addition, individuals had to report significant positive psychotic-like symptoms as measured by the CAARMS. Significant psychotic-like symptoms were defined by the scoring parameters adopted previously during baseline assessment. Individuals could not have been diagnosed as having a first episode of psychosis before the review assessment.

2. Psychotic – Individuals were deemed to be psychotic if they demonstrated extremely poor functioning and both intense and frequent significant positive symptoms as indicated by the CAARMS and observed by all those involved in the young person's subsequent care. These individuals would therefore be judged to require treatment with anti-psychotic medication.

3. Partial or Full remission – Since remission is a relatively new concept and has not been outlined or defined explicitly by users of the CAARMS, a definition was proposed by the FARMS clinic. Individuals were deemed to have reached 'Functional Remission' if they still presented with significant psychotic-like symptoms reaching the criteria for an ARMS but had demonstrated a significant improvement in current functioning. A significant

improvement of functioning was defined as a C-GAS/GAF score of ≥ 76 sustained for a period of two months prior to follow up assessment. Individuals were deemed to have reached 'Symptom Remission' if they no longer demonstrated significant psychotic-like symptoms (i.e. those fulfilling baseline criteria for an ARMS) but reported no significant improvement in functioning. Psychotic-like symptoms had to have remitted for a period of at least two months prior to the follow-up assessment. Finally, individuals were deemed to have reached a 'Full Remission' if both the 'Functional' and 'Symptom Remission' definitions were met (i.e. a significant improvement in psychotic-like symptoms no longer reaching the threshold for an ARMS and a significant improvement in function as indicated by a C-GAS/GAF score of ≥ 76 sustained for a period of two months prior to follow-up assessment). Once again clinically significant positive symptoms were defined as those scoring a global rating score of 3 or more on the CAARMS.

Assessment training and reliability

Both members of the FARMS clinic undertook individual and group training for the assessment and scoring of the C-GAS, HoNOSCA, HDRS and YMRS prior to study commencement. Individual training involved the use of approved clinical case vignettes for the C-GAS and HoNOSCA (313) whilst group training was undertaken for all of these measures as part of a mandatory training requirement for working with children and adolescents within the sponsoring NHS trust (training standards set by the CAMHS Outcomes Research Consortium; CORC). In terms of training and experience of using the CAARMS, the FARMS Consultant Psychiatrist had undergone significant training and was recognised nationally and within the locality as an accredited CAARMS trainer. The author received one to one and group teaching and supervision for a period of six months prior to study commencement from the psychiatrist, gaining 'live' experience within local Child and Adolescent and Early Intervention in Psychosis services. Both individuals also attended an intensive one day work shop held at Manchester University and facilitated by one of the authors of the CAARMS (Professor Alison Yung). In terms of administering the DAWBA both members were self-taught although both had previous experience of

administering structured diagnostic interview schedules. Familiarity with the questions and structure of the DAWBA was obtained by administering the assessment measure during routine clinical work several months prior to the study commencement.

In order to ensure good inter-rater reliability by both members of the FARMS research clinic, the first six assessments conducted at the clinic were conducted by both members of the research team. After each of these assessments, scores and ratings (for the CAARMS and C-GAS) were compared to ascertain level of agreement. At times of disagreement in relation to scores, discussion took place in order to reach a consensus. After this, assessments were in the majority of cases, conducted by the author with the support of the young person's CAMHS or EIP care co-ordinator. Scores and rating were reviewed and discussed with the FARMS Consultant Psychiatrist at a weekly supervision meeting. In some instances assessment sessions were recorded with the young person's permission and analysed and used for training purposes within the Early Intervention in Psychosis service. To ensure the CAARMS was rated consistently throughout the study joint assessments were conducted by both members of the FARMS Clinic on a quarterly basis (every three months). To ascertain inter-rater reliability for the CAARMS a linearly weighted kappa was conducted using the individual rating scores obtained during all joint assessment sessions. The results demonstrate good levels of reliability (κ= 0.75). Inter-rater reliability scores were not recorded for the CGAS and HoNOSCA, although good inter-rater reliability had been achieved previously during mandatory/CORC training.

Ethics and ethical considerations

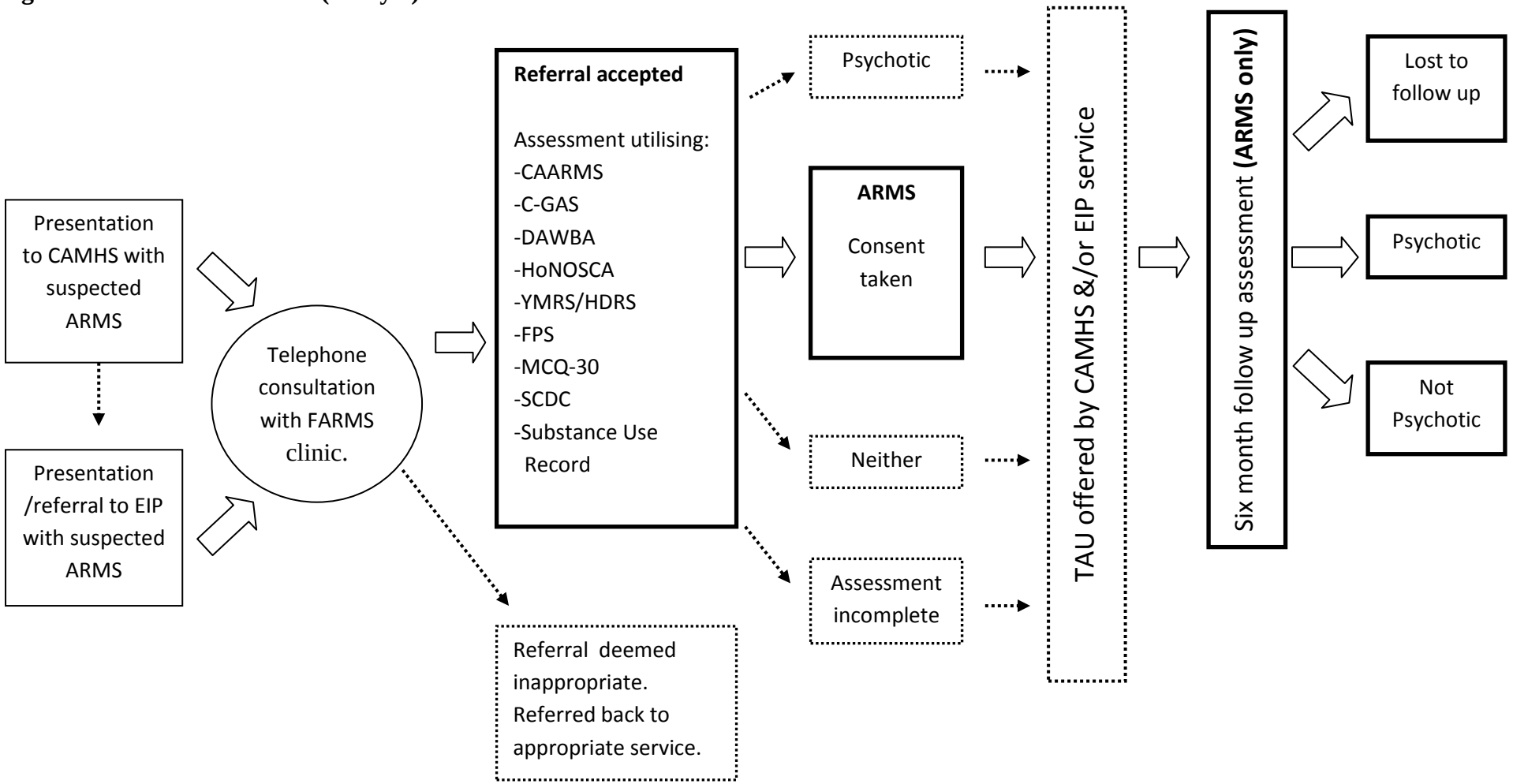
Ethical approval for the study was granted by Durham University, School of Medicine and Health Ethics Committee and the NHS National Research Ethics Service for County Durham & Tees Valley 2 Committee (Copies of University and NHS ethical approval can be seen in Appendix 3).

Informed consent was obtained from all participants at baseline assessment and in the case of younger adolescents (those below 14 years of age) and children under the care of the local authority consent was also obtained from a parent/carer/significant family member with parental responsibility. Consent was also taken in advance for permission to contact participants, their care co-ordinators and review medical notes at the six month follow-up stage. Individuals were given at least a week to make a decision about participation. It was made clear that research participation or refusal would not affect their on-going clinical care. Information relating to confidentiality and safe handling and storage of information was extensively outlined both verbally and in written form (see Appendix 4).

Data Analysis

Data analysis was conducted in the computer statistical packages IBM SPSS version 19 (314) and Stata version 12 (315). For the purposes of hypothesis testing (except in the instance of hypothesis 3) appropriate non-parametric tests were employed based on the number and non-normal distribution of observations in the datasets. For hypothesis 3, an abbreviated version of the student's t-test was performed (Stata command 'ttesti') based on the number of observations, groups means and variances in order to allow comparison with data sets where only summary descriptive statistics were available. This approach was also taken when comparing results from the present sample with comparable data taken from the EDIE-2 trial.

Figure 1. FARMS flow chart (Study 1)

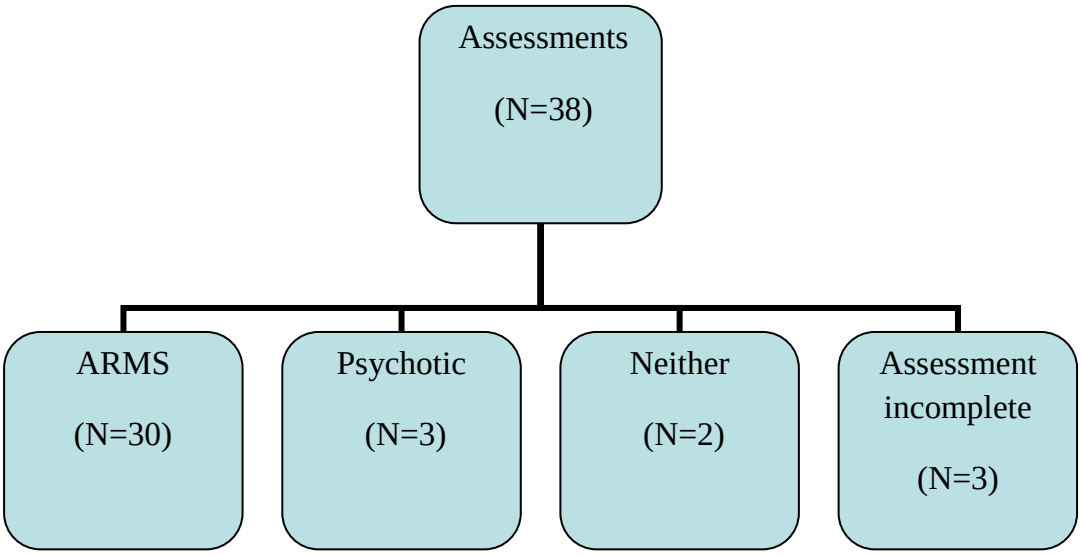


4.3 Results

Study Sample

A total of 38 adolescents were assessed by the FARMS clinic between January 2010 and April 2011. Thirty individuals were identified as having an At Risk Mental State and all consented to research participation. Three individuals disengaged half way through the assessment process. Three individuals were already deemed to be psychotic at baseline assessment and two individuals met neither the ARMS or psychosis threshold criteria (Figure 2).

Figure 2. Number of assessments and assessment outcome at the FARMS Clinic.



Demographics

A summary of the demographic details for those identified with ARMS is presented in Table 3. The data suggest an average age of 15.8 years with a high proportion from lower socio-economic backgrounds (the socio-economic data presented here and the proportion of individuals from lower socio-economic backgrounds seems to exceed the national average and distribution within the North East geographical region; 316). Sex distribution within the sample was relatively evenly distributed whilst all participants were of a White British ethnic origin. The demographic details of those assessed by the FARMS clinic but not included in the study were also recorded, however the proportion of individuals not included was judged to be too small to make a valid statistical comparison.

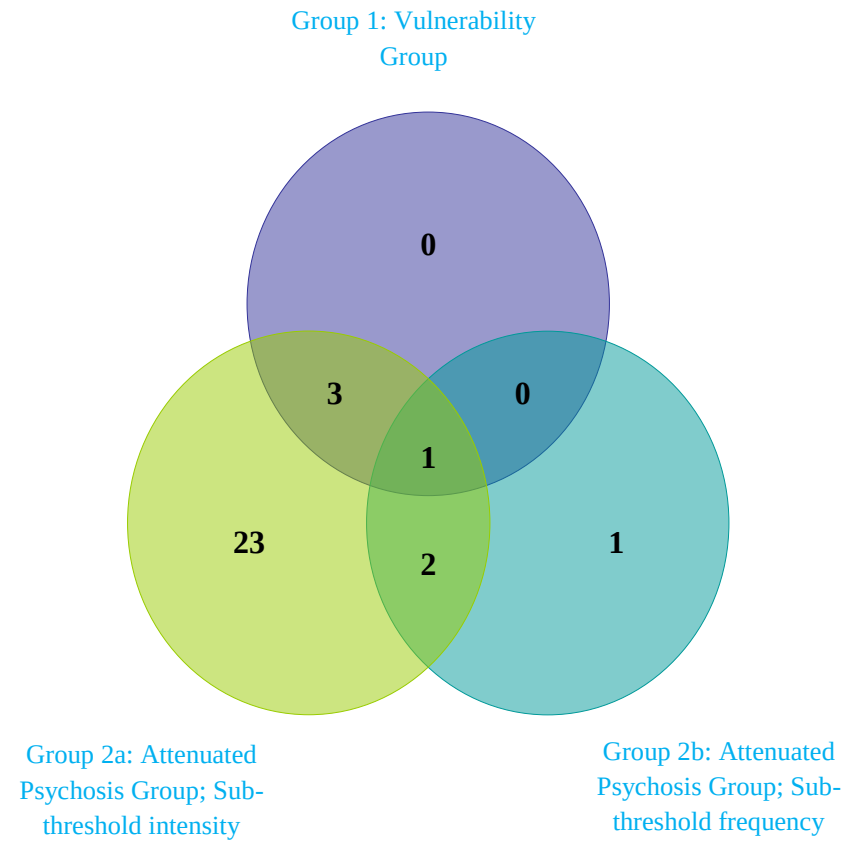
Table 3. Demographic characteristics at baseline assessment

Demographic variable	
Age, mean years (s.d.)	15.78 (1.4)
Gender, n (%)	
Male	14 (47)
Female	16 (53)
National Statistics Socio-Economic Classification, n (%)	
1:Managerial and professional occupations	0 (0)
2: Intermediate	8 (26)
3: Small employers and own account workers	5 (17)
4: Lower supervisory and technical occupations	2 (7)
5: Semi-routine and routine occupations and unemployed	15 (50)
Ethnicity, n (%)	
White British	30 (100)

CAARMS Status

Figure 3 indicates that all but one individual (29/30; 97%) met the criteria for Group 2a (Attenuated Psychosis Group; Sub-threshold intensity). Only four individuals had a family history of psychosis (4/30; 13%) whilst four individuals (4/30; 13%) met the criteria for Group 2b (Attenuated Psychosis Group; Sub-threshold intensity). Six individuals (6/30; 20%) met the criteria for more than one ARMS group. One individual meet the criteria for groups 1, 2a and 2b. None of the sample met the criteria for Group 3 (BLIPS Group).

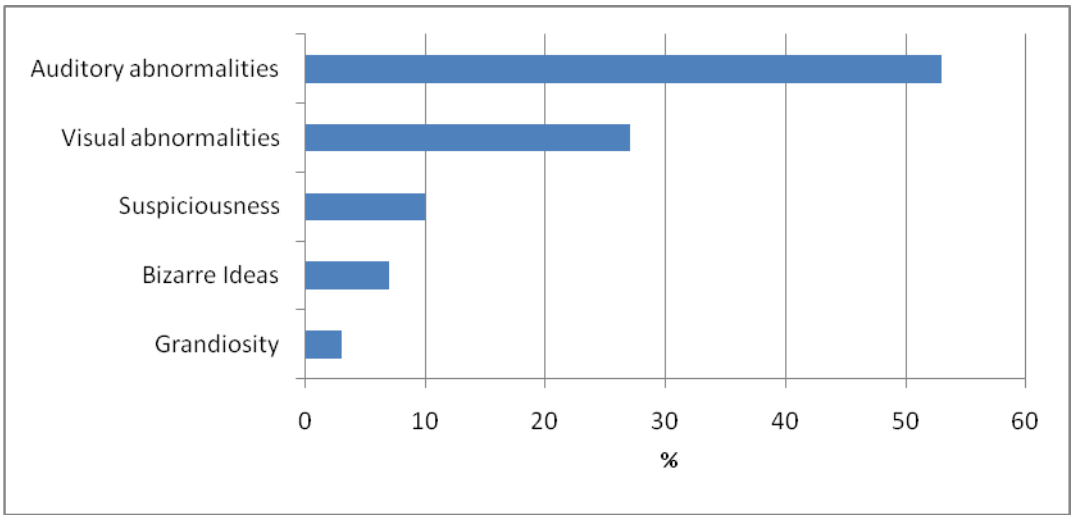
Figure 3. CAARMS Status (by group)



'Positive' Symptomatology

In most cases auditory (16/30; 53%) and visual perceptual disturbances (8/30; 27%) were commonly reported as being the first clinically significant symptoms to develop (Figure 4). In terms of duration of untreated illness, estimates ranged from 8 to 104 weeks with a mean duration of 32 weeks (s.d.=21.9).

Figure 4. First clinically significant positive symptoms reported (%)

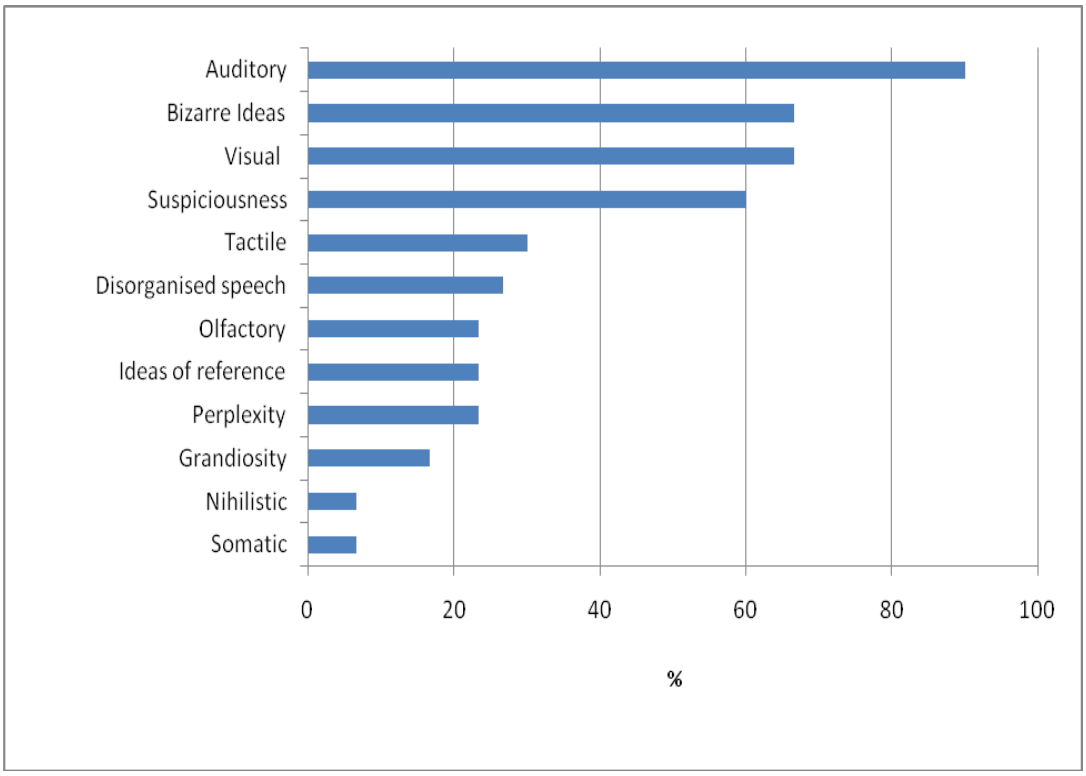


As for the presence of specific and significant positive symptoms at baseline assessment, Table 4 & Figure 5 indicate that the vast majority of participants presented with some form of auditory perceptual disturbances (27/30; 90%). Bizarre ideas (20/30; 67%), Visual Changes (20/30; 67%) and Suspiciousness/Persecutory Ideas (18/30; 60%) were also experienced by a high proportion of participants.

Table 4. Presence of significant 'positive' symptoms at baseline assessment (N=30)

Symptom	***n***	***%***
Auditory Changes	27	90
Bizarre Ideas	20	67
Visual Changes	20	67
Suspiciousness/Persecutory Ideas	18	60
Tactile Changes	9	30
Disorganised Speech	8	27
Ideas of Reference	7	23
Olfactory Changes	7	23
Delusional Mood/Perplexity	7	23
Grandiose ideas	5	17
Somatic Ideas	2	7
Nihilistic Ideas	2	7

Figure 5. Presence of significant 'positive' symptoms at baseline assessment (%)



Global rating, frequency and duration, associated distress and intensity scores for positive symptoms are outlined in Table 5. These indicate that *Perceptual Abnormalities* were the most intense and distressing symptoms experienced within the cohort. Intensity and distress associated with symptoms of *Unusual Thought Content* and *Non Bizarre Ideas* appear to be at similar levels whilst symptoms of *Disorganised Speech were* associated with relatively low levels of intensity and distress. When the data is directly compared to that of EDIE-2 (the largest UK dataset of predominately adult ARMS individuals; n= 288, age range 14-34), *Perceptual Abnormalities* within the FARMS cohort were found to be significantly more severe, frequent and distressing (Global rating, t= 4.28, p= .001, CI= 2.94 to 3.31; Frequency, t=-2.10, p= .036, CI= 2.59 to 2.97; Distress, t=-3.77, p= .001, CI= 43.19 to 51.65). However, Non *Bizarre Ideas* were found to be more severe and distressing within the EDIE-2 cohort (Global rating, t= 2.02, p= .044, CI= 3.36 to 3.67; Distress, t= 4.28, p= .001, CI= 59.99 to 67.11).

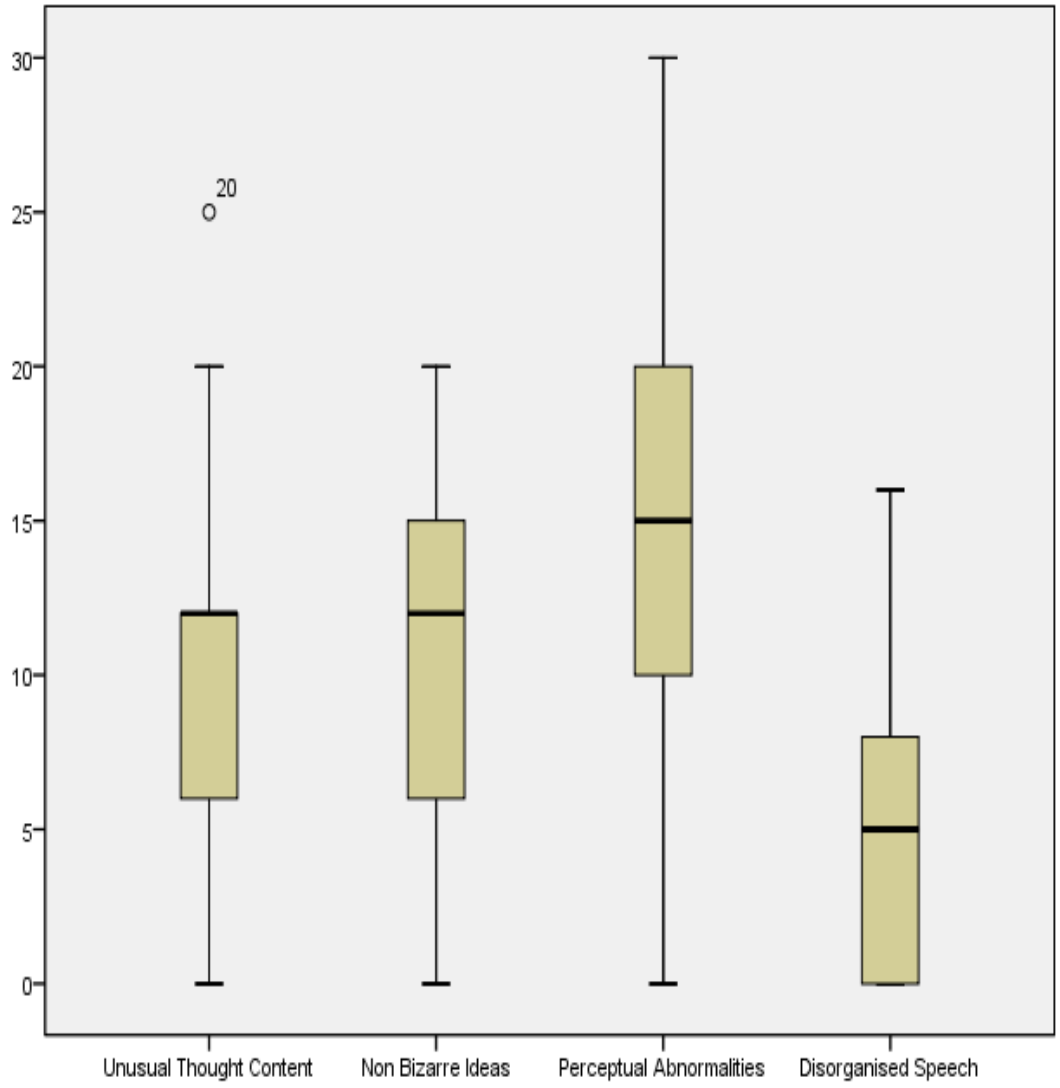
Table 5. Positive symptom ratings scores (CAARMS and PANSS)

	FARMS Mean (s.d.)	EDIE-2 Mean (s.d.)
CAARMS		
Unusual Thought Content		
Global rating	3.30 (1.5)	2.66 (1.9)
Frequency	2.73 (1.3)	2.52 (1.9)
Distress	42.50 (36.2)	40.48 (38.2)
Intensity	10.47 (6.5)	-
Non Bizarre Ideas		
Global rating	3.03 (1.2)	3.57 (1.4)*
Frequency	3.13 (1.1)	3.61 (1.4)
Distress	40.17 (35.3)	65.99 (31.0)*
Intensity	10.40 (5.8)	-
Perceptual Abnormalities		
Global rating	4.13 (1.1)	3.02 (1.7)*
Frequency	3.40 (1.3)	2.72 (1.7)*
Distress	72.00 (25.4)	44.86 (38.6)*
Intensity	14.93 (7.0)	-
Disorganised Speech		
Global rating	1.63 (1.2)	1.51 (1.4)
Frequency	2.07 (1.5)	1.99 (1.9)
Distress	16.83 (24.8)	18.84 (28.8)
Intensity	4.80 (4.2)	-

*p <0.05 (t-test)

Figure 6 demonstrates that symptoms of *Perceptual Abnormalities* appear to have the highest intensity and impact (in terms of combined severity and frequency scores on the CAARMS). *Unusual Thought Content* and *Non Bizarre Ideas* appear to have a similar level and range of scores whilst symptoms of *Disorganised Speech* demonstrate the least intensity at the time of baseline assessment.

Figure 6. Box and whisker plot for overall intensity scores and positive symptoms (CAARMS profile)



Functioning

In terms of functioning, Children's Global Assessment Scale (C-GAS) scores ranged from 39 to 66 with an overall mean score of 53.0 (s.d.=6.9) indicating a significant level of impairment (lower scores on the scale indicate poorer levels of current functioning). This score was not significantly different to that obtained for the EDIE-2 trial (EDIE-2 Mean GAF= 50.99, t=-1.02, p= .31, CI= 50.04 to 52.31). In terms of specific functioning, social functioning (contact with peer groups, social skills, romantic relationships) as evaluated by the functional matrix, were deemed to have significantly declined in most ARMS cases (n=25; 83%) during the previous six months. Chronic difficulties or a pattern of declining functioning were also commonly identified in academic and occupational areas (school, college or occupational performance, attendance and conduct; n=23; 77%) but not in practical areas associated with independence and self-care (n=11; 37%).

ICD-10 Multi-axial Framework

Axis I: Clinical psychiatric syndromes

In total 21/30 (70%) participants were found to meet the threshold for at least one current ICD-10 Axis I diagnoses. Individuals were most likely to meet the criteria for a depressive illness (13/30; 43%), an anxiety disorder (6/30; 20%) or pervasive developmental disorder (5/30; 17%). Three individuals were currently being prescribed medication for their depressive symptoms upon baseline assessment (two fluoxetine; one mirtazapine). Of all the participants, 7/30 (23%) were found to have two current co-morbid ICD-10 Axis I diagnoses.

Table 6. Frequency of ICD-10 Axis I diagnoses at baseline assessment

ICD-10 Clinical Diagnosis	*N (%)*
Mood (affective) Disorder	***13 (43)***
F32.0 Mild depressive episode	***6***
F32.1 Moderate depressive episode	***6***
F33.4 Recurrent depression disorder, currently in remission	***1***
Anxiety Disorder	***6 (20)***
F41.1 Generalized anxiety disorder	***3***
F43.1 Post-traumatic stress disorder	***2***
F.40.1 Social phobia	***1***
Pervasive Developmental Disorder	***5 (17)***
F84.9 Pervasive developmental disorder, unspecified	***4***
F84.5 Asperger's syndrome	***1***
Behavioural Disorder	***2 (7)***
F90.1 Hyperkinetic conduct disorder	***1***
F91.9 Conduct disorder, unspecified	***1***
Other Disorder	
F10.20 Alcohol dependence syndrome (Currently abstinent)	***1***
F50.9 Eating disorder, unspecified	***1***

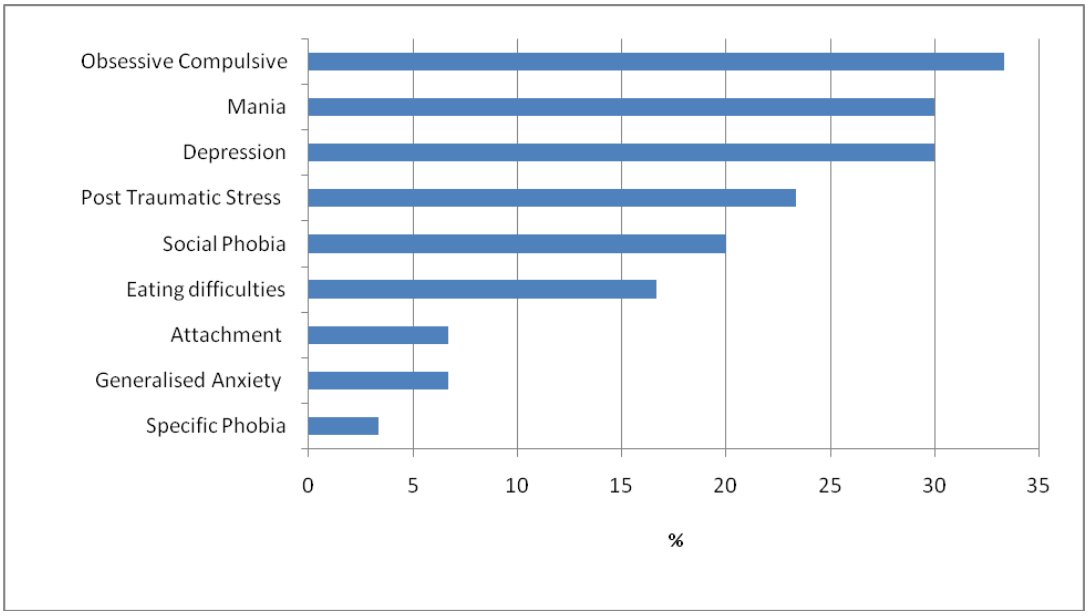
In order to aid decision making in the assignment of ICD-10 Axis I diagnosis, data obtained from the HDRS, YMRS and SCDC were used to assess affective symptomatology and developmental difficulties. Data from the HDRS confirmed an elevated level of reported and observed depressive symptoms within the cohort. The overall mean score of 10.9 (s.d. =6.4) indicates at least a mild severity of depression and is considered to be outside the range encountered in a non-depressed population. The standard deviation and range of individual scores (0-22) indicates much variability. As for symptoms of mania and elevated mood, the mean YMRS score and standard deviation (Mean=3.73; s.d. = 5.3) also indicates a high degree of variability between individual's scores, but this time an overall lower level of symptomatology (with the mean score falling within the normal population range). Scores obtained for the SCDC were also used to aid diagnostic decisions but were completed by only a few parents/significant family members (17/30; 57%), rendering further statistical comparisons of this measure unfeasible.

Further analysis (using a series of Wilcoxon rank sum and Chi-square tests) for those reaching the threshold for a depressive illness indicated that these individuals were significantly more likely to be male ($\chi 2$=4.693, p= .03) and reported more problems with *Disruptive and aggressive behaviour* on the HoNOSCA (z= -2.23, p= .031) in comparison to the rest of the cohort. In terms of positive symptoms, those with a depressive illness were less likely to report Suspiciousness/Persecutory Ideas ($\chi 2$= 4.434, p= .035) but experienced more distressing symptoms of *Unusual Thought Content* (z= -2.18, p= .031) and *Perceptual Abnormalities* (z= -2.25, p= .025). Not surprisingly these individuals also demonstrated significantly higher scores on the HDRS (z= -2.20, p= .028), significantly higher *Emotional and related symptom* scores on the HoNOSCA (z= -2.27, p= .039), were more likely to have engaged in self-harm in the previous six months ($\chi 2$= 9.020, p= .003) and attempted suicide during their lifetime ($\chi 2$= 4.434, p= .035). No other significant differences were observed on any other symptom measures.

As well as meeting the threshold for an Axis I diagnosis many participants were recorded as experiencing sub-threshold difficulties. Sub-threshold difficulties were defined as significant symptoms and difficulties that did not reach diagnostic criteria

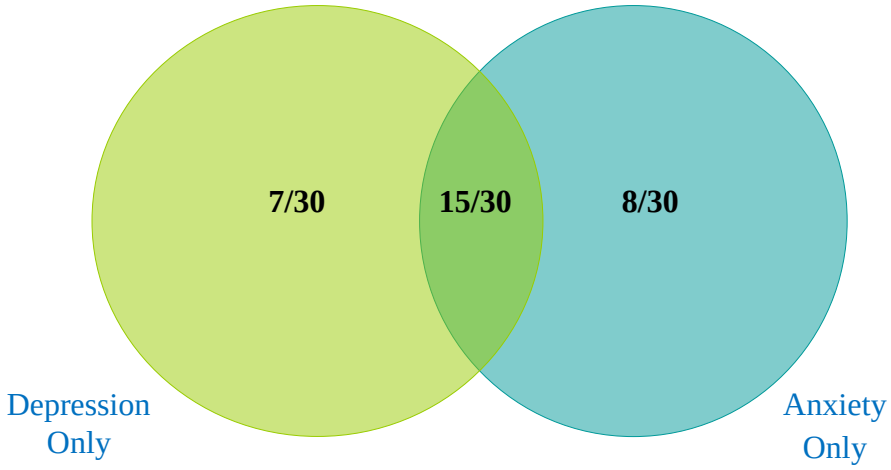
for an Axis I diagnosis using ICD-10 because they were either deemed as being secondary to [and potentially caused by] the primary Axis I diagnosis or were reported not to be particularly distressing, significantly frequent, persevering or significantly detrimental to the person's functioning at that time. The most frequent of these sub-threshold symptoms appeared to be obsessive compulsive symptoms (10/30; 33%), depression (9/30; 30%) and abnormally elevated or irritable mood ('Mania'; 9/30; 30%).

Figure 7. Frequency of sub-threshold symptoms at baseline assessment (%)



Symptoms of depression and anxiety (including sub-threshold ones) appeared almost ubiquitous in our cohort of young people with an ARMS label. Firstly, 19/30 (63%) participants met the criteria for an Axis I diagnosis of depression or anxiety whilst all individuals (30/30) experienced threshold or sub-threshold depression and/or anxiety symptoms (e.g. Obsessive Compulsive disorder, Post Traumatic Stress disorder, Social phobia etc).

Figure 8. Proportion of individuals with ARMS experiencing threshold and sub-threshold depression and/or anxiety



Axis II and III: Specific disorders of development and intellectual disability.

Only one young person within the cohort presented as having an Axis II difficulty (i.e. specific developmental disorder). This individual had been identified as having both dyslexia and dyspraxia. Since intellectual disability was used as part of the study's exclusion criteria, no participants were identified as having a mild or severe generalised learning disability. However, after baseline assessment, two individuals were subsequently referred for a psychometric assessment to explore the possibility of an underlying mild learning disability. The outcomes of these assessments are not known at this time.

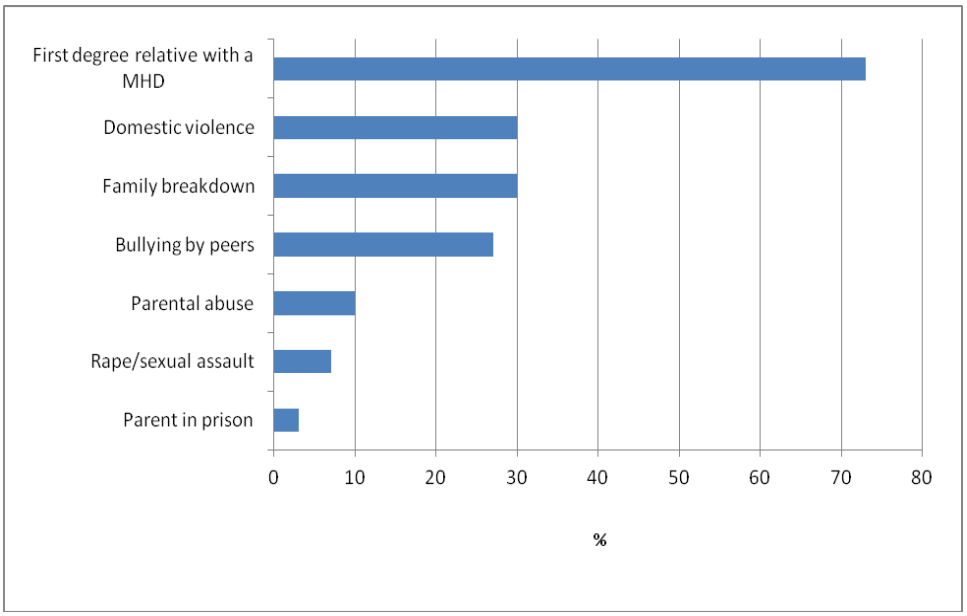
Axis IV: Associated medical conditions.

Associated medical conditions were identified if they were currently exerting a significant impact upon the participant's quality of life at the time of baseline assessment. Epilepsy and recurrent seizures (ICD-10 ref: G40) were identified in three (10%) participants. Asthma (ICD-10 ref: J45) was also identified in three individuals (10%). The only other conditions identified included dermatitis and eczema unspecified (ICD-10 ref: L30), cerebral palsy unspecified (ICD-10 ref G80.9), neuromuscular scoliosis (ICD-10 ref: M41.4) and Legg–Calvé–Perthes syndrome (ICD-10 ref: M91.1).

Axis V: Associated abnormal psychosocial conditions.

In terms of abnormal and stressful psychosocial conditions experienced by the cohort (Figure 9) the vast majority of participants (22/30; 73%) were found to have a first degree relative with a diagnosable mental health problem. A high proportion of participants had also witnessed, sometime during their life, incidents of domestic violence (9/30; 30%) whilst an equal number had experienced some form of breakdown within their nuclear family (parental marital breakdown, divorce or significant breakdown in the child parent relationship). Individuals also reported incidents of significant bullying by peers (currently or in the recent past), parental abuse (severe and significant neglect, physical or verbal abuse), experiences of rape or sexual assault or having a parent in prison (see Figure 9).

Figure 9. Frequency of abnormal psychosocial conditions (%)



Related data was also collected in relation to the number of general traumas experienced by participants during their lifetime. For example, this included being involved in a frightening accident or, as previously mentioned, being physically or sexually assaulted or witnessing incidents of domestic violence. Eighteen (60%) individuals disclosed remembering significant traumatic experiences during their lifetime. On average individuals reported having experienced at least one (mean=1.6; s.d.=1.8) significant traumatic experience.

Family perceptions

Baseline data from the Family Perceptions Scale (FPS) are presented in Table 7 alongside data obtained from a local non-clinical community sample of adolescents (n=670; age range 12-17; 317) in order to test Hypothesis 1.

Adolescents with an ARMS will have a significantly negative view of Family perceptions/functioning, compared to a normative sample of adolescents (as

measured by the Family Perceptions Scale).

The data indicates that ARMS individuals appear to have significantly more negative views of family functioning in the areas of Nurture (z= 2.39, p= .017), Problem solving (z= 2.52, p= .012), Expressed Emotion (z= -2.60, p= .009) and Communication (z= 1.97, p= .049) when compared to a community sample of adolescents. This is also reflected in a higher FPS total score (z= 2.25, p= .024).

Table 7. Family Perception Scale scores (FARMS and Normative samples)

	FARMS cohort Mean (s.d.)	**Normative Mean (s.d.)**
FPS		
Nurture	15.73 (5.0)	17.69 (4.7)*
Problem solving	16.43(4.9)	18.48 (5.3)*
Expressed emotion	14.27 (4.3)	12.04 (4.2)*
Behavioural boundaries	11.17 (3.3)	11.33 (3.7)
Responsibilities	11.63 (3.8)	12.49 (3.9)
FPS total score	40.70 (16.5)	45.70 (18.7)*
Communication index	23.70 (5.7)	25.94 (4.7)*

*p <0.05 (Wilcoxon rank sum)

Hypothesis 2

Negative perceptions of family functioning will be significantly associated with symptom distress and intensity (as measured by the Family Perceptions Scale and Comprehensive Assessment of At-Risk Mental States).

In order to test Hypothesis 2, a correlation matrix was established (Table 8). Individuals with more maladaptive family perceptions (lower scores) in the areas of Behavioural boundaries and Responsibility experienced significantly more distressing Non Bizarre ideas (p=.028, CI= -0.047 to -0.664; p= .029, CI= -0.047 to -0.664). However family perception scores were not associated with any other areas of symptom intensity or distress.

Table 8. Correlation matrix of Family Perception Scale scores and CAARMS intensity and distress scores

	Family Perceptions Scale Index						
	Nurture	Problem solving	Expressed emotion	Behavioural boundaries	Responsibility	FPS total score	Communication index
Unusual Thought Content Intensity	-.04	-.08	-.02	-.18	-.22	-.17	.01
Non Bizarre Ideas Intensity	-.04	.11	.09	-.18	-.06	-.05	-.04
Perceptual Abnormalities Intensity	-.09	.03	.02	.16	.24	.06	-.11
Disorganised Speech Intensity	-.20	-.03	.25	-.01	.26	-.10	-.19
Unusual Thought Content Distress	-.17	-.21	.13	.24	-.08	-.16	-.18
Non Bizarre Ideas Distress	-.26	-.27	.10	-.40*	-.40*	-.36	-.24
Perceptual Abnormalities Distress	.04	.10	.09	.05	.16	.07	-.17
Disorganised Speech Distress	-.22	.02	-.01	.00	.26	.01	-.10

*p <0.05 (Pearson correlation coefficient)

Metacognitive beliefs

Baseline data from the Metacognitions Questionnaire short form (MCQ-30) are presented in Table 9 alongside data obtained from an adult non-clinical community sample (n=182; age range 18-69; 310) in order to test Hypothesis 3.

Adolescents with an ARMS will have significantly higher (maladaptive) Metacognitive scores when compared to an existing normative sample (as measured by the Metacognitions Questionnaire).

The data indicates that ARMS individuals appear to have significantly worse (higher) metacognitive belief scores than individuals drawn from a 'normal' non-clinical population. This should be interpreted with caution however as the normative data is taken from an adult sample.

Table 9. Metacognitive scores (FARMS and Normative samples)

	FARMS cohort Mean (s.d.)	**Normative Mean (s.d.)**
MCQ-30		
Positive beliefs	11.33 (4.6)	9.60 (3.5)*
Negative beliefs	17.73 (4.6)	9.30 (4.0)*
Cognitive confidence	14.87 (5.3)	9.51 (4.0)*
Need for control	14.43 (4.0)	8.34 (2.6)*
Cognitive self-consciousness	15.03 (4.5)	11.65 (4.7)*
Total MCQ score	73.40 (15.1)	48.41 (13.3)*

*p <0.05 (t-test)

Hypothesis 4

Metacognitive scores will be significantly associated with symptom distress and intensity (as measured by the Metacognitions Questionnaire and Comprehensive Assessment of At-Risk Mental States).

In order to test Hypothesis 4, a correlation matrix was established (Table 10). Individuals with more maladaptive metacognitive beliefs (higher scores) in the Negative beliefs domain experienced significantly more intense *Perceptual Abnormalities* (p= .022, CI= -0.071 to -0.677) and distressing *Unusual Thought Content* (p= .021, CI= -0.071 to 0.677).

Table 10. Correlation matrix of Metacognitive belief scores and CAARMS intensity and distress scores

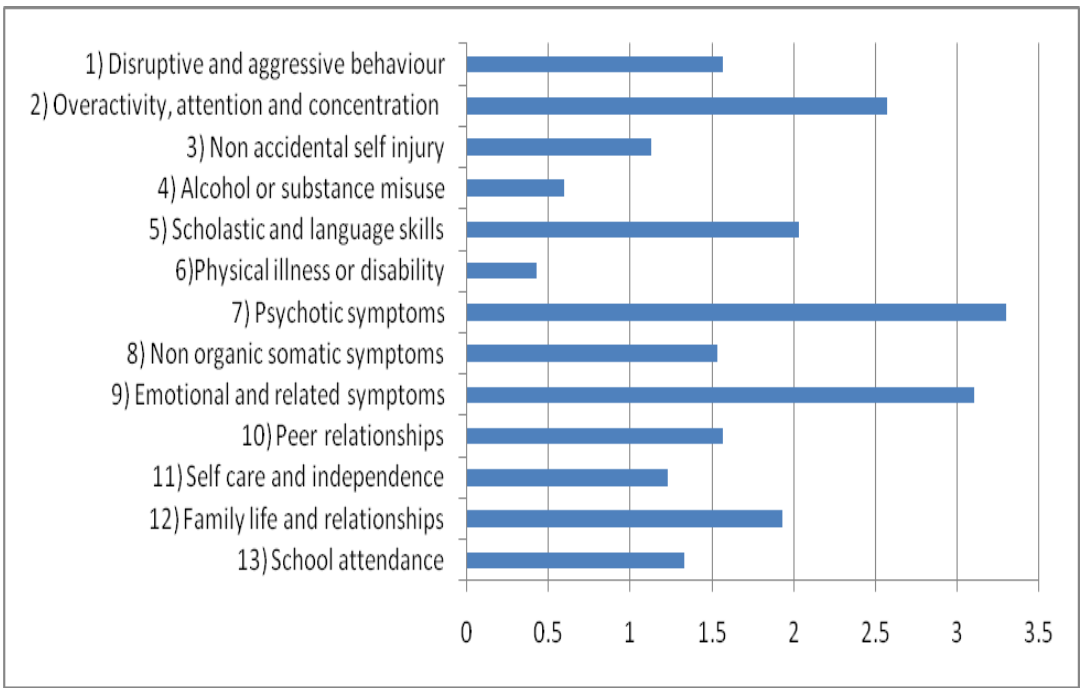
	Metacognitive Beliefs					
	Positive beliefs	Negative beliefs	Cognitive confidence	Need for control	Cognitive self consciousness	Total MCQ score
Unusual Thought Content Intensity	.26	.09	.08	.30	.10	.25
Non Bizarre Ideas Intensity	-.03	.10	.04	.33	.16	.17
Perceptual Abnormalities Intensity	-12	.42*	-.07	.29	-.09	.12
Disorganised Speech Intensity	.19	-.09	.01	.32	.36	.20
Unusual Thought Content Distress	.06	.42*	-.01	-.01	-.29	-.01
Non Bizarre Ideas Distress	.08	.21	.23	.09	-.15	.15
Perceptual Abnormalities Distress	-.01	.22	-.15	.04	-.25	.01
Disorganised Speech Distress	-.20	-.04	-.15	.11	.04	-.08

*p <0.05 (Pearson correlation coefficient)

Other Symptomatology

As a general measure of psychological symptomatology, the mean total HoNOSCA score of 22.3 (s.d.=4.8) indicates a high degree of global difficulty. Item seven (*Psychotic symptoms*) was the most heavily endorsed and highest scoring item on the HoNOSCA. Items nine (*Emotional and related symptoms*) and two (*Over activity, attention and concentration*) were also heavily endorsed. The mean severity score for each difficulty can be seen in Figure 10.

Figure 10. Mean HoNOSCA scores for all thirteen items



Also within this cohort, a high proportion of individuals reported having attempted suicide (9/30; 30%) or had engaged in significant self-harm (16/30; 53%) within the previous six months.

In terms of current alcohol consumption 16/30 (53%) participants self-reported some form of weekly alcohol consumption although only five participants reported binge drinking (defined as more than five drinks over a two hour session in males, four drinks in females) on a weekly basis. Therefore the mean estimate of weekly

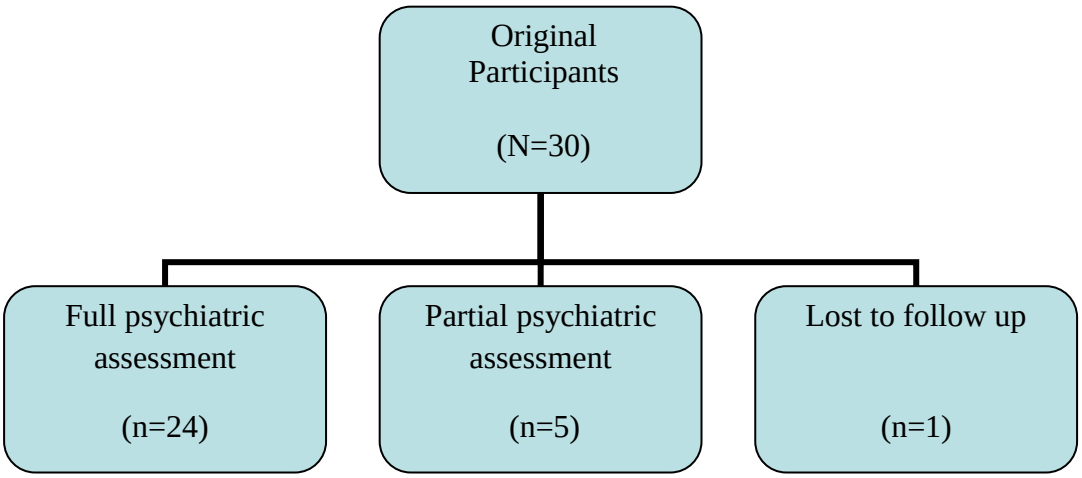
alcohol consumption within the cohort was low and highly variable (mean=3.4 units; s.d.=4.5). None of the participants reported using any illegal substances upon baseline assessment. Self-reported alcohol consumption six months prior to baseline assessment (mean= 12.6 units; s.d.=19.6) indicates significantly greater consumption (Wilcoxon signed rank test, $z = -2.812$, $p = .005$). Twenty one participants also reported some form of weekly alcohol consumption at this time point whilst 13 participants reported binge drinking on a weekly basis. Regarding illicit substance use; two individuals reported some form of regular cannabis use. One of these individuals also reported the previous use of methadone whilst another participant reported the use of cocaine. The frequency and amount of consumption were often hard to establish because of difficulties in participant recall, potentially sensitive nature of the question and lack of corroborating evidence (e.g. urine testing).

Six Month follow up data

Study Sample

Of the 30 original participants, 24 (80%) were available and consented to full face-to-face psychiatric assessments. Five (17%) participants refused a full follow-up assessment at this stage but provided consent for their medical records to be reviewed and for the author to obtain information from their treating clinician. No significant differences were found between those completing a full or a partial psychiatric assessment in terms of key baseline demographic and symptom scores ($p > 0.05$ in all cases). Therefore, at the six month follow-up stage it was possible to establish the current mental state (either psychotic or not psychotic) for 29/30 (97%) participants. For the one individual who could not be assessed, information was obtained from a variety of professionals and agencies and indicated that they had disengaged from mental health services completely and were suspected to be homeless (and therefore were unable to be located or contacted). Collection of this information was deemed to be ethical and appropriate given that the participants had provided consent at baseline assessment for the research team to contact them and those involved in their care at the six month follow-up stage.

Figure 11. Number and type of assessments conducted at the six month follow up stage.



Six month outcomes

Data obtained from face to face interviews, medical records and discussions with other mental health professionals indicated that only one participant (1/29; 3.4%) had become psychotic during the previous six months. Since the transition rate at this stage was extremely low it was not possible to conduct further statistical analysis exploring the possible predictors of transition to psychosis.

For the one individual who became psychotic, baseline data indicated that they were male, had a first degree relative with a psychotic episode (father), presented with a below average level of functioning (C-GAS=39) and reached the threshold for a Generalised Anxiety Disorder and Conduct disorder, unspecified. In addition they also presented with a variety of other sub-threshold difficulties (both manic and depressive symptomatology, significant traumatic experiences and recent self-harm and suicide attempts). This individual was subsequently prescribed risperidone upon conversion to a psychotic illness.

At the six month follow-up stage it was found that eight participants 8/29 (28%) had been fully discharged from specialist Child and Adolescent and Early Intervention in Psychosis mental health services. Discharge at this time was interpreted positively (i.e. that the individual and/or mental health service had seen a significant improvement in symptoms/functioning and therefore no longer required the support of services) as none of the participants were found to have moved out of area. Repeated non-attendance was another possible reason for discharge but deemed unlikely given the assertive outreach approach adopted by the Early Intervention in Psychosis service.

In terms of support and interventions offered after baseline assessment, a review of medical records and information obtained from care co-ordinators indicated that individuals had received a variety of possible interventions (Table 11). All had received some form of active monitoring and case management. In terms of medical treatment (and discounting the individual who had become psychotic), six participants (21%) had been started on medication after baseline assessment. Of these one was prescribed quetiapine (100mg daily) whilst the remainder were prescribed fluoxetine (10mg-40mg daily). In terms of psychological therapies, Table 9 indicates that approaches following a cognitive behavioural or family therapy framework were favoured although the vast majority of these were difficult to characterise and therefore labelled as non-specific (i.e. the duration/number of sessions or manual/framework adopted was not explicitly stated in the medical notes).

Table 11. Support/interventions offered after baseline assessment (N=29)

Support/interventions offered	**N (%)**
Monitoring & Case Management	**29 (100)**
Cognitive Behavioural Therapy	**7 (24)**
Formal individual (6 sessions)	**3**
Non-specific	**3**
Formal group (8 sessions)	**1**
Family Therapy	**7 (24)**
Non-specific	**6**
Formal (6 sessions)	**1**
Medication	**6 (21)**
Fluoxetine (10-40mg daily)	**5**
Quetiapine (100mg daily)	**1**
Solution Focused Therapy *(Non-specific)*	**4 (14)**

Since detailed information and face-to-face psychiatric information was obtained from 24 participants it was possible to conduct a more in depth analysis of how the participants overall condition, symptoms and functioning had progressed six months after initial identification. Of the 24 participants assessed, one was the aforementioned individual who had become psychotic. Sixteen participants were still deemed to meet the criteria for an ARMS whilst seven had achieved partial or full remission. For those making some kind of remission at this stage, three individuals met the criteria for a 'symptom' remission, two for a 'functional' remission and two for a 'full' remission (symptoms and functioning).

In terms of positive symptomatology, participants six month scores on the CAARMS were compared to scores previously obtained at baseline assessment (a matched pairs design). The data outlined in Table 12 indicates that there was a significant improvement on several CAARMS symptom ratings subscales at six month follow-up using a series of Wilcoxon signed ranks tests (*Non Bizarre Ideas*

Global rating z =-2.599, p= .009; *Perceptual Abnormalities Global rating* z =-2.448, p= .014; *Perceptual Abnormalities Frequency* z =-2.500, p= .012; *Perceptual Abnormalities Distress* z =-2.979, p= .003; *Perceptual Abnormalities Intensity* z =-2.785, p= .005; *Disorganised Speech Global rating* z =-3.291, p= .001; *Disorganised Speech Frequency* z =-2.842, p= .004; *Disorganised Speech Distress* z =-3.066, p= .002; *Disorganised Speech Intensity* z =-2.754, p= .006).

Table 12. Positive symptom ratings scores and Functioning (Baseline and Six Month follow up data; N=24)

	Baseline Mean (s.d.)	**Six Month Mean (s.d.)**
CAARMS		
Unusual Thought Content		
Global rating	3.12 (1.6)	2.33 (2.1)
Frequency	2.75 (1.4)	1.87 (1.7)
Distress	39.58 (36.8)	27.71 (32.2)
Intensity	10.33 (6.9)	7.29 (7.8)
Non Bizarre Ideas		
Global rating	3.00 (1.2)	2.00 (1.8)*
Frequency	3.17 (1.2)	2.42 (1.8)
Distress	41.88 (38.0)	32.08 (40.5)
Intensity	10.42 (5.7)	7.50 (8.3)
Perceptual Abnormalities		
Global rating	4.25 (0.8)	3.38 (1.7)*
Frequency	3.67 (1.1)	2.79 (1.4)*
Distress	73.54 (23.9)	46.04 (34.5)*
Intensity	16.13 (6.8)	11.71 (7.4)*
Disorganised Speech		
Global rating	1.71 (1.2)	0.62 (1.2)*
Frequency	2.17 (1.5)	0.92 (1.6)*
Distress	17.50 (22.7)	2.50 (9.0)*
Intensity	5.08 (4.2)	2.21 (5.0)*

*p <0.05 (Wilcoxon signed-rank test)

As for the presence of significant positive symptoms at six month follow up, Table 13 indicates a pattern of general reduction in frequency and intensity for all positive symptoms when compared to baseline data. A series of Chi-square and Fisher's exact tests (the latter utilised where n≤5) indicates that there was only a significant remission in the presence of *Visual Changes* ($\chi 2$= 5.371, p= .02) and *Disorganised Speech* ($\chi 2$= 10.286, p= .01). However, these results should be interpreted with caution given the low figures involved.

Table 13. Presence of significant positive symptoms at baseline assessment and Six Month follow up (N=24)

Symptom	***Baseline, n, (%)***	***Six Month, n, (%)***
Auditory Changes	22 (92)	15 (63)
Visual Changes	16 (67)	11 (46)*
Suspiciousness/Persecutory Ideas	15 (63)	8 (33)
Bizarre Ideas	14 (58)	12 (50)
Tactile Changes	8 (33)	5 (21)
Ideas of Reference	7 (29)	1 (4)
Delusional Mood/Perplexity	6 (25)	2 (8)
Disorganised Speech	6 (25)	3 (13)*
Olfactory Changes	5 (21)	4 (17)
Grandiose ideas	4 (17)	1 (4)
Somatic Ideas	2 (8)	0 (0)
Nihilistic Ideas	1 (4)	0 (0)

*p <0.05 (Chi-square test)

In terms of functioning at six month follow up, the mean C-GAS score of 61.13 was a significant improvement when compared to the mean baseline score of 54.04 (Wilcoxon signed-rank test, z =-2.811, p =.005). A significant improvement was also noted between mean six month and baseline Total HoNOSCA scores (16.17 vs. 22.46; Wilcoxon signed-rank test, z =-2.848, p =.004).

Hypothesis 5

Transition to psychosis and maintenance of an ARMS at six month follow up will be associated with lower (maladaptive) psycho-social functioning scores at baseline assessment (as measured by the Children's Global Assessment Scale).

In order to test Hypothesis 5, the C-GAS scores of the sixteen individuals still fulfilling ARMS criteria and the one individual with psychosis were compared to those of the seven individuals who had made some form of functional and/or symptom remission. It was found that the mean C-GAS scores for those with a sustained ARMS or psychosis at the six month follow up stage indeed had significantly worse (lower) functioning scores at baseline assessment (mean =51.82 vs 59.43; Wilcoxon rank sum, z= -2.67, p= .005).

Further analysis also indicates that these individuals had significantly worse *Perceptual Abnormalities* Global rating (mean = 4.47 vs 3.71; Wilcoxon rank sum, z= 2.12, p= .047), Frequency (mean =4.00 vs 2.86; Wilcoxon rank sum, z= 2.07 p= .047), Intensity (mean= 18.18 vs 11.14; Wilcoxon rank sum, z= 2.18, p= .028) and HoNOSCA total scores (mean=24.00 vs 18.71, Wilcoxon rank sum, z= 2.33, p= .019) at baseline assessment.

4.4 Discussion

The findings from this study indicate that adolescents with an ARMS present to mental health services with significant levels of impairment. In terms of current levels of functioning, a mean C-GAS score of 53 is comparable to that observed in other studies (60, 92-95) and indicates a significant degree of difficulty in day to day functioning. More specifically adolescents frequently report a decline or chronically poor functioning in social aspects of their lives which is predictable given that other cohorts of ARMS patients have exhibited significantly impaired and comparable levels of social functioning as first and multi-episode psychotic patients (97, 98).

In terms of symptomatology, it appears that perceptual abnormalities, especially auditory hallucinations are the most frequent, distressing and severe 'positive symptoms' experienced by adolescents presenting with an ARMS. These findings are supported by an adolescent specific study (209) but not by those mainly recruiting working age adults (71, 95) who report symptoms of suspiciousness and non-bizarre ideas as being the most frequent and severe positive symptoms. Although bizarre ideas and heightened suspiciousness are common within this sample of adolescents they appear to be less prevalent when compared to these comparative samples.

As for the possible mechanisms explaining the development, maintenance and distress associated with these sub-threshold symptoms the findings of this study are mixed. Indeed the data clearly demonstrates that adolescents with ARMS have a significantly more negative view of aspects of family functioning when compared to unaffected peers, thus at least partially confirming Hypothesis 1. This echoes previously reported findings in this area (137-139). However, the assumption that impaired family perceptions would be associated with symptom distress and intensity (Hypothesis 2) is not supported by our data. Previous adolescent ARMS studies have found that family functioning is associated with symptom exacerbation and reduced social functioning in 'at-risk' adolescents (138). The following data only supports a potential role in the development of distress associated with Non

Bizarre Ideas (suspiciousness, grandiosity etc.) which, given the number of comparisons being made, may be the product of chance. However if young people are indeed experiencing paranoid beliefs then it is highly likely that they would perceive their family environment as hostile. In exploring the role of metacognitive beliefs the data is suggestive of impaired beliefs within the FARMS cohort (Hypothesis 3) but once again does not indicate an association with symptom intensity or distress (Hypothesis 4). Previous studies have shown that ARMS individuals exhibit higher levels of negative metacognitive beliefs (136, 292) when compared to non-patient controls, whilst the cognitive model of psychosis suggests metacognitive beliefs are directly responsible for increasing the anxiety and distress caused by psychotic symptoms (136).

According to the ICD multi-axial framework utilised it was observed that the majority of adolescents presented with clinically significant levels of depression and/or anxiety. As well as high levels of depression and anxiety, pervasive developmental disorders were also more frequently observed within the cohort than might be expected by chance alone. The low levels of reported substance use before and at the time of baseline assessment are inconsistent with findings elsewhere and may reflect concealment bias by participants because of imagined repercussions from family members, mental health services and possibly the law.

A high frequency of sub-threshold obsessive compulsive symptoms was observed during assessment and may indicate a particular vulnerability or thinking style that is relevant in the development and maintenance of psychotic symptoms. The recording of significant psychosocial conditions and lifetime trauma indicates that more than half (18/30; 60%) of the cohort had experienced at least one traumatic incident during their life time. This figure is slightly below that outlined elsewhere (70-97%; 133, 134). Many of the young people had experienced significant psychosocial stress in having a first degree relative with a significant and diagnosable mental health problem whilst several individuals reported experiencing domestic violence, family breakdown or significant bullying. The level of reported bullying experiences recorded are comparable with figures reported elsewhere (103).

Regarding the intake criteria, the data are relatively consistent with the picture that the vast majority of participants with an ARMS present with sub-threshold symptoms. The absence of individuals presenting with a BLIP (CAARMS Group 3) does, however, raise concerns relating to the capturing of such young people by services. It may be that such individuals are not being referred to the appropriate services for assessment, instead being labelled as having 'drug induced psychotic episodes'. Compared to other studies, the reported 'duration of untreated illness' of 32 weeks within this cohort is relatively short given that other services report time frames between 13 and 22 months (103, 110, 111). It is uncertain if these estimates are genuinely related to maturational processes, the involvement of parents in seeking help earlier or a bias in recall and measurement of emerging symptoms.

The demographic profile of participants for this study indicates a relatively equal proportion of males and females presenting to services although a high percentage of these come from less economically advantaged home environments. A slightly lower proportion of males within this cohort (14/30, 47%) is at odds with other studies (65%; 69, 95) and is not consistent with the notion that males are more likely to develop psychosis and therefore experience the prodrome at a younger age (318). This finding may suggest that an underlying bias in accessing services exists for female adolescents who present with psychotic-like symptoms and functional decline. As for the assessment of socio-economic status and the emerging pattern of those presenting it is unclear if this is normal given the lack of data presented elsewhere.

In answering how young people with an At-Risk Mental State fare over the short term we observed a remarkably low transition rate to a full blown first episode of psychosis during our 6 month follow-up period. At this stage it is too early to deduce whether this is because participants received swift and effective treatment which delayed or prevented transition or the consequence of including a high number of 'false positive' cases within the sample (those who were never at risk of psychosis). The transition rate of 3.4% is below figures published by a recent six month cohort study (5%; 141), those conducted previously within UK clinical

services (10%; 69) and the only specific adolescent study to be conducted so far (14%; 217). The finding is also at odds with the views of certain research groups who have demonstrated that adolescents are significantly more likely to make the transition to psychosis (153) and that this age group should be over sampled to inflate conversion rates (152). Possible explanations may be that adolescents are dissimilar to their adult counterparts and are more likely to become psychotic beyond and outside of the usual 6 month time frame (60, 62) or that for developmental reasons they are more prone to fluctuations in functioning (storm and stress; 230), perceptual and ideational disturbances (206) and therefore represent a high proportion of 'false positive' cases.

The proportion of participants no longer fulfilling ARMS criteria at six months because of significant improvements in functioning and/or symptomatology (7/24; 29%) falls between remission rates described elsewhere (15-60%; 106, 111). However, these studies refer to data collected after a one year follow up period, not six months. Within our cohort, the identification of ARMS and input from clinical services could be interpreted as the mechanism behind some of the high levels of symptom and functional remission observed. Significant improvements were noted in relation to perceptual experiences, disorganised speech and suspicion/persecution alongside psycho-social functioning. These findings are supported by other studies who report significant improvements in symptomatology and functioning, 6-8 months after initial ARMS identification (222). However, the variability and non-specific nature of the support offered to young people by mental health services is not surprising given the variability in clinics around the world and the absence of any official treatment guidelines (159).

Finally, our data confirmed that those with a sustained ARMS or transition to psychosis at the six month follow-up stage have significantly worse psychosocial functioning (thus confirming Hypothesis 5) and perceptual abnormalities at baseline compared to those achieving remission. Numerous studies aimed at exploring possible predictors of transition to psychosis have identified that poorer functioning at baseline predicts onset of psychosis (60, 92, 93, 148, 149). Naturally it also follows that it is more difficult (and may take longer) for an individual to achieve

remission if their symptoms and functioning are indeed worse upon initial presentation to mental health services.

4.4.1 Strengths and potential limitations

To the author's knowledge this is the first study to prospectively characterise and assess the short term outcomes of adolescents with an At-Risk Mental State within the UK. The sample size of 30 participants is small when compared to international multi-site studies but is acceptable given the 'hard to reach' nature of adolescents and the level of resources and time-frame allocated and available to this project. The follow up rate of 97% at the six month stage is comparable to other studies working with this patient group and is adequate in answering the aims and questions initially set out by the project.

Although the inclusion of 30 participants in this study demonstrates the authors ability to recruit 'hard to reach' individuals for research purposes, the small sample size, combined with the use of non-parametric statistical techniques in order to test the various hypotheses proposed, allows for an increased risk of committing a Type II error (accepting the null hypothesis when the null hypothesis is false). A post-hoc power analysis is therefore useful in order to inform the design and resourcing of future studies that may want to replicate this research but also reduce the chances of committing such an error. A quick calculation based on our observed Family Perceptions data for example suggests that an ARMS sample (the experimental group) and a community based sample of adolescents (a control group) would have to consist of 176 participants each, in order to be suitably powered in this instance (see Appendix 5). This would prove a major challenge in terms of future recruitment strategies. Another more feasible strategy to improve power may involve transforming collected data (via logarithms) so that parametric statistical techniques maybe adopted during analysis.

The main limitation of this study however is the potential for bias during recruitment and assessment. In terms of sample ascertainment, this study was reliant upon mental health professionals working within Child and Adolescent and Early

Intervention in Psychosis services to actively contact the FARMS clinic in order to make a referral. This process allows for a whole subgroup of ARMS patients (potentially those experiencing a Brief Limited Intermittent Psychotic episode or substance induced psychotic symptoms) not to be referred to the clinic because clinicians within these services do not consider this subgroup to be genuinely at risk of developing psychosis. Attempts to reduce this bias were conducted throughout the study (regular attendance at team meetings, the provision of ARMS and CAARMS training for teams) and potentially limited by the fact that both members of the FARMS clinic were clinicians actively working within CAMHS and EIP services at the time of study recruitment.

This study therefore only characterises adolescents with ARMS who actively present to mental services and fails to capture those who do not make their way to services. However at this time, apart from screening in the community (which has the potential to generate more stigma and higher false positive rates) no research group has been able to overcome this issue. Thankfully there appears to be no bias in the final stage of recruitment for this study in obtaining consent. All individuals assessed by the FARMS clinic and identified as having an At-Risk Mental State were agreeable to take part at the baseline stage.

The potential for bias during assessment is a problem common to all researchers and clinicians working within the field of mental health given the tendency to conceal or potentially embellish symptoms. Although response bias and self-reporting of symptoms will undoubtedly still exist, the researchers both undertook extensive training and had considerable experience of working with and engaging young people with psychotic symptoms. All data provided during assessments was crossed referenced, where possible, with information obtained from other family members, other involved professionals (teachers, social workers, other mental health professionals) and historical documentation (medical records). The assessment practices adopted in relation to the possible diagnosis of a pervasive developmental disorder were relatively weak in practice. This is because completion rates for the Social and Communication Disorder Checklist (SCDC) were particularly low and the FARMS clinic was reliant upon young people and their families accepting a

referral to CAMHS for through assessment when a PDD was suspected. The frequency of the diagnosis PDD-NOS as opposed to a specific diagnosis such as Aspergers syndrome could be the result of the study's inability to conduct a complete PDD assessment, although a review of studies indicates that PDD-NOS is a common diagnosis in adolescent psychosis (129).

In exploring the potential roles of family perceptions and metacognitive beliefs within the context of adolescent ARMS, methodological improvements could have been made. A major limitation in this respect was the lack of an available more appropriate comparative data set. In theory this could have been obtained (rather than relying on secondary data) via recruitment of adolescents from local non-clinical and psychosis populations. Individuals could then have been matched on potentially key factors such as age, gender, socio-economic statutes and/or levels of anxiety and depression to ensure a more robust method of hypothesis testing. Similarly, although the use of data from the EDIE-2 trial as a comparative group was useful to highlight the potential differences between ARMS age groups, this was not ideal given that it will have included several adolescents because of its intake criteria (age range 14-35). The option and ability to recruit from these samples was outside and beyond the initial scope of the FARMS study. An opportunity to assess whether family perceptions and metacognitive beliefs were associated with symptom and functional improvement over time was also missed as these assessment measures were not administered at the six month follow up stage.

A further limitation was that the low transition rates observed in this study did not allow for an exploratory examination of significant predictors of transition to psychosis. Further recruitment and a more thorough consideration of data collected during baseline assessment would have supported the use of more robust statistical methods such as cluster analysis in order to classify symptom profiles and identify possible ARMS sub-groups. Such a method may have been more appropriate in characterising how adolescents present to mental health services with an ARMS.

Finally, the inability to conduct full face-to-face psychiatric assessments at the six month follow up stage for all participants rendered it unfeasible to compare

symptom and functioning scores (baseline vs. follow up) for the whole cohort. This situation, however, was unavoidable given the refusal of several participants to consent to this follow-up assessment. This and the fact that the study was unable and did not attempt to control for possible treatment effects means that the follow-up/outcome data presented should be interpreted with caution, although it appears that those refusing a full assessment were no different in terms of key demographic and symptom scores at baseline.

4.4.2 Clinical Implications

The findings from this study indicate that adolescents with ARMS have significant levels of symptomatology and impairment upon presentation to mental health services. Therefore they are likely to benefit from appropriate identification and treatment. The symptom, demographic and functioning profiles generated during analysis, should aid and inform the training of other clinicians working within Child and Adolescent and Early Intervention in Psychosis services in how to identify individuals presenting with an ARMS. For example these young people may have been previously identified as just being anxious or depressed. Effort should also be directed in helping these clinicians identify and refer certain ARMS patient groups that must exist but are virtually non-existent in this cohort (e.g. those with substance induced positive psychotic like symptoms, individuals experiencing a BLIP [Group 3] or individuals with a genetic vulnerability and decline in functioning without positive symptoms [Group 1]).

In terms of treatment; the low transition rates and high levels of symptomatic and functional remission observed indicate that this patient group may not require treatment via antipsychotic medication in the first instance. Clinicians should be trained in psychological therapies which help young people understand, challenge and manage auditory and visual disturbances, bizarre ideas and suspiciousness/persecutory ideas which are commonly reported at initial presentation. The high levels of depression and anxiety observed alongside

maladaptive levels of social functioning, family perceptions and metacognitive beliefs should also be targeted by psychological techniques where appropriate.

4.4.3 Future Research

Future research should consider trying to replicate the findings using a much larger multisite study with a longer follow up period of at least two years. Plans are in place to continue the FARMS project and follow up individuals within this cohort for this time period to see how symptoms and functioning progress over the longer term.

Additional data analysis could be undertaken to answer, for example, whether differences exist in the presentation of adolescents with ARMS in terms of age and gender. Further recruitment and characterisation of 'at-risk' adolescents combined with previous data collected with 'at-risk' adult populations, may allow for further multivariate analysis across age groups in order to provide mathematical support for the existence of ARMS sub-groups that present to mental health services. In addition it has not been established how this cohort of 'at-risk' adolescents differs from an age and sex matched peer group sampled from within generic CAMHS services. Based upon previous literature it is possible that sub-threshold perceptual disturbances are also commonly experienced within this adolescent population (206).

Further investigation into the roles of metacognitive factors and family perceptions in the development and maintenance of sub-threshold psychotic symptoms is also required in order to support or challenge existing theoretical frameworks and potentially identify specific roles for cognitive and family based therapies. As previously discussed, participants should be recruited from other groups (non-patients, first episode psychosis patients) in order to undertake more meaningful and robust experiments.

4.4.4 Conclusions

The findings indicate that young people with an ARMS present to mental health services with significant and similar levels of symptomatology when compared to their adult counterparts. Individuals frequently present with highly distressing perceptual abnormalities and significant symptoms of depression and anxiety.

In terms of short term outcomes, transition rates to psychosis are low whilst many experience significant improvements in functioning and positive symptomatology. These findings need to be confirmed in a larger cohort of adolescents but they should significantly influence and inform the provision of services offered to these young people as well as directing clinical training needs.

5 Follow-up of the At Risk Mental State (FARMS) project: Study 2

5.1 Introduction and Aims

It is suggested that individuals with an ARMS present to services with substantial impairments in functioning, symptomatology and quality of life (69, 88-90, 100, 101). However, it is unclear how individuals experience and understand the term 'At-Risk Mental State' or 'ARMS', given its potential to create unnecessary anxiety and stigmatization (170). Previous research from genetic testing for conditions such as Huntington's disease and breast cancer show that people are not always keen to know their own risk status (177). Informal observations suggest that young people and their families experience a range of feelings and emotions when presented with this 'ARMS' label. Some individuals experience relief and tend to feel 'better', possibly because they are deemed not to be psychotic (179), whilst others demonstrate concern, scepticism and denial to the news (159). In order to offer effective services, mental health professionals require information about how patients experience their condition as well as how they feel about the services offered to them. Although there are a handful of services who have defined care pathways for those with an ARMS (69, 70) little is known about patient satisfaction in relation to the support offered. In the absence of official treatment guidelines it is unclear what interventions are routinely offered within the NHS to individuals not participating in on-going treatment trials.

Obtaining detailed knowledge about this age group is extremely important given that they be more sensitive to the effects of wrongful identification such as stigma (1, 170). The following study is therefore required to investigate the personal experiences of adolescents identified as having an ARMS in the context of their journey through mental health services.

5.1.1 Research Aims

The primary aim of this study was:

a) To qualitatively explore the personal understanding and experiences of adolescents identified as having an ARMS

5.1.2 Research Objectives

The principal objectives of this study were:

a) To explore how adolescents come to understand and experience having an ARMS label using an appropriate qualitative methodology.

b) To explore how adolescents with an ARMS label experience the treatment and support offered by mental health services.

5.2 Methodology

Recruitment and Sampling

Individuals for this study were recruited purposively from those participating and providing informed consent for FARMS Study 1 (see FARMS study flowchart; Figure 1). These individuals were perceived to be ideal for sharing their perspectives on the main phenomena under investigation (i.e. how do adolescents experience the ARMS label and the subsequent support offered by mental health services?) and were readily available to the author for potential recruitment. Interviews were offered to all individuals upon reaching the six month follow up stage of FARMS Study 1 unless they were deemed to have made the transition to a first episode of psychosis, were seen as unsuitable for participation by their treating care co-coordinator or data saturation (during data analysis) had already been obtained. Those who were psychotic at this stage were excluded based upon the assumption

that they would be unable to provide informed consent and coherent data. Treatment and clinical care was also deemed to be a higher priority at this time than research participation. Participant suitability as judged by the young person's care co-ordinator and data saturation are discussed further under the heading of data analysis and quality assurance. This method of sampling was deemed acceptable when considered in relation to a previous qualitative study of ARMS individuals (172) and other studies utilising Interpretative Phenomenological Analysis (IPA) in psychosis related research (178).

Interview schedule and Survey design

A semi-structured one to one interview design was chosen as it allows participants a chance to think, speak and be heard which facilitates a more in depth personal discussion (319). The method also provides a greater degree of flexibility allowing the researcher to modify questions in light of the participants responses, probe interesting areas that arise and explain concepts in a variety of forms (320). This flexibility was perceived to be especially important given the age of participants involved and author concerns regarding the development of rapport and free flowing conversation during the earliest stages of the interview process. This situation also allows the respondent (the experiential expert) to lead the discussion and provides the maximum opportunity to tell their own story (321), therefore this approach tends to be favoured by previous studies adopting IPA methodologies (319). Other practicalities such as the participant's geographical locality, possible social anxiety/suspiciousness (a potentially common difficulty in this patient group) and the variability of the six month follow up stage meant one to one interviews were more convenient to conduct compared to focus groups.

Despite the participant's close involvement and the potential for them to lead the discussion, it is still important to develop an interview schedule, which may help identify potential difficulties that might be encountered and facilitate a more coherent experience for those involved. During the development of the interview schedule, methods to establish rapport, avoid leading questions and to follow the respondent's interests were adopted (322). The content and structure of the

interview schedule was informed by the aforementioned background literature, the studies aims and objectives as well as previous clinical and research experience. The design process was iterative with questions, ideas and prompts changed as ideas were explored with the study supervisor. Funnelling techniques and prompts were employed when constructing the schedule, whereby the participant's general views are initially sought before 'funnelling' and prompting individuals into more specific areas of concern (321). The schedule was piloted and reviewed before study commencement with the help of the study supervisor, staff from the EIP service and a current service user.

The interview schedule did not have a fixed question order, allowing participants and the interviewer the opportunity to expand on issues that were particularly relevant and interesting. Questions were deliberately open ended to allow a minimum amount of interruption or constraint by the interviewer (see Appendix 6 for the schedule).

Data Collection

All interviews were conducted between June and November 2010 at the convenience of the participant. In all instances these were conducted within a private and confidential room at the participant's local CAMHS or EIP service. All interviews were recorded and used to create verbatim transcripts within one week of the interview having taken place. It was decided that transcription would follow a denaturalistic technique (a technique less interested in the actual speech patterns themselves but more focussed on the informational content of the speech: 323). During transcription words were recorded exactly as they were pronounced, grammatical errors in speech were left uncorrected and involuntary vocalisations (such as laughing and crying) were noted. This method of transcribing is perceived as obtaining a 'true' record of the conversation and honouring and respecting the participant's voice.

Ethics and ethical considerations

The research project was ethically approved by the Durham University School of Medicine and Health Ethics Committee and the NHS National Research Ethics Service for County Durham & Tees Valley 2 Committee. Informed consent was obtained from all participants and in the case of younger adolescents (those below 14 years of age) and under the care of the local authority, consent was also obtained from a parent/carer/significant family member. Information relating to confidentiality and safe storage of information was extensively outlined in verbal form. In order to preserve anonymity, each participant was assigned a unique study code, which was used in all transcriptions and subsequent data analysis. All participants were given a £20 gift voucher for participation. It was made clear on several occasions that this monetary sum was to reimbursement participants for their time and expenses and not as a means of influencing their responses.

The interviews potential to generate distress (in relation to the discussion and exploration of young person's mental health) was carefully considered and managed. Topics deemed to be particularly sensitive were left until the latter stages of the interview once rapport had been established (320). Debriefing (an opportunity for participants to ask questions and discuss issues relating to the interview) was given to all participants. In all instances the young person's care co-ordinator was on hand in order to deal with any clinical as opposed to research issues that arose. Previous research however has shown that participants of qualitative research, if properly managed, usually find the experience therapeutic ('getting things off ones chest') and altruistic ('it can help somebody else'). Such research often meets a need that is not addressed by routine services by giving 'voice', clarity and understanding to participants (324).

Data Analysis and quality assurance

In order to analyse the qualitative data obtained, Interpretative Phenomenological Analysis (IPA) was deemed to be the most appropriate methodological framework to answer the research question. IPA is a relatively new qualitative research

technique that focuses in detail upon how individuals experience and perceive major life events (322). In some ways this technique goes against the traditional positivist paradigm in health research (with its emphasis on reliable, quantitative measures) by focussing on an in depth understanding of personal experience and meaning.

IPA is informed by three key areas of philosophy: phenomenology (the study of experience and how we come to understand our lived world), hermeneutics (the theory of interpretation) and idiography (the study of the particular or individual). The Phenomenological aspect of IPA is heavily influenced by the philosophers Husserl and Heidegger. Husserl stated that it was important to help individuals understand their own everyday experiences in depth using reflection and putting to one side or bracketing our everyday beliefs (325). By thinking and reasoning about the phenomenon at hand from several different perspectives we might help illuminate a given experience for the individual and others in a similar situation. Heidegger (326) suggests we make sense of our world through comparison. Therefore we can interpret and make sense of an individual's relationships and interactions with the objects, language and culture that surround us. For IPA, Husserl's work emphasises the importance of a focus upon experience and its perception. Whilst Heidegger and other philosophers help us consider that all of us have a personal world which can be understood by the relationships we have with others and the wider context.

In regard to hermeneutics, Schleiermacher (327) was one of the first to categorise hermeneutics and interpretation into grammatical and psychological forms. The grammatical form was concerned with the exact and objective textual meaning, whilst psychological referred to the individuality of the author or speaker. Schleiermacher believed that there is something unique about the techniques and intentions of a given writer. Hermeneutics, therefore, should aim to understand the writer and the text. Thus an analyst can offer a perspective on a text which the author cannot. Heidegger (326) also contributes to our understanding of hermeneutics by suggesting that information can have visible and hidden meaning. A writer, reader or analyst always brings their fore-conceptions (prior experience, assumptions and preconceptions) and cannot help producing or analysing new

stimulus based upon their prior knowledge. According to Gadamer (328) it also must be considered that new information under interpretation can in turn influence our fore-structures. Finally hermeneutic writers discuss the importance of understanding parts by studying the whole but to understand the whole one should also look at the parts. This notion is part of the hermeneutic circle (322).

Finally, idiography is concerned with the particular using detail and deep analysis. Any person offers us a personally unique perspective on a phenomenon of interest and therefore warrants investigation. Delving deeper into the particular is viewed as bringing us closer to the universal by helping us understand how we and other people might deal with a situation. Therefore although idiography does not eschew generalisation it prescribes a different way of establishing those generalisations.

The IPA technique therefore aims to avoid making prior assumptions and hypotheses and sees the research participant as the expert who can offer understanding by relaying their own stories, feelings and experiences (an 'insider's perspective'). The IPA approach is especially useful when one is concerned with complexity, process or novelty as it allows researchers to reveal unanticipated phenomena, rather than embarking on a project with a predetermined set of hypotheses. However, interpretation and analysis of data is labour intensive with much coding and organising of data to generate themes of shared experiences. Analysis is then developed around verbatim exerts which illustrate and support a particular point of view.

Previous studies using this technique have looked at a whole range of health related issues such as genetic testing (329), drug addiction (330) and chronic back pain (331). In the field of psychosis it has been used to explore how people experience group CBT for auditory hallucinations (188), how service users deal with stigma (178) and how people perceive hope and recovery (192). Within the NHS, IPA has great appeal by listening to the voices of service users, helping them explore and understand their experiences and offering researchers the opportunity to integrate research and practice (319). The approach is consistent with NHS objectives of involving service users in the delivery and evaluation of mental health services

(332). Interpretative Phenomenological Analysis is also perceived to be particularly suited to researching in unexplored territory where information is currently lacking.

The idiographic stance of IPA and its commitment to detail and depth of analysis means that small purposively selected samples are the norm within this type of research. Although an initial review of IPA studies found a mean sample size of fifteen (319), Smith et al., (322) recommend a sample size of between three to six. It has been suggested that such a sample should provide sufficient data to determine potential similarities and differences between participants without the danger of being overwhelmed by the amount of data. Participant recruitment for this study was therefore ceased taking into account these recommendations and upon the perception of data saturation. Data saturation is the point at which qualitative information collected by the researcher becomes repetitive and contains no new ideas or themes. At this stage the researcher becomes relatively confident that the inclusion of additional participants is unlikely to inform data analysis further (333). Since IPA is a detailed exploration of a person's life experiences it is also important that participants are chosen who are able to engage with an interviewer and are both able and relatively comfortable in articulating their experiences and opinions (319). For this reason individuals judged by their care co-ordinator to be unable to fulfil this requirement were not considered for study inclusion.

For the purposes of this study, data analysis initially took place on a case by case basis. The first step in the process involved immersing oneself with the first interview and transcript through a period of re-reading and reflection. Once comfortable with the transcript a free textual analysis was undertaken. Notes and comments were initially made in relation to the semantic content of what the participant had discussed during the interview (descriptive comments). In general key words, phrases or explanations used by the participant were recorded and highlighted. The level of analysis at this stage is about taking things at face value and identifying the key thoughts and experiences outlined.

After the initial descriptive analysis a more interrogative and interpretative examination of the transcript and initial notes was conducted. Analysis at this stage

is at a much higher conceptual level, moving away from the more explicit claims of the participant and incorporating elements of personal reflection, experience and questioning by the analyst. Attempts are made to identify issues which are perceived to be important in understanding the participant's world and the matters they are discussing (conceptual comments). This stage of analysis requires much reflection, trial and error and refinement of ideas.

Once completed the next stage involved the development of emergent themes from the key highlighted text and conceptual comments. This took the form of producing a summary statement aimed at describing what was important in the various comments attached to a piece of transcript. Emerging themes are the beginning of organising the data into meaningful groups and therefore it is important to code for as many potential themes as possible at this stage as it is not clear what might become interesting later. An example of the free textual analysis, highlighting process and the identification of emergent themes can be seen in Appendix 7.

After establishing a set of initial emergent themes within the transcript the next step involved the mapping of how themes fit together to provide an overall concept and higher level of understanding. Searching for connections and links between emergent themes involved several analytical techniques. The first of these was abstraction whereby all the emergent themes were placed into a chronological list (see Appendix 8). The list was then reviewed with themes being moved around to form clusters of related themes. Abstraction therefore involves putting like with like with some themes acting like magnets pulling certain themes towards them. For example, emergent themes that relate to particular narrative moments or key life events may cluster. Such a process is known as contextualisation since contextual and narrative elements are identified that connect themes during analysis. Once a cluster is formed a new name for the cluster or a super-ordinate theme is created. This process is aided using extracts from the transcript itself. Organising and grouping relevant transcript extracts helps the analyst to review the internal consistency and specificity of each emergent theme (see Appendix 9).

The next stage in the analysis involved the repeating of this process for the

remaining transcripts. Here it is important to bracket and note the ideas that have already emerged from the initial analysis of the first case to ensure later work is not significantly influenced by what has already been found. Systematically adhering to the process previously outlined facilitates this process by allowing new themes to emerge. Once each transcript has been analysed in this way it is important to look for patterns and connections across cases. This may involve identifying themes which are the most frequent or potent. This will usually lead to the reconfiguring or re-labelling of themes. The final results of this process can be presented visually in a master table where themes are presented that are recurrent in at least two thirds of all the participants interviewed. Counting the occurrence and presence of themes in this way ensures the findings are representative of the participants interviewed but without losing the detail from an individual perspective. A master table presented in this way also aids the data analysis writing up process (See Appendix 10 for an excerpt from the master table produced).

In terms of quality assurance in qualitative data collection and analysis, reflexivity (the process of reflecting upon ones background, motivation and prior assumptions and how this may influence data collection and analysis) is important to consider (334). Although all IPA data analysis is interpretative the analyst and in this instance the author, contemplated how their position as a mental health professional for the Early Intervention in Psychosis Service may have influenced participant's accounts during the interview stage and any subsequent interpretation of the responses given. Thus, in order to explore the author's involvement with the study a reflexive log was kept throughout the research process. This involved reflecting on a regular basis (usually after conducting interviews or after the generation of potential themes) upon the ways in which the authors own values, experiences, interests and beliefs may have shaped the subsequent data and interpretations. Important reflections were discussed with the study supervisor and addressed where possible.

In summary the primary analysis and generation of themes was reliant upon the interpretation of the author and reviewed and modified by the study supervisor who had previous experience in IPA analysis. This review process confirmed the

appropriateness of the connections and themes identified from the original transcripts.

5.3 Results

Demographics

In total six individuals from the first seven recruited by Study 1 were identified as being suitable for study inclusion. The one individual that was not considered was deemed to be inappropriate given their limited engagement and verbal skills at baseline assessment and on-going assessment for a mild learning disability. All six identified individuals provided informed consent and were interviewed at the six month follow up stage. The key demographic details of each participant at the time of the interview are outlined in Table 14. The Current Status column indicates that one individual had demonstrated significant improvements in their levels of functioning and symptomatology (Full Remission) whilst another individual had seen a significant improvement or remission in their positive psychotic-like symptoms (Symptom Remission) at the time of the interview.

Table 14. Key demographic details

Participant	Age (years)	Sex	Current Status
AA	16	Male	Full Remission
BB	13	Female	ARMS
CC	16	Female	ARMS
DD	16	Female	ARMS
EE	15	Male	Symptom Remission
FF	18	Male	ARMS

Identified Themes

From the interview transcripts, three super-ordinate themes emerged during analysis. These were labelled as follows and adopted actual quotations from the participants that succinctly summarised the content of each theme.

1. *"It is better to say it"*
2. *"How others would take me"*
3. *"Just to have somebody to talk to"*

***"It is better to say it"* (FF, 46)**

The statement by FF nicely summarises the overall feeling that young people wanted to be told about their condition after being categorised as having an ARMS. FF, possibly based on their past experiences believed that withholding information could just make things worse over the longer term and it was refreshing for mental health services to be upfront with him about his condition:

> "*You were really straight forward and that's the way I prefer it. I don't like it when people tiptoe around things cos then, when you actually realise it [that you are ill] it just hits you hard and causes too much stress. It is better if you are going to be told something like you have schizophrenia or we believe that you are suffering from a form of depression, it is better to say it." (FF, 46).*

Being open and honest about their condition appeared to make CC feel respected as an adult and a person. This initial sharing of information and feeling of respect between the young person and the service may have gone on to greatly facilitate future engagement and their therapeutic relationship with their treating clinician. Had information not been shared at this stage the realisation and acknowledgement of their condition at a later date could have made the situation a whole lot worse:

"I think you did good at like telling me the truth and things… like if you didn't tell me I would have probably been more upset." (CC, 242).

Several reasons were forthcoming as to why the sharing of information and providing individuals with a label at this stage was so important. For EE, the news was perceived as a relief because they realised that in fact many other people had been identified as having the condition. Knowing that others have similar difficulties was seen as comforting and came to normalise not only their psychotic experiences but their overall identity (who they are and what they thought of themselves as a person).

"Yeah, it felt more of a relief to sort of know you weren't alone. There was an entire service that dealt with people like you. It wasn't just a small group of people, so you feel a lot more sort of comfortable knowing that you are not a freak or something." (EE, 240).

In this excerpt there appears to be a strong desire not to be entirely unique or that different from other people as this would lead to the perception of being a "freak". We can also see here that EE recognises the scale of how many individuals have similar difficulties given that an "entire service" has been established. This acknowledgement of a specialist service for their condition also seems to reassure EE. This sentiment is touched upon by AA who reasons that if the condition has been recognised and has a name then mental health services should be able to help them. AA also finds reassurance in the fact that a mental health professional appears to have listened and confirmed their feelings and beliefs that something was wrong with them. The ARMS label in this instance appears to empower AA to obtain more information about their condition which seems to be important for someone who possibly has difficulties in dealing with uncertainty.

"I didn't really have much of a reaction, it was more if anything it was kind of a relief kind of thing because I knew there was obviously something wrong and the fact that somebody acknowledged that and I'd been seen and everything and I kind of had something to go away with that I knew

somebody else had already noticed, then I could work with that… I think it was, it maybe helped rather than it hindered because I knew that at least something was going to be done, at least that I was going to like see [my care co-ordinator] and everything and if I would have left and I hadn't been given anything then I might have been more worried about the future and stuff because I didn't know what was going on. With, given the At Risk Mental State kind of label thing it was helpful cos then I could read up and I knew how it was going to be dealt with and everything like that." (AA, 26).

FF on the other hand provides a more detailed and vivid description of how the information and label came to validate and make sense of their past experiences and behaviour. This recognition by the service that something was not quite right and providing a name for the condition not only confirmed their prior beliefs but also meant that other people had an understanding of their current mental state and that help maybe forthcoming**.**

"To be honest if you had actually diagnosed me with something like schizophrenia or something like that I think it would explain quite a lot, like why I am different around certain people and why when I'm depressed I start hearing things or seeing things in shadows, stuff like that basically…It actually calmed me down, knowing that like… you had some idea of what was going on with me." (FF, 18).

However, the initial reaction of one participant is not so clear cut to those previously outlined. Although BB was happy about being explicitly told about her condition from the onset;

"It was better though that I knew what I had instead of being clueless about everything, rather than something random." (BB, 140).

her reactions to this news was markedly mixed. BB initially describes in the interview a relief in not being diagnosed as "schizophrenic" and therefore being more accepting of themselves as a person.

"Well I was, it was okay because at least I wasn't labelled as schizophrenic or anything so it was; because it means that I don't exactly have what I thought I had so it was okay." (BB, 30).

"More like happy, happy with myself. So I wasn't labelled as a, like, as a, you know [a schizophrenic]" (BB, 43).

Although these statements seem to suggest that the news had been positive especially in potentially protecting BBs self-esteem and developing self-concept, the interviews progression uncovered that actually her earliest reaction had been slightly different.

"Well I didn't, like at first when I started getting it [psychotic symptoms] I didn't really know what it was and I just thought it was one of those things and then once I was told about it and stuff I felt like insecure and didn't really like myself and then being said that I had At Risk Mental State wasn't really a good thing neither but it was better than thinking that [I was schizophrenic]" (BB, 81).

This excerpt seems to indicate that BB was confused and struggling to make sense of her developing symptoms and initially did not consider herself to be unwell. Information and potential misunderstanding of this information seems to have led to feelings of insecurity and self-loathing. Only when she had fully grasped and understood the meaning of the ARMS did she feel any sort of relief which in turn seems to have eventually led to positive acceptance.

Despite these negative experiences (potentially as a result of misunderstanding), the overall consensus (even from BB) was one of sharing information with young people and being open and honest about their condition from the outset. In all instances this strategy was perceived as having a positive effect in the immediate and short term.

"How others would take me" (CC, 106).

The way other people would react and whether it was wise to tell them about their condition was a major issue for the young people interviewed. Both BB and CC especially felt anxious about being accepted by society in general and the things people may say about them in the future if anyone knew about their condition. For this reason keeping quiet was perceived as the best option.

> *"I don't go mentioning it to anybody cos I'm scared of what they think of me or what they say or they would think I was a psycho."(BB, 95).*

> *"Yeah like if I am going out with people they are going to look at us and think what's wrong with her, just things like that." (CC, 139).*

Despite this anxiety about being stigmatised, these presumptions on the whole did not match up to actual experiences. In terms of friendships these appeared to be largely unaffected even when they found out about the participants condition.

> *"They don't really react that much to it, they just act[ed] the same." (DD, 63).*

> *"They were worried….but there was no real change." (AA, 135).*

Although individuals were understandably reluctant and cautious to inform their friends about their condition, two chance incidents for BB and FF brought their condition out into the open. For BB the experience of having their thought diary read by one of their friends was actually positive as her worst fear of being perceived as 'crazy' or a 'psycho' was not confirmed. In fact the incident indicated to BB that despite her condition people were still willing to accept her as a friend. This acceptance seemed to be a massive boost for her self-image and esteem which had been slightly dented by being labelled as having an ARMS previously.

"I kept a diary of my thoughts and feelings and things, like I was told to do and I took it to school in case I had an experience and as I was writing, one of like my closest friends, who she didn't actually know about my problems, she snatched it off me cos she thought it was just like a general book I was writing in and she had a look and she felt so sorry for me. So that made me a bit more happier that she didn't exactly think I was completely crazy." (BB, 100).

Although the unveiling experience described below does not appear to have been as significant to FF in terms of his self-esteem, it did serve to confirm that his friends were both supportive and generally concerned about his wellbeing.

"Most of my friends saw me taking my medication and they asked, they realised that it wasn't multivitamins or anything like that cos they saw the actual pill packet and asked what I was doing and I thought well there is no point in hiding it and I told them. And they just asked how I got to the state I was in and if there was anything they could do to help." (FF, 120).

It is interesting to consider that if it had not been for these chance incidents, would young people have informed their friends about their condition? Although it appears that EE had not explicitly told their friends about having an At Risk Mental State in this next excerpt, he had made them aware that he had been accessing mental health services. EE also appears comfortable in providing friends with exact details should the situation arise indicating that he has a trusting and secure relationship with his friends at this time. His symptoms and mental health difficulties again do not appear to have damaged his relationship with his closest peers.

"Not specifically, but some of my closest friends do know that I go for instance to CAMHS but then they have been perfectly supportive of it and perfectly understanding … If they were worried for instance and they ask why do you keep having appointments then I probably would tell my closer mates [about my condition]" (EE, 56).

Despite positive interactions with close friends, individuals did experience some negative stigmatisation from their peers. Although BB had been particularly worried about experiencing this type of behaviour previously, the experience when it occurred did not appear to be particularly upsetting. Her friends' opinions and their unconditional acceptance appears to be the only view that really mattered upon reflection on these incidents.

> *"Yeah a few people have cos I have the odd few people who take the mick out of me but then I have my close friends that don't like, don't, haven't really changed much, when I have told them." (BB, 114).*

AA also experiences some derogatory remarks although again does not appear to be particularly phased or unnerved by these experiences. There appears to be a feeling that these comments are not significant since these people are not his friends whilst name calling is just part of a normal teenager's existence.

> *"There are a few [who] aren't really friends who are like you are a nutcase or whatever but that's just really [what happens]" (AA, 140).*

As well as the reaction of peers, how family members reacted was also considered important. For all participants things remained largely unaffected at home, with parents reacting in a supportive and understanding manner. EE jokes that they were not cast aside by their family and somewhat surprisingly his parents had not reacted in an overprotective manner. This was clearly something he had been particularly relieved about, possibly because such a reaction by their parents would have had a detrimental effect on his current life style.

> *"Not really, they seem quite supportive … no drastic changes or anything. I wasn't suddenly sort of shunned or nothing like that [laughter] … I was worried that they might become a bit protective but they understood that it wasn't, it didn't mean, it didn't actually make anything different." (EE, 73).*

For CC, her experience in relation to her parents is also positive. As for wider family members however, CC describes some angst from her brother, but this is just passed off as being part and parcel of having a sibling. Even this experience with her brother is potentially positive as it indicates to CC that nothing has changed within the family because of her condition.

> *"They were supportive and they understood. They were fine, just me brother who worked me a bit but that's what they do." (CC, 112).*

For AA, the sharing of information and the reaction of the wider family does not appear to be as important as it was for CC. The excerpt below indicates that although he was comfortable with other family members knowing about his condition there was no need or desire to go into explicit detail or go out of his way to inform them. This attitude towards seems to suggest they are not ashamed or embarrassed by their condition and not particularly concerned if others were to find out. Again this indicates that they believe their family will understand.

> *"I don't think I've really told them much. They knew I was being seen, coming here, but other than that I don't think they really knew or what. I think it was only my mam and dad who knew anything detailed. It wasn't like kept from them, deliberately; it wasn't like hiding things round the house, that kind of thing." (AA, 100).*

Overall despite initial anxiety as to how other people would react and perceive them, it appears that friends and family members were accepting and understanding. This acceptance significantly increased self-perceptions and esteem as well as giving those interviewed the ability to deal with and brush aside any negative reactions or experiences that had been forthcoming.

***"Just to have somebody to talk to"* (DD, 134)**

The quote by DD nicely summarises what participants found particularly valuable and useful in terms of the support offered to them by mental health services. At an initial level young people were reassured by just having someone who was actively listening to them as well as having an opportunity to openly talk about their concerns. The issues discussed during therapeutic sessions however did not always have to be related to their specific difficulties and could focus on unrelated topics indicating that young people were happy at times just to have a general chat.

> *"It was just somebody there and like sometimes if I was getting like to the point where I was getting into too much, like if I got too much out into the open, then we [would] just talk about something else like in general, [like] animals or anything but it seemed like whenever I came cos I could just talk and talk and talk even though I probably battered their [the clinicians] head, I just talked [laughter] … I got what I needed which was just the general talk that's all that I needed like just to get everything out." (BB, 195).*

The sentiments of BB are also shared by AA who saw the presence of someone to talk to as a sign that people were actively trying to help him overcome his difficulties.

> *"I think it was probably just knowing that somebody was helping was probably the biggest help, just knowing that someone was there and they were writing it down or whatever, they were actively trying to help, probably made me feel better." (AA, 217).*

There also appeared to be a particular desire and benefit in discussing their problems with someone other than a family member. For example both BB and CC appear to take great comfort in talking to someone other than their parents. In this instance talking seems to be a mechanism allowing young people to share their problems and worries in a safe environment without upsetting people who are particularly close to them.

"I just get everything out in the open and I don't have to worry about anything and stuff … cos I don't exactly want to go and tell my mam about like if I have had an experience or anything cos she is my mam and everything but I mean I just don't want to make her feel upset." (BB, 182).

"I felt better because I didn't know the person like if I talked to me mam. It just felt different and better if you know what I mean." (CC, 38).

Talking to someone other than a parent was particularly useful for DD who perceived her parents, especially her father not to fully understand the difficulties and problems she was facing. Spending time with someone who understood and was prepared to listen to how they were feeling helped them understand their condition and in their words made things better.

"It made it better because I could talk more about it, say more about it. Like how things are and how I felt and that." (DD, 85).

Not only did talking aid understanding but the sharing of upsetting experiences, questions and general teenage problems seemed to act as a protective and therapeutic mechanism ensuring these stressors did not build up over time. AA discusses how his therapeutic clinical sessions resembled a weekly chat that dealt with issues as and when they arose. Although the extract below indicates that some form of cognitive behavioural therapy has been incorporated into sessions, AA perceives this as just a part of chatting.

"It was mainly about a kind of working a kind of week by week [routine] and every time he [the clinician] sees me he would ask me if there was anything happening, if anything had stressed me out and if anything like that. And if anything had, he would work through he would say, how do you cope with that better, could it have been worse, that kind of thing. It was mainly just talking things through." (AA, 192).

Talking about day to day things with someone who was supportive, almost like a friend, was especially comforting for EE. The thought of their clinician as a friend serves to indicate a potential lack of opportunity and a desire to talk in depth about their difficulties with their peers.

> *"For instance like, talk about school and home for instance. I just needed someone to talk to like a friend who was more than happy to do that. So it wasn't as if he [the clinician] was just there to sort of do his job kind of thing and then that was it. It was a lot more comforting to have someone who was like a friend." (EE, 173).*

This opportunity to talk and communicate to peers with similar difficulties was discussed at lengths by almost all participants. Although such an opportunity had not been made available to them, both AA and CC outlined the potential benefits of having had some sort of interaction with peers also with an ARMS label.

> *"I think it's probably more that you know somebody else who is going through the same thing. I think that helps quite a lot just in your own mind, just maybe put you at ease a bit." (AA, 253).*

> *"I think that would be helpful because they are experiencing it or experienced it and they can tell you how they dealt with it and how they coped." (CC, 235).*

Unsurprisingly, given EEs previous comments about needing to talk to someone who was like a friend, they went on to outline many ideas about how to facilitate peer contact. Ideas included some form of social group, contacting a young person who volunteered via email or having a direct face to face chat. In this excerpt EE touches upon the issue of talking to someone who has actually experienced an At Risk Mental State first hand.

> *"Yeah, someone has been through the same thing, like the option. If you want to they could come in as well and talk to them about their experiences with it … so you can sort of get a first-hand perspective of what it's like from someone who has been through the same things as you or something very similar." (EE, 261).*

FF provides a more in depth description of the importance of talking to someone who can provide a real empathy because of their own personal experiences.

> *"Sometimes when you are talking to people and like they are giving you advice and stuff you can't help but think they don't really get what you are going through. I mean yeah there's obviously teenage drama that happens that obviously everyone has been through that but when it comes to things like a close relative is dying and you already have severe depression and then you have to give another horrible decision and then everything getting piled up on top of you, you don't know how to cope. That's what, that would be a time where you try and talk to someone and they give you advice but you don't feel like they fully grasp the situation so that would be a time when it would be useful to talk to someone who has either been through a similar situation or has the same thing as you." (FF, 283).*

Overall the importance of a therapeutic chat with an experienced clinician or a young person with similar symptoms, experiences and difficulties was explicitly and implicitly implied as the most important support that could be offered by mental health services rather than any specific interventions per se.

5.4 Discussion

The findings from this qualitative study indicate that young people are keen to know about their condition and respect clinicians who inform them about this. As postulated by others who work with ARMS categorised individuals, the provision of a label appears to confirm that treatment is forthcoming (177) and is perceived as positive news because individuals are not currently psychotic (179). These findings are similar to that of Wisdom & Green (181) who found that many of their sample of depressed teenagers reported relief when hearing about their diagnosis as it confirmed that their distress had a name and they were not the only people to experience such symptoms. The concern, scepticism and denial to the news about one's risk status, observed and predicted by other researchers (159, 177) was not apparent within our sample.

The hostility and stigma experienced by people who are psychotic or have an elevated risk state for other conditions such as Huntington's disease (1) was feared but was not significantly experienced by young people with an ARMS. Unlike individuals with a label of psychosis many did not perceive or experience a loss of contact with friends they had had prior to their illness (198). On the whole most young people reported no major changes in how they were perceived by their family and friends and therefore appeared able to deal with any hostility that was forthcoming.

In terms of treatment and support it appears that young people found the opportunity just to talk to a mental health professional particularly beneficial rather than any specific medical or psychological therapy. The findings are in keeping with the experiences of adult Early Intervention in Psychosis service users who highly valued therapy which allowed them to communicate their difficulties and also promoted interpersonal interactions with clinicians (172). Talking to someone other than their parents was also highlighted by the young people whilst suggestions were made into how contact and communication could be facilitated between peers with similar psychotic experiences. It is well established that people with psychosis develop

friendships with people who understand and have experienced the condition themselves as they assume that others will not understand or be accepting of their condition (198). Therefore psychosocial engagement programmes that encourage activities typical of young people but also allow opportunities to meet and discuss issues with people who have similar experiences are desired and potentially essential to the recovery process.

5.4.1 Strengths and potential limitations

To the author's knowledge this is the first study to directly interview young people about their experiences of having an At Risk Mental State. Given the study's methodology, the data collected should represent in depth and personal accounts of young people's experiences in relation to their condition and the subsequent support offered by mental health services.

Part of the process of conducting and reviewing qualitative research is to reflect upon the experiences of carrying out the research and looking at one's own prior knowledge and personal circumstances. Reflective diaries and subsequent discussion of identified points during supervision facilitate this process and some of these reflections need to be discussed. One of the main challenges during this study was the facilitation of an in depth discussion between the interviewer and the young person. At times participants found it particularly difficult to describe and explain their experiences possibly because of difficulties in their ability to recall events and feeling comfortable with the whole interview process. At the time of the interview many still were symptomatic with mild levels of paranoia/suspiciousness, anxiety and difficulties in concentration and attention (common ARMS symptoms). These difficulties at times led to relatively short and superficial interviews especially for participant DD. It was assumed that the most important participant experiences were easily recalled and therefore stated during the interview process. Such difficulties should have been foreseen given that problems have been outlined previously when interviewing participants who are relatively young and have psychotic-like illnesses (335). This limitation is certainly an issue from an IPA perspective since data

collection and analysis using such a technique requires rich detail in order to infer personal experience and meaning. Future recruitment for any IPA studies within this population should consider sampling only the most articulate individuals (via more stringent intake criteria than those employed here). However, such a recruitment strategy seems to infer that the narratives and personal accounts of only the most articulate individuals are worthy of study and this should not be advocated. An alternative to this maybe to utilise other qualitative methodological approaches (as opposed to semi-structured interviews) that allow adolescents to feel comfortable in articulating their experiences in depth. A participatory action research approach (which re-addresses the balance between participant and researcher and is designed specifically by the participants themselves) is one such alternative (336).

The use of the semi-structured interview schedule, subsequent data analysis and the author's dual role as interviewer and mental health clinician during this study requires further scrutiny. Firstly, semi-structured interviews are acceptable from an IPA perspective but must be designed carefully not to directly impose any prior assumptions held by the researcher; *"You are trying ... to allow the participant to tell you what it is like to live in their personal world. You are not trying to find out what they think about your views of their personal world."* (322 $^{p\ 61}$). Upon reflection the interview schedule for this study appeared to be heavily influenced by the author's (conscious and/or unconscious) desire to uncover how adolescents experienced the initial labelling process, potentially ignoring other aspects and experiences of having an ARMS. This area of interest is indeed a potentially fascinating area but may only represent a small part of the genuine adolescent experience. This could be the result of the author's clinical background (as opposed to being an academic researcher or service user per se) or their personal stance towards the ARMS concept and labelling. It is also important to take into account here that the author was in part responsible and present during the initial process of providing participants with the ARMS label (because of the design and process employed during FARMS Study 1). It is therefore high plausible that participants might have found it difficult to voice more negative or critical accounts of services and other areas during the interview process because of this role. Studies that have utilised other service users to conduct interviews have predominately obtained more

critical and potentially 'honest' accounts of service provision (337). Most importantly from an IPA perspective it could be argued that the author had become an integral part of the participant's personal experience even before data collection and analysis. Within IPA, the researcher is supposedly a funnel or filter through which participants experiences are constructed, however in this instance the researcher has already constructed part of the participant's experiences. Given these factors the theme; *"It is better to say it"* might have been expected to arise during the process of data analysis. However, previous studies have indicated that the presentation of any diagnosis is a personally meaningful and significant event (181). For these reasons the theoretical transferability of these findings (i.e. the reader's ability to make links between these accounts and those individuals in a similar context) could be compromised. This theme therefore requires credibility checking potentially via the participants themselves in order to achieve trustworthiness (something that should have been considered and utilised during the conception and execution of the study).

In order to address these issues, a hypothetical replication of this study may consider using an unstructured interview technique (which is an attempt to implement IPA's inductive epistemology to the full) with one overall core question (i.e. 'What does it mean to have an At-Risk Mental State?'). Another alternative worthy of consideration and potentially less daunting to adolescent participants may have been for the author to have considered an alternative semi-structured interview schedule informed and amended by a current ARMS service user. Both methods are more likely to produce an interaction defined by the participant rather than the prior assumptions and desires of the interviewer. In terms of dealing with the author's dual research and clinical role, the option of using an independent (possible service user) interviewer could have been considered (although identifying and training a competent individual may be complex and time consuming). This combined with the removal of financial reimbursements and the conducting of interviews within non NHS settings may create a more relaxed atmosphere and reduce any possible response bias in experiences reported and data interpretation.

Finally, the decision to exclude individuals who had become psychotic is potentially biased as individuals who become psychotic may have significantly different experiences to those not making a transition within the first six months. The decision not to include this group was based upon the ethical issues of consent and need for treatment and should not be construed and interpreted to mean that the experiences of psychotic individuals are of any less value in enlightening others about the At Risk Mental State.

5.4.2 Clinical Implications

The findings from this study indicate that clinicians should always inform young people and their families about the identification of an ARMS. Clinicians have a key role to play in ensuring individuals and family members understand what the term means and that transition to psychosis is not inevitable or predetermined. Providing sufficient time for everyone to ask questions (a thorough debrief) and supplying appropriate psycho-educational material may be adequate in resolving misunderstandings, anxieties and possible concerns.

In terms of treatment it appears that young people prefer psychological or 'talking therapies'. This should be initially offered to all individuals since many see a significant benefit of having someone (other than a family member) to talk to. Given the level of impairment, the need for a 'supportive chat' should be provided by an experienced mental health clinician in order to monitor and manage ongoing symptoms.

Finally it could be potentially beneficial to facilitate social contact between young people with ARMS. As previously discussed this may lead to a sharing of useful management strategies and help young people normalise their experiences. Possible ideas include establishing regular social groups (i.e. playing football, going to the cinema etc.) or arranging one to one sessions between young people supported and observed by a clinician. Indirectly, these practices may improve levels of social

functioning.

5.4.3 Future Research

In terms of future qualitative research, it may be wise to contemplate interviewing individuals that go on to make the transition from an ARMS to psychosis (possibly at recovery) in order to compare the reactions and experiences of these individuals against those not making the transition. Such a study may identify important qualitative factors and experiences that facilitate the transition process.

Another area of qualitative study worthy of consideration is the experiences of parents and siblings who will no doubt have interesting accounts of living with someone with an ARMS. The needs of the siblings are often excluded despite their potential value as agents of recovery and the fact that they may come to perceive themselves as being at higher risk of developing psychosis too (191). Siblings have reported that they appreciate talking about their brother or sister's condition and how it has affected them but opportunities rarely exist. Such a study may prove both informative and therapeutic.

A recent movement in health research over the past few years has been to combine mixed methods to obtain a more complete picture or understanding of a concept since the integration of data achieves '*a whole greater than the sum of the parts'* (338 [p1147]). An example of this process is the identification of relevant qualitative themes via interviews and subsequently generating a hypothesis from this data and testing it quantitatively via a survey design. This approach of combining methods and any subsequent data collected is not appropriate from an IPA framework and standpoint and therefore was not considered for this study. However from a nomothetic perspective it may be beneficial to create a greater synergy between qualitative and quantitative methods. Future research using a more integrated mixed methods approach in this instance may consider whether individuals who experience poor service and react negatively to the ARMS label (qualitative methods/data) have

worse functioning and symptom outcomes over the short to medium term (quantitative data).

5.4.4 Conclusions

The findings of this study indicate that this group of young people reflect positively about being told about their condition from the outset, describe no significant change in their interaction with peers and family members and outline the benefits of talking to a mental health clinician as a form of treatment and support. These findings should significantly influence and inform the provision of services offered to young people as well as directing clinical training needs.

6 Professional Attitudes towards the At Risk Mental State: The (PAARMS) project

6.1 Introduction and Aims

Whilst there is an ever expanding research literature relating to the 'At-Risk Mental State (ARMS) for psychosis (339) it is not clear how this concept is understood and perceived by specialist and non-specialist mental health professionals. It is highly probable that a psychosis risk syndrome will be included in the impending Diagnostic and Statistical Manual for Mental Disorders version five (DSM-V; 86, 87). However, the validity and utility of the ARMS construct is far from universally accepted. Indeed, opponents of the concept suggest it may create stigma and expose young people to potentially harmful and unnecessary treatments (183, 340).

Young people who access Child and Adolescent Mental Health Services (CAMHS) and Early Intervention in Psychosis services (EIP) who develop psychosis may be at greater risk of poor illness outcome when compared to working age adults (27, 202). However, they may also be more sensitive to the adverse effects of antipsychotic medication (204). Therefore the appropriate identification and management of younger individuals at potential risk of psychosis is a high stakes issue.

At present there are no published reports of the attitudes of CAMHS or EIP professionals in relation to the ARMS concept although attitudes of general psychiatrists have been measured. In a comparison of attitudes held by general psychiatrists and primary healthcare physicians there was widespread endorsement of the clinical utility of ARMS, better identification as well as a marked preference by psychiatrists to treat ARMS with atypical antipsychotic as opposed to psychosocial therapies and monitoring practices (225).

Understanding professional attitudes and their experiences associated with the ARMS concept is therefore a neglected and potentially important area. The present study was therefore conducted to investigate the attitudes and experiences of Child

and Adolescent and Early Intervention mental health professionals who regularly work with or come into contact with adolescents with ARMS. The study should provide insight into how frontline clinicians outside of large scale clinical trials and highly specialised services perceive and endorse this concept.

6.1.1 Research Questions

a) What are the common experiences and major clinical issues faced by Early Intervention in Psychosis (EIP) professionals working with adolescents suspected and/or identified as having ARMS?

b) How do Child and Adolescent Mental Health (CAMHS) professionals perceive and understand the ARMS concept?

6.1.2 Research Aims

1. To qualitatively investigate and describe the common experiences of EIP clinicians who currently work with adolescents suspected and/or identified as having ARMS.

2. To quantitatively evaluate the knowledge and attitudes of clinicians in a CAMHS service in relation to the ARMS concept.

6.1.3 Research Objectives

1. To explore the experiences of EIP clinicians in relation to the assessment, identification and management of adolescents suspected and/or identified as having ARMS using an appropriate qualitative methodology.

2. To quantitatively evaluate mental health professionals, working within a CAMHS service in relation to their contact, knowledge, ability and confidence in identifying adolescents with an ARMS.

3. To evaluate and quantify mental health professionals, working within a CAMHS service in relation to their knowledge and attitudes regarding management, treatment and the clinical utility of the ARMS concept.

6.2 Methods

6.2.1 Study Design

The following study adopted a mixed methods approach. In the first instance a semi-structured interview based design was adopted in order to investigate, in depth, the common experiences of EIP clinicians. These qualitative findings then informed the design of a self-report questionnaire used in a wider survey designed to quantitatively investigate the current level of knowledge and attitudes held by CAMHS clinicians.

4.2.2 Recruitment and Sampling

For the qualitative study a purposive sample of care co-ordinators with a designated remit of working between EIP and CAMHS services within Tees, Esk and Wear Valleys NHS Foundation Trust were identified. Individuals were then considered for participation if they had been involved in the assessment and care co-ordination of two or more adolescents suspected of having ARMS in the previous six months. Permission to contact and approach the six identified individuals was granted by the service manager. The following inclusion criteria was deemed to be appropriate for the aims of the study given that these individuals were perceived to have the most experience and current day to day contact with adolescents with ARMS.

For the self-report questionnaire survey, all Child and Adolescent Clinicians working within Tees, Esk and Wear Valleys NHS Foundation Trust were initially identified for potential study inclusion using staff lists obtained from locality team managers. Trainees and students currently on CAMHS work placements were excluded from the study as well as individuals working for learning disability and forensic CAMHS. The sampling frame was thus 180 CAMHS clinicians.

Within Tees, Esk and Wear Valleys Foundation Trust, CAMHS clinicians are responsible for the timely referral of young people with a suspected ARMS to specialist Early Intervention in Psychosis services (70). Early Intervention in Psychosis services provide a wide variety of psychological and medical therapies for those with ARMS, sometimes sharing care with CAMHS. For the purpose of the survey CAMHS clinicians were divided into psychiatrists, psychologists, Primary Mental Health Workers (PMHWs; community-based professionals with a focus on mental health screening and interfacing with primary care) and generic CAMHS clinicians (those working with longer-term cases in mental health services).

4.2.3 Interview Schedule and Survey design

A semi-structured one to one interview design was chosen for the qualitative study for reasons outlined previously (Chapter V, Section 5.2). The semi-structured questionnaire schedule did not have a fixed question order allowing participants and the interviewer the opportunity to expand on issues that were particularly relevant and interesting (321). Questions were deliberately open ended to allow a minimum amount of interruption or constraint by the interviewer. The content and structure of the interview schedule was informed by the aforementioned background literature, the studies aims and objectives as well as previous clinical and research experience. The schedule was piloted and reviewed before study commencement with the help of the study supervisor and the EIP service manager (The interview schedule for this study can be seen in Appendix 11).

In order to survey CAMHS clinicians, a short self-report questionnaire was constructed by the author and two senior CAMHS clinicians with clinical experience of working with young people labelled as having ARMS. The content was informed by clinical experience and provisional findings from the qualitative study. The survey used a response format that mainly consisted of check boxes (dichotomous) and four-point likert rating scales (polytomous) in order to minimise the participant in answering. Free text boxes were also included in order to provide opportunities for respondents to clarify or elaborate on their responses. The brevity of the questionnaire and ease of response was viewed as important in achieving potentially high completion rates. The questionnaire requested information from respondents regarding five areas:

a) Prior experience of working with the Early Intervention in Psychosis (EIP) service and individuals identified as having an ARMS (present or absent).
b) Understanding of the main postulated features of the ARMS.
c) Confidence in identifying the ARMS.
c) Attitudes towards management of the ARMS, once identified.
d) Views on the utility of the ARMS concept.

The questionnaire was further reviewed by the chair of the Tees, Esk and Wear Valleys Children and Young Peoples Clinical Audit and Effectiveness group before study initiation (A copy of the questionnaire can be seen in Appendix 12).

6.2.4 Data Collection

All interviews were conducted between June and July 2010 at the convenience of the care co-ordinators participating. Permission to conduct the interviews during working hours was obtained from the care co-ordinators' line manager. This in turn meant that interviews were kept relatively brief lasting anywhere between 20-35 minutes. All interviews were recorded using digital audio equipment and used to create verbatim transcripts within one week after the interview. Transcription was performed using a denaturalistic technique (a technique less interested in the actual speech patterns themselves but more concerned with the informational content of the speech; 323). During transcription words were recorded exactly as they were pronounced, grammatical errors in speech were left uncorrected and involuntary vocalisations (such as laughing and crying) were noted. This method of transcribing is perceived as obtaining a 'true' record of the conversation and honouring and respecting the participant's voice.

The survey was distributed in both paper and electronic form between August and November 2010 to all child and adolescent clinicians identified via team managers. To ensure high response rates the survey was publicised by the lead author at local CAMHS team meetings.

6.2.5 Ethics and ethical considerations

Approval to conduct the staff interviews as part of a service evaluation was granted by the Tees, Esk and Wear Valleys Clinical Audit and Effectiveness Department and therefore was considered exempt from external ethical review. Informed verbal consent was obtained from all participants before interview commencement. Participants were assured of confidentially and anonymity with each participant

assigned a numerical pseudonym (PP1, PP2 etc), which was used in all transcriptions and data analysis. The use of audio recordings and the safe storage of information was also extensively outlined before interviews were initiated.

Approval was also given to conduct the staff survey as part of a service evaluation and again was granted by the Tees, Esk and Wear Valleys Clinical Audit and Effectiveness Department. In order to ensure participant anonymity potentially identifiable demographic details were limited to locality CAMHS team and professional background only.

6.2.6 Data Analysis and quality assurance

In order to analyse the qualitative data obtained, thematic analysis was deemed to be the most appropriate methodology to answer the overall research question. Thematic analysis is defined as 'a method for identifying, analysing and reporting patterns (themes) within data' (341). It is a process that encodes qualitative information, often generating lists of related themes, making the information more accessible and understandable to others (342). Themes are usually formed by patterns found in the data that, at a minimum, describes and organises information and at a maximum, interprets aspects of a phenomenon.

Although the methodology is widely used within psychology and health related qualitative research, thematic analysis in many instances is not acknowledged, possibly because it does not appear to exist as a named analysis unlike discourse analysis or grounded theory, for example. There is also less of a clear agreement about how it should be conducted which can be perceived as a weakness but also one of its strengths. Since it does not have any pre-existing theoretical framework this makes thematic analysis flexible in that it can be applied to a variety of data sets as well as not being restricted to the part of the data it may report. Analysis using this technique may report experience, meaning and the potential reality of participants. For the inexperienced qualitative researcher, it is more accessible as it does not require the detailed theoretical and technological knowledge as required by

grounded theory and discourse analysis. Researchers find thematic analysis to be of most use in the early stages of research enquiry (342).

The flexibility, its use in initial exploratory studies and the methods applicability to all types of data sets is a major strength given the fact that this study is one of just a handful of studies aiming to qualitatively explore the experiences of mental health professionals working within the psychosis field (185). By providing a clear framework and account of how the analysis was completed, any disagreement in how thematic analysis should be conducted is potentially overcome. This rule of providing a transparent account of the methods adopted applies for all 'good' qualitative research studies (334).

Data analysis initially took place on a case by case basis. The first step was to immerse oneself with the first interview and transcript through a period of re-reading and reflection. Once comfortable with the transcript a free textual analysis or coding process was undertaken, highlighting and describing the perceived key elements of what the participant had discussed during the interview. The codes generated identify items of interest to the analyst and refer to the most basic elements of the transcript and the phenomenon under investigation (341). Once completed the next stage involved searching for emergent themes from the key highlighted text. In this instance the emergent themes were generated inductively from the raw data as opposed to being based on prior theory or research (342). This took the form of creating a summary statement describing what was important or the meaning behind a particular aspect of the highlighted text. Emerging themes as opposed to codes are often broader and are the beginning of organising the data into meaningful groups. It is important to code for as many potential themes as possible at this stage as it is not clear what might become interesting later. An example of the free textual analysis/coding, highlighting process and the identification of emergent themes can be seen in Appendix 13. Once the transcript was coded for as many potential themes as deemed possible, themes were ordered chronologically and typed into a list with the location of key supporting text also attached (See Appendix 14 for an example of a list of emergent themes). At this stage the aforementioned process was repeated for all the remaining transcripts.

Lists of emergent themes were then printed with each theme from each transcript on a separate piece of paper. Themes were then rearranged to form clusters of related themes where possible. Other themes that did not seem to belong anywhere were placed in a miscellaneous theme, temporarily, as they may become useful and demonstrate relationships during the on-going review process (See Appendix 15). The process of organising themes is continuous and involves an on-going review of inter-relationships, combining themes, refining them or even discarding themes where there are few data to support them. Themes that were related and clustered together became super-ordinate themes and were given their own distinct names. Names were chosen which seemed to accurately conceptualise and represent the cluster of themes they represented. After settling on the number and names of these super-ordinate themes these were further broken down into several subordinate themes (See Appendix 16 for the final list of themes).

Although the process of coding and the generation of emergent themes can be aided using computer software, a more traditional paper and pen method was favoured. The method of paper and pen is clearly more flexible in allowing choice and creativity in how to conduct and organise each stage of the data analysis and interpretation process.

Reflexivity (the process of reflecting upon one's background, motivation and prior assumptions and how this may influence data collection and analysis) is important to consider in qualitative research (334). Although all qualitative data analysis is interpretative the author contemplated how their position as a mental health professional for the Early Intervention in Psychosis Service may have influenced participant's accounts during the interview and any subsequent interpretation of the responses given.

Thus, in order to explore their involvement with the study, a reflexive log was kept throughout the research process. This involved reflecting on a regular basis (usually after conducting interviews or after the generation of potential themes) upon the ways in which the author's own values, experiences, interests and beliefs may have

shaped the subsequent data and interpretations. Important reflections were discussed with the study supervisor and addressed where possible.

Quantitative data collected via the survey was initially coded and entered into the statistical package SPSS version 19 for statistical analysis (314). Each survey was initially entered and then re-checked to ensure accurate data entry. A variety of parametric and non-parametric tests were employed where appropriate.

6.3 Results

6.3.1 The common experiences of EIP clinicians currently working with adolescents suspected and/or identified as having ARMS.

Demographics

In total six EIP care co-ordinators were identified and participated in the qualitative study. Individual demographic details are not reported given that such information could potentially compromise the identity of the participants involved. Overall the sample consisted of four females and two males. The number of adolescents suspected or identified as having ARMS on participants current cases loads ranged from one to ten. All workers had a nursing background, had received accredited CAARMS training within the past two years and had worked with ARMS cases for a least two to a maximum of five years.

Identified Themes

From the interview transcripts, four main super-ordinate themes emerged during analysis. These were subsequently labelled:

1. The At-Risk Mental State label.
2. Treatment practices.
3. Working with adolescents.

4. Service development.

Each super-ordinate theme was further broken down into smaller more concise subordinate themes. Verbatim excerpts are included throughout the results section and have been selected based on their clarity and relevance to the themes identified and discussed.

The At-Risk Mental State label

All participants discussed the acceptability and utility of the At Risk Mental State label. This theme was further broken down into two subordinate themes: Acceptability vs. Negativity and Avoidance and Rephrasing.

Acceptability Vs Negativity

Overall clinicians had mixed views about the acceptability of the At Risk Mental State label from both a personal view point and based upon their clinical experiences and observations.

In terms of a young person's first reaction to being told about the At Risk Mental State, several clinicians described how the label did not invoke heightened levels of anxiety (which is usually the cases when a diagnosis of psychosis or schizophrenia is given) but in fact it came to reassure the young person that there was not something seriously wrong with them at this time. Many young people found the label positive as they used it to validate and explain their unusual experiences but without the stigma that is sometimes attached to these difficulties:

> *"It doesn't get young people thinking, 'Oh God I'm becoming a crackerjack or becoming a loon' for want of better terms … it's good in young person speak, it's more understandable for them.'" (PP 1, 73).*

"So to think that they have got some symptoms that puts them at risk is a much easier thing to come to terms with than saying that they have actually got psychosis." (PP3, 182).

"Some people are looking for a label, they are looking for something; 'this is why I'm feeling like this or this is why I'm different.'" (PP2, 208).

These experiences and beliefs however were in stark contrast to that of other clinicians. The first reaction by some young people as described by one clinician was one of hostility and defensiveness:

"So you think I'm a 'psycho' or I don't want to be a 'schizo' or a 'psycho' and that's kids terminology they don't understand." (PP3, 169).

Other clinicians strongly believed that the ARMS term was in fact highly anxiety provoking and too difficult and vague for young people and families to comprehend:

"Do you not think if you're speaking to a 14 year old and you say, 'all right we're going to take 6-12 months because you're an At Risk Mental State' and they're thinking 'oh my God what does that mean'? And even if you explain it, it doesn't sound too friendly does it?" (PP5, 150).

"I know that there are some people, some individuals and families who do want to know exactly (what is) going on, it can be very frustrating." (PP6, 127).

One clinician completely disagreed with the notion that young people with an ARMS realise that something is wrong and find relief and reassurance in the presentation of the label. This clinician outlined that many young people don't realise they have emerging mental health problems and the term comes as a surprise, possibly causing stress and making the situation far worse:

"I think the term 'At-Risk', I think, would send fear through a lot of people. I think they present that way because a lot of people don't even consider themselves to be developing any serious mental health problems they just know that they have particular anxieties and that they are struggling at the minute. I think if you kinda present it and say well you know you might be at risk of developing a psychosis I think that can increase the stress for that person it could make things worse really." (PP4, 98).

Avoidance and Rephrasing

Regardless of whether the clinicians perceived the ARMS label to be positive or negative many of them reported an avoidance of actually using the full term (At Risk Mental State for Psychosis) with young people and their families. It was found that many of the clinicians try to re-phrase the information and explanations they provide and avoid the word 'psychosis' altogether. As can be seen below clinicians indicate to young people that they are more at risk of developing a serious mental health problem but this problem may not necessarily be psychosis.

"I don't actually ever say to a client, this is the At Risk (Mental State). 'You've been diagnosed as having the At Risk Mental State'. I'll say 'I'm going to be working with you for the next 6-12 months and we are going to be looking at these experiences that you've had and trying to reduce you know, help you understand what's happening and help you reduce the anxieties around them' so that you know, you know. And just normalise it for them, but I never actually say to anybody, this is what label we going to give you ever… I think it's something we use as professionals but I don't think we use it when we are talking to the young person.." (PP5, 136).

"I guess its best explained to some of them by saying, 'You have got a risk of developing a more severe illness but we are trying to work with you to prevent that from happening'. That's kind of how I put it across anyway." (PP3, 150).

"No I've never said At Risk Mental State. I think, I just explore their experiences and their difficulties and explain that you know…I think just using the term that you have an At Risk Mental State is I think is a label and it carries a stigma … You word it differently basically and say that you know generally everybody at some point could be at risk of developing a serious mental health problem and that again that is about normalising things a little bit for them I suppose." (PP4, 118).

Treatment Practices

Current treatment practices from both a personal and service wide perspective were frequently discussed by the clinicians. This theme of treatment practices was further broken down into three subordinate themes: '*Medication is a big decision'*, 'T*he importance of social inclusion'* and '*Are we successful*?'

'Medication is a big decision'

Although all clinicians reported using a whole host of psychological therapies and interventions (such as cognitive behavioural therapy, solution focussed therapy, stress vulnerability models, anxiety management, social inclusion strategies) in order to reduce distress and 'normalise' young people's experiences, the most common topic of discussion was the use of medication.

In most instances the use of medication was avoided and only seen as a last resort after psychological therapies had been tried:

"We try and reduce the use of medication in younger people for as long a period as possible and not use it at all if possible … I would go along with (it) if a Consultant or another senior professional felt that they would benefit from a form of medication then I would agree with that tentatively, given that we have explored every other avenue." (PP1, 150).

"I think you have got to respect the individual don't yah rather than just going straight in with medication and thinking, oh yeah, they have got this or they are looking a bit depressed we will give them some antidepressants. We need to track back, look back and see what is going on. Whether we can do a CBT type approach and stem their problems back and keep away from medication if possible." (PP2, 174).

"It's about us not stepping in too early with any kind of medical mode (and) using medication … its always something that we only consider if its massively necessary. I think its important that we steer away from that as much as we can I suppose." (PP4, 50).

"I don't like them to be on any medication. I would rather we do the work first and then if we need to after that then maybe look at that. But I haven't had any … of the kids that we have had through for (an) At Risk Mental State, none of them have been on medication." (PP5, 115).

One clinician reported that medication was not always a viable treatment option because of the disagreement in the team about which medication, if any, should be prescribed for young people identified as having an ARMS.

"Over the years, I have had people who have been treated medically with low dose anti-psychotics and certainly in recent years they have not been treated due to the conflict with what consultants want or think what (young people) should be getting prescribed for (an) At Risk Mental State." (PP3, 54).

Medication use in this patient group was also seen by two clinicians to be highly controversial and a tough ethical decision. Misattribution of a young person's symptoms to be indicative of an emerging psychosis was one of these issues which could potentially lead to the unnecessary exposure to medication. Another concern was that the use of even low dose medication could be construed by some professionals and family members to mean that the young person was actually psychotic:

"I think it can have a role sometimes if people are experiencing very distressing thoughts but then there is the ethical dilemma of, you know if someone hasn't got a diagnosis why would you be prescribing medication and then you know the potential for side effects." (PP6, 106).

"Its not a long term sort of intervention that I advocate … I think we can get caught in the trap of if somebody is on an antipsychotic then they have a psychosis and that is not necessarily (the case). It can be used for other symptoms associated with their At Risk Mental State if that is what we are dealing with." (PP1, 172).

The importance of social inclusion

Of all the psychological therapies and supporting therapies discussed during the interviews, the merit and importance of using social inclusion as a support mechanism and a potential intervention was spontaneously endorsed by the majority of clinicians. Social inclusion and interaction with fellow peers was seen as an effective way of getting young people back into a 'normal' life and dealing with the commonly experienced problem of social isolation. Of all the potential strategies used to engage young people in becoming more socially active, clinicians believed that group activities were the most successful.

"We get them out, we do the football projects, sports projects, walking groups things like that. Lots of people who present with an At Risk Mental State might be isolating themselves, withdrawing from society so its about getting them back into the swing of things really." (PP4, 59).

"I think social inclusion as part of the treatment plan … so part of my treatment plan is to normalise as much as possible so we look at getting them back into normal life." (PP1, 145).

"Recently we have been doing some groups for the younger ones and they have been really successful in sort of sharing information and sharing coping strategies, that kind of thing." (PP6, 84).

Are we successful?

The success of treatments and interventions was primarily discussed in terms of how many young people made the transition to a full blown psychotic episode. Although one clinician pointed to four or five adolescents who had made the transition over their career with the EIP service, others pointed to much lower rates or even *"None"* (PP5, 69):

"I would say out of the length of time I have been with this service I would say maybe about three that have got older and have gone on to become clientele; maybes more if I have a good think back ... four of five out of lets say thirty, thirty plus." (PP1, 116).

"I haven't seen any go from at risk to psychotic and I know I had this discussion with (a colleague) a couple of weeks back and he can recall a couple that were maybes in the (inpatient ward). I didn't know the client he was talking about anyway. That person wasn't mine and then there is also that issue of were they psychotic to start with. I have never seen anybody who was diagnosed with an At Risk Mental State who has gone on to have a full blown psychotic episode." (PP3, 89).

In terms of what happens to the majority of young people who do not become psychotic, many were discharged back to CAMHS or primary care depending upon a current assessment of their needs.

"They will either go back to CAMHS or which has been the situation where CAMHS have felt that they haven't had any role they have decided to discharge." (PP1, 253).

"Most of mine are going back to primary care." (PP5, 69).

Reasons put forward as to why transition rates seem to be low in this age group were ventured by one of two participants. One participant alluded to the fact that it could be the inadequacy of assessment tools used within an adolescents population.

"It's maybe the sensitivity of the assessment tool and kind of thinking more about being inclusive rather than exclusive, it may be that." (PP6, 153).

Other clinicians were more optimistic suggesting that interventions and the successful engagement of the young people themselves were responsible for this observed pattern.

"Young people are more open to interventions, are more susceptible, not susceptible but sort of receptive to sort of change … I think they respond very well to input/treatment and they take it away. I think they respond very well to visual aids and support you know rather than just talking to them. I think if they are interacting within their treatment I think they respond very well." (PP1, 191).

"Well I do think whether we've sort of helped in not you know we've done work around keeping them safe, giving them the information. If we hadn't done that, would they have become psychotic? Cos I do a lot of work around stress vulnerability and stuff when they're at risk so I'm wondering if these young people are taking it on board and thinking we need to keep away from that, that and that and they are keeping themselves well and that's why they haven't developed it." (PP2, 263).

Either way transition rates based on the personal experiences of clinicians appear low and are perceived as being a successful outcome of the treatment and support offered.

Working with Adolescents

Despite relatively high levels of prior experience working with adolescents and those with an At-Risk Mental State, the clinicians all reported difficulties and complexities associated with identification and assessment practices.

Is it just normal adolescent behaviour?

The first major complexity that was apparent was the difficulty in ascertaining which behaviours were just aspects of normal adolescence, those that were aspects of another mental health problem or behaviours which were more consistent with an emerging psychosis.

> *"There is the developmental issues, you know. Is this looking at normal adolescence? Does it look like adolescent anxiety or depression or is it something else altogether?" (PP6, 43).*

> *"I would say there are lots of complex issues with children you know, imaginary friends. Some kids have had imaginary friends since the age of two and three and four year old and they have never grown out of having imaginary friends but then when they get to fourteen somebody thinks that should be for us because they are suddenly psychotic. So I think there are lots of other complex issues, lots of emotional problems that are going on, lots of developmental problems, emotional developmental stages and I think there are lots to be taken into consideration. Lots of adolescents have a decline or a wavering in functioning from one time to the other. That shouldn't necessarily be taken as outside of normal adolescent development. So I think a lot of what you see is normal adolescent development, but it's often taken out of context and medicalised as something different." (PP3, 38).*

> *"(It's deciding if it's a) true psychosis coming through or whether its just teenage anxiety from associated sort of stressful situations or low mood situations such as traumatic experiences that have resulted in someone*

becoming sort of suicidal or self-harming. (They are) talking about voice experiences when actually when it is all withered out through the At Risk Mental State assessments, it is more internalised thoughts and confusion." (PP, 27).

"You've got a person's difficulties on top of what a teenager will experience. Things, you know (like) kind of emotional regulation and hormonal problems and I think they are still developing. So there is all that kind of difficulty to take into account I suppose." (PP4, 141).

Associated complexities of working with this client group.

The complexity of unravelling symptoms was not the only problems associated with working with adolescents suspected of having an At Risk Mental State. Clinicians discussed other difficulties such as additional time pressures, risk management and concern regarding potential disengagement:

"There are lots of other issues like overdosing and self harming issues … so there is a lot of more crisis type things going on." (PP3, 125).

"Its all the adolescent stuff and all the family stuff. There is always a lot of stuff to untangle which is why I think when people put certain time limits on it, like we will review it in … we might not even get to know them by then, it could take six months to get there (and) act upon whatever's coming out and know when to stop and start taking it slowly. Otherwise they will disengage." (PP2, 350).

Another clinician identified another yet unexpected difficulty in working with adolescents:

"I think sometimes with teenagers you give them a lot of ideas if you give them too much information I really do. This is why I say to you when I do the CAARMS I always go out first and ask them to tell me what's going on before

I take that out because I think they get ideas off it because if you take that initially (you get), 'Oh yeah, yeah that happens to me"(PP5, 171).

One clinician described the influence of peer groups as another complexity when working with young people. Some young people want to be like their friends and peers and therefore they report psychotic like symptoms to be accepted and be just like them:

"I can see a big difference in working with the under 18s to the adults in terms of how important peers are and sort of the influence of peer groups and you know we have some recent examples of people becoming caught up in other peoples stories about hearing voices and it all kind of gets mixed up" (PP6, 43).

In terms of how clinicians managed to overcome and work with these difficulties, strategies included immersing oneself in the teenage world and trying to become and think like a teenager. Adolescent focussed training that ensures people understand what to expect and what is normal when working with adolescents was also suggested.

"I have thought of you know within the last year or two about what it is to be an adolescent and how that would impact on an assessment." (PP6, 70).

"Some of my colleagues probably would benefit from more CAMHS focussed training … so they can familiarise themselves more with what's expected and what they should expect from a young person compared to an adult.." (PP1, 290).

However one person believed there was no substitute for clinical experience when working with young people.

"I think having somebody with a CAMHS background or somebody that is more comfortable with that age range makes it a little bit easier to nip things in the bud really" (PP1, 206).

Service development

All participants talked about possible ways to improve clinical services and the standard of care offered to all young people with a potential ARMS. Potential service development opportunities were grouped into two themes; 'Consensus and Guidelines' and 'Training'.

Consensus and Guidelines

Clinicians described how in many cases there was a lack of consistency, agreement and at times uncertainty within teams and between services in terms of how to work with individuals identified as having an At Risk Mental State:

"I think people are not quite sure what to do with them afterwards and a much more consistent approach I think would be better because we are locality based, we don't have anybody overseeing it as such and so you get a difference in, in sort of the team you are working with about their approach." (PP6, 29).

"I think yeah it would be nice for everyone to be kind of singing off the same kind of hymn sheet really. I suppose knowing exactly what an At Risk Mental State is for every clinician, 'cos I think it does vary and maybes just some kind of training that might standardise that so everybody knows exactly what the definition is and what that means and how to assess that and how (to) manage and treat people that present with an At Risk Mental State. Yeah it would be helpful." (PP4, 23).

Participant two raised several points about this issue and highlighted a clear need for guidance relating to treatment plans and agreement as to whether the service actually supports people who are identified as having an ARMS:

> *"I think there needs to be a lot more consensus with people in agreeing this is what needs to be done, they need a plan …If somebody is scored at risk, they are in that category (and this is) what do we do and everybody working to the same." (PP2, 98).*

> *"I've heard that a few times, people saying we are not an 'at risk' service so therefore we can't deal with at risk cases. But I was told when I came in, I got the CAARMS training and we do, we do take kids who are at risk for monitoring purposes and then if they develop a psychosis then we treat." (PP2, 52).*

Despite the absence of guidelines two clinicians appeared to be relatively clear in the timeframes they adopted for monitoring and treating purposes:

> *"For me when somebody's at the At Risk Mental State I keep them for six to twelve months … if people are functioning really well I will get (them) discharged after six months but usually it's up until twelve for me." (PP5, 60).*

> *"Generally with (an) At Risk Mental State it would be six months. So we would pick them up and we would obviously tell them that it's for six months and that it's for a short period of work to help and support (them), so they know exactly how long they have got and then obviously after them six months it would be reviewed with the hope that you know those difficulties will be reduced." (PP4, 83).*

When discussing the issue of guidelines, clinicians described how the implementation of such guidelines would improve working across services and within teams:

"It would be easier to work with CAMHS to get that multi-agency going. If we have guidelines to go off rather than me just making these suggestions and obviously the work load sort of pressures and stuff like that and it would be the same with the team. Everybody in the team would be working to these guidelines rather than everybody having their own opinion of well I'm not doing this and were not supposed to do that and we don't take at risk and you know sometimes you just you know feel like your banging your head against a brick wall." (PP2, 117).

Clinicians also suggested that any guidelines would have to address and decide upon the issue as to which service was best placed and the most appropriate to work with this patient group:

"There are some questions asked about the people we are taking on and whether it is necessary for them to be in secondary services or in tier 3 or 4 (services)." (PP6, 43).

"It doesn't take much to fit an At Risk Mental State and whether or not we are doing people a disservice by bringing them into a tier four mental health service I don't know if that's the right thing or not. But then the big question is who would see this client group?" (PP3, 252).

In response to this issue and as a possible solution to be incorporated into any guidelines, one clinician stated that a stand -alone 'at risk' service would prove beneficial:

"I think if somebody was just there, just to provide at risk support then that would be something to look at in the future. Just have maybe a couple of workers that don't work with people that are floridly psychotic but work with people who have got the At Risk Mental State, giving them support and basic things like social skills, anxiety management skills, stress vulnerability." (PP3, 257).

Training

Various services and certain aspects of the At Risk Mental State were identified by the clinicians in relation to future training needs:

> *"I feel that the CAMHS teams would benefit from At Risk Mental State training …Overall I think a culmination of recognising appropriate referrals, monitoring requirements, use of assessment tools (etc)." (PP1, 269).*

> *"I suppose more kind of, any kind of training that relates to treatment around people with At Risk Mental State (would be useful). So what kind of psychological therapies work best, what approaches work best, things like that might be helpful I think." (PP4, 34).*

Use of assessment tools and the accurate identification of at risk cases within Early Intervention and CAMHS services was a common theme throughout the discussions relating to training. Some clinicians thought that more training in this area was required whilst others were frustrated that all other previous training had been solely related to this area.

> *"I think CAMHS could do with some training, 'cos they don't know the tools that we use." (PP5, 27).*

> *"There is a continuing need for training and I think it has been quite limited to assessment rather than what do we do with those clients with the At Risk Mental State." (PP6, 28).*

> *"I got the CAARMS training and that is the only training I have had. I haven't had any updates or not that I can think of anyway." (PP2, 15).*

In line with a previous statement, another clinician strongly believed that any future training must involve CAMHS staff in order to improve working relations and outline any newly created guidelines for working with this client group:

> *"And CAMHS coming, have a big sort of training session. This is the CAARMS and this is… It would be lovely to have a big training session with CAMHS in and go this is the CAARMS and this is our guidelines, this is if someone is scoring at risk, this is what we would suggest." (PP2, 194).*

Although one clinician reported never having any formal training in this area they thought that informal on the job training, supervision and experience had been beneficial for their learning and development:

> *"I suppose my training has been on the job really and kind of working with other colleagues and picking it up of how they can assess people and what they look out for and what kind of our criteria is really (used). So it's more through experience than it is through specific training opportunities." (PP4, 13).*

6.3.2 How do Child and Adolescent Mental Health (CAMHS) professionals perceive and understand the ARMS concept?

Response rates and demographics

One hundred and twenty-one of the 180 CAMHS clinicians (67%) completed the survey although it was found that all clinicians from one locality based team failed to respond. The majority of the sample described themselves as generic child and adolescent clinicians (55%), whilst other responding mental health professionals included psychiatrists (18%), psychologists (15%) and Primary Mental Health Workers (PMHWs; 12%) .

Prior Experience

The level of prior contact with EIP services and young people with ARMS is outlined in Table 15. The data shows that a significant relationship exists between prior contact with EIP services and professional background (Chi-Square test; $\chi 2 = 8.862$, $p = .031$) with the majority of psychiatrists reporting some form of prior contact. In terms of having worked with a young person identified as having an ARMS, again psychiatrists reported having worked with this client group more than any other profession (Chi-Square test; $\chi 2 = 8.879$, $p = .031$).

Understanding of the main postulated features

When clinicians were asked to decide upon three symptoms (from a checklist of twelve) that they perceived to be key in the identification of ARMS; *perceptual distortions*, *unusual ideation* (e.g. paranoia) and *poor or declining functioning* were the most commonly endorsed responses (Figure 12). When endorsement of these three symptoms was analysed in relation to confidence in identifying ARMS there was found to be no significant relationship according to a series of Chi-Square tests ($p > .05$ in all cases).

Confidence in the ability to identify ARMS

Familiarity with and confidence in the ability to identify ARMS by professional background is outlined in Table 15. Overall 60% of respondents regardless of professional background stated that they were familiar with the concept whilst 55% rated themselves as confident in identification. A significant proportion of those who stated that they were familiar (70%) and confident (72%) had had prior contact with EIP services (*Familiarity*, Chi-Square test, $\chi 2= 12.710$, p= .002; *Confidence*; Chi-Square test, $\chi 2= 15.058$, p= .001). Both familiarity (Chi-Square test; $\chi 2= 25.854$, p= .001) and confidence ratings (Chi-Square test; $\chi 2= 27.949$, p= .001) were also significantly associated with prior contact with this client group.

In terms of *familiarity* and *confidence* by professional background again the majority of psychiatrists rated themselves as thus. Although a high proportion of psychologists deemed themselves to be familiar with the concept (67%) a much smaller number were confident in their ability to identify ARMS (39%). The inverse was true for PMHWs with only 21% of respondents stating familiarity with the concept but 43% feeling confident in identification. Just over half of generic workers rated themselves as being familiar and confident with the concept of ARMS. However only familiarity ratings (Chi-Square test; $\chi 2= 19.192$, p= .004); not confidence (Chi-Square test; $\chi 2= 8.954$, p= .176) was significantly associated with professional background.

Clinical Utility

In terms of whether the ARMS concept constitutes a meaningful clinical syndrome 58% either agreed/strongly agreed with this statement. The majority of psychiatrists (82%) believed it to be a meaningful clinical syndrome. A minority of those surveyed (18%) however felt unable to answer this question because of limited knowledge and understanding.

When asked whether the ARMS label was helpful or harmful there was a general consensus that the term was 'helpful' in some way. Forty-one percent of respondents (n=46/113) indicated the term was helpful without any apparent negative effects whilst 40% (n=45/113) of respondents saw it as having both positive and negative connotations. Again a high proportion of respondents (n=21/113, 19%) did not feel able to provide an informed answer for this question.

This question was followed in the survey by a free text box for participants to state in more detail the reasons why the ARMS label was either helpful, harmful or both. Common responses using a free textual analysis suggested that the label was often helpful from a clinicians/professionals perspective in terms of identifying risk and informing care plans. For the young person themselves they may potentially benefit from access to specialist services, earlier intervention and a means of explaining and making sense of their experiences. Negative responses indicated that the label could potentially be harmful in raising the young persons and/or families anxiety, incorrectly identifying young people, exposing individuals to unnecessary treatments and confusing other professionals who do not understand what the ARMS label actually means.

Management

Ninety-two percent (n=108/118) of respondents believed that individuals with ARMS required some kind of support from mental health services. As for the services best placed to do this 88% of those providing a response suggested that EIP services should be involved whilst 71% endorsed the view that CAMHS should have a role to play.

In terms of the type of support and treatment that should be offered the overwhelming choice was a strategy of 'watchful waiting' which was endorsed by 96% of those providing a valid response. Psychological therapies (such as cognitive therapy) and psycho education were also heavily endorsed (80% and 79% respectively). Low dose antipsychotic medication was not heavily supported (31%)

whilst omega three fatty acids received the least support of the possible treatment options (8%).

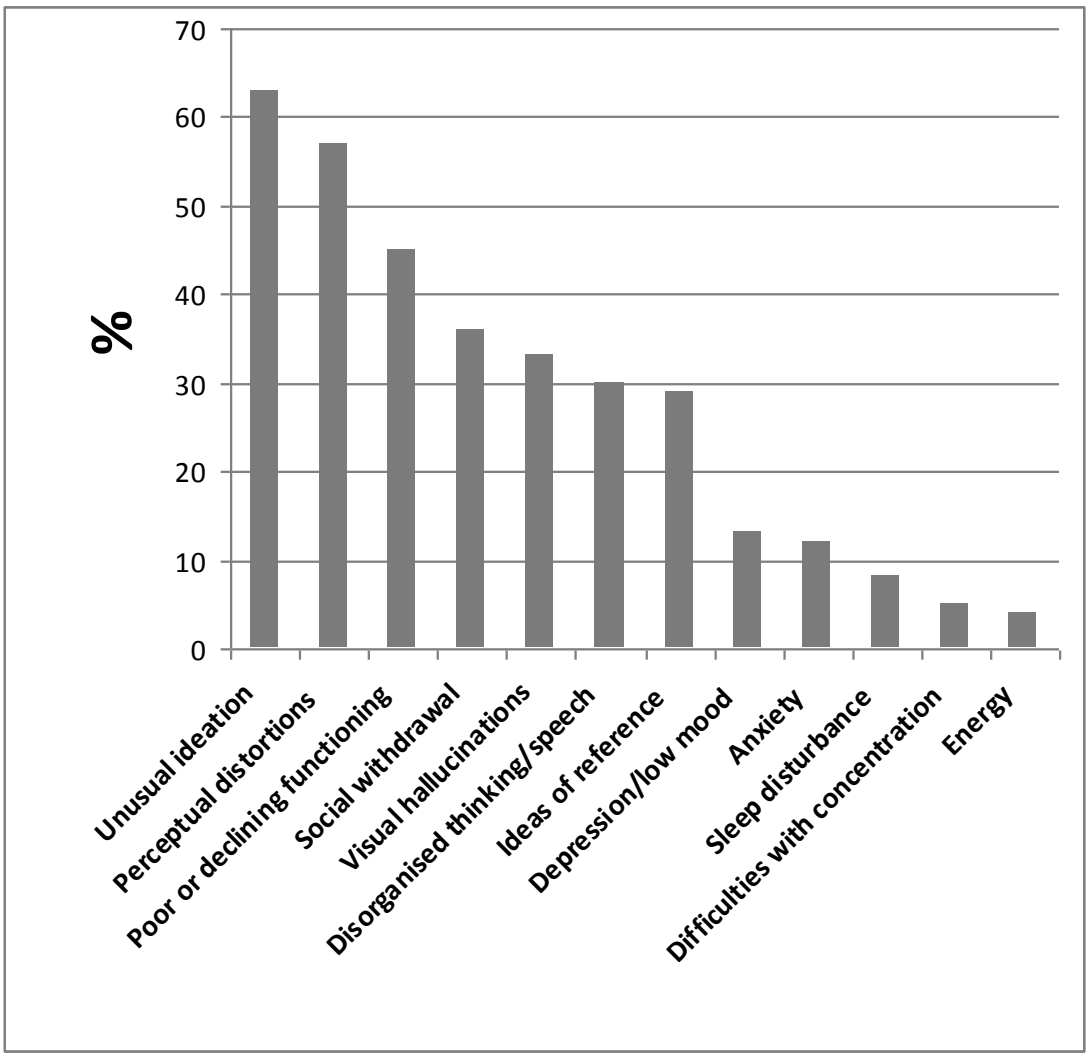
Any other comments

At the end of the survey participants were given the opportunity via an open-ended response box to comment upon any aspects of the ARMS concept. Using a free textual analysis of responses given, the overwhelming majority of those providing a response (45/52) reported a limited knowledge and/or a desire for further training in relation to the ARMS concept (most notably in the areas of identification, management and when to make a referral to EIP services).

Table 15.The responses of Child and Adolescent Mental Health clinicians to the attitudinal questionnaire organised by professional background.

	Number of respondents endorsing Yes or Agree/Strongly Agree (%)				
Question	**All**	**Psychiatrists**	**Psychologists**	**PMHWs**	**Generic**
Have you ever worked alongside a clinician from the EIP service in the assessment or treatment of any of your clinical cases?	69/121 (57)	18/22 (82)	11/18 (61)	5/14 (36)	35/67 (52)
Over the past 12 months I have worked with a young person who has been confirmed as having an ARMS?	45/120 (38)	14/22 (64)	4/18 (22)	4/14 (29)	23/66 (35)
I am familiar with the concept of ARMS?	71/119 (60)	18/22 (82)	12/18 (67)	3/14 (21)	38/65 (59)
I feel confident in identifying a young person with ARMS?	65/119 (55)	17/22 (77)	7/18 (39)	6/14 (43)	35/65 (54)
The ‘ARMS’ concept constitutes a meaningful clinical syndrome?	67/116 (58)	18/22 (82)	9/18 (50)	6/14 (43)	34/62 (55)

Figure 12. Symptoms endorsed as being key to applying the 'At-Risk Mental State' label (respondents limited to endorsing only three of the following twelve symptoms).



6.4 Discussion

The findings from both studies demonstrate that there are a number of key issues that are important to professionals working with young people with a potential At-Risk Mental State.

In terms of the utility and usefulness of the ARMS label, clinicians appear to have varying attitudes towards the construct. In line with the observations by Yung et al., (179) and McGlashan et al., (159) it seems that some professionals report that young people find the label useful and use it as a means of validating and coming to understand and explain their emerging and distressing experiences. This is in contrast to other young people who react angrily and defensively to the news possibly because they do not perceive themselves to be unwell and find being labelled 'at-risk' to be scary and confusing. CAMHS professionals also see the potential benefits and pitfalls of presenting young people with the ARMS label although on the whole the vast majority indicate the label is 'helpful' in some way.

Regardless of whether EIP clinicians perceived the ARMS label to be positive or negative many of them reported an avoidance of actually using the full term (At Risk Mental State for Psychosis) with young people and their families. This avoidance appeared to be in many instances related to the word 'psychosis'. Several of the clinicians reported rephrasing their explanations along the lines that the young person was indeed at risk of developing a serious mental health problem but not necessarily psychosis. This is a very interesting finding given the low and declining transition rates observed and that a high proportion of ARMS individuals eventually reach the threshold for another diagnosis such as anxiety or depression at short term follow-up (60, 145). These findings may have been expected given that previous research suggests that health professionals are reluctant to inform a patient about a diagnosis of psychosis (226) whilst in another survey many clinicians admitted to having doubts about the utility and validity of the ARMS term itself (103).

The respondents endorsed the view that this patient group should be offered some form of intervention although anti-psychotic medication is not a widely supported option. For EIP care co-ordinators medication was perceived as being a 'last resort' and only viable if every other treatment option had been explored. Possible side effects and the potential for stigma and misunderstanding were some of the reasons put forward for its avoidance. In terms of CAMHS clinicians only 31% recommended its use which is in stark contrast to the views of psychiatrists in Singapore (225). Our method of sampling professionals from a variety of disciplines, a focus on CAMHS (in contrast to adult-based services) as well as cultural issues may account for these disparities. However the findings overall, demonstrate that low dose anti-psychotic medication is not an acceptable first line treatment option to mental health professionals working with adolescents in 'real world' settings. In terms of other treatments, monitoring, psycho-education and psychological therapies were well supported by CAMHS professionals. Surprisingly it was an informal and previously untested intervention focussing on social inclusion that was perceived by EIP professionals to be the most useful when working with an adolescent patient group.

As for the number of individuals making the transition from an ARMS to psychosis, the personal experience of clinicians appears to suggest that figures are low. Indeed two experienced clinicians suggested they had never observed any young person make the transition. Reasons put forward for these observations were that young people in particular may respond well to the support offered. Since the literature is limited in terms of estimating transition in adolescents it is unclear if these findings are similar elsewhere although a handful of researchers suggest high rates in this age group should be the norm (152, 153). It is also unclear at this stage if low transition rates are the result of timely and effective interventions or a high rate of 'false positives'. This latter explanation is viable given the developmental complexities associated with this life stage (73, 174) and the difficulties in identification reported by EIP clinicians.

The reliable recognition of the syndrome appears to be a major issue given the interesting accounts of EIP clinicians and the fact that a high proportion of CAMHS professionals do not feel confident in doing so. The influence of peers, developmental/hormonal changes, personal transitions, poor and immature coping strategies are just some of the reasons outlined than can make identification in this younger age group more problematic. These findings are consistent with the commentaries that infer working with adolescent suspected of having an ARMS is more complex than working with an adult population (73, 174).

In terms of service improvement and development, clinicians discussed a need for consensus and consistency in assessment and treatment practices. One way to achieve this was the creation of agreed guidelines which, as well as standardising care, could potentially improve working relationships between teams and services. The need for clear guidelines highlights the limited evidence base in this area. Only a handful of services nationally have drawn up their own local guidelines and care pathways (69, 70). The CAMHS survey data is informative here as it suggests that a consensus between child and adolescent mental health professionals already exists in terms of preferred treatment choice and the services best placed to offer support.

Possibly because of the complexities of working with this client group and an absence of national guidelines, training was identified as an important issue worthy of consideration. Training in several areas (assessment, referral and interventions) was perceived as being required by both EIP and CAMHS professionals.

6.4.1 Strengths and potential limitations

The study provides a unique insight into the personal beliefs, feelings and experiences of clinicians working with adolescents suspected of having an ARMS. To our knowledge such research has not been conducted elsewhere. As for the CAMHS survey a response rate of 67% could be considered acceptable given the competing demands and time pressures faced by NHS clinicians. However response bias in this survey cannot be excluded. In particular one entire CAMHS team did not participate in the study, increasing this risk. It is also uncertain whether our findings would generalise to CAMHS in other areas and to specialist youth services such as those serving patients with intellectual disability as these were not included in our sampling frame. The survey questionnaire has not been previously externally validated. More detail in relation to previous contact with the ARMS and clinical experience may have contributed greater depth to our findings. It is also important to note, in this sample, that self-reported confidence was not significantly associated with competence (i.e. ability to identify the most pertinent features of the ARMS).

Part of the process of conducting and reviewing qualitative research is to reflect upon the experiences of carrying out the research. Reflective diaries facilitate this process and some of these reflections need to be discussed. One of the main challenges associated with interviewing is ensuring participants feel relaxed and have time to express their opinions. Although all of the staff interviews were conducted with the service managers full approval, at times it felt as if interviews were conducted at a rapid and rushed pace. This feeling of being rushed combined with the authors own anxieties during the interview led to a possible counter transference effect. Sufficient time was therefore not always provided by the interviewer/author to allow the participants to reflect upon their responses. Questions were potentially moved onto too quickly hence creating relatively short interview durations.

The author's dual role as a researcher but also as a colleague of the participants was on reflection seen as advantageous during the interview process. Being perceived as a colleague potentially facilitated the process of rapport and may have resulted in a more open discussion. Prior knowledge of working with adolescents with an ARMS meant that it was possible to peruse interesting issues that arose rather than missing opportunities by asking for clarifications (which could have been the case given that an independent researcher may have found certain information during the interview confusing). The shared experience of the author and the participants provided a safe and potentially therapeutic environment whereby the issues expressed were valued and understood.

However, shared experience and prior knowledge can become a hindrance to effective thematic analysis if not appropriate managed (342). In these instances the study supervisor was consulted to ensure consistency in coding and theme generation whilst interviews were reflected upon to identify any potential interference. Having one of the participants informally view the themes generated towards the end of the analysis process proved helpful in ensuring data quality (this strategy was not considered during creation of the study's methodology).

As with the survey of CAMHS clinicians, the findings from the thematic analysis may not generalise to those working in other mental health services because of the specific and purposive nature of the clinician sample. However, the findings from this qualitative study are exploratory and were never conceived to be generalised based upon the study's methodology and design. It is possible that some of the issues raised during this study simply reflect the current position of the TEWV EIP service in terms of its evolution and development and as such may be temporally bound. Results must therefore be considered in the context of the service in which the project was conducted. Finally, the study represented the author's first attempt at a qualitative data analysis and was therefore a major learning experience. Seeking regular supervision from the study supervisor and peers who had previous experience of qualitative research helped alleviate many feelings of uncertainty.

6.4.2 Clinical Implications

Both studies provide highly relevant and important information that should inform and possibly improve current clinical practice. Information giving is one of these areas. Although it is unclear in the context of the PAARMS study whether young people themselves like to be explicitly informed about their condition, EIP clinicians appear to skirt around the concept of psychosis, rightly or wrongly altogether. These feelings of uncertainty and discomfort suggest a need for regular peer or group supervision in order to obtain advice, support and an opportunity to reflect upon the process of information giving to young people and their families. Group supervision may also be useful for those finding a particular ARMS assessment stressful or difficult which is highly likely given the complexities associated with this client group.

There is also scope to develop locally agreed care pathways and guidelines informed by the following data. At this time it is clear for patients and clinicians dealing with a first episode of psychosis what to expect in regards to assessment, treatment options and duration of care. However this is clearly not the case for those with a possible ARMS. Although no locally agreed guidelines are in place, the data from this study highlight that an informal consensus already exists in terms of treatment options. Monitoring, psycho-education, psychological therapies and social inclusion are widely used and heavily endorsed by EIP and CAMHS professionals. Low dose anti-psychotic medication is not perceived to be an acceptable first line treatment strategy but could be considered if initially strategies prove to be ineffective. Guidance for psychiatrists and other prescribers must therefore be generated in order to ensure they are aware as to when it is acceptable to prescribe low dose anti-psychotic medication. A suggestion for a stand-alone ARMS service was proposed by one clinician and is an idea worthy of consideration in any proposed care pathway. A handful of services separate from CAMHS and EIP already exist in the UK and are demonstrating positive outcomes (69). Considering service development such as this should be a high priority given that the EIP clinicians interviewed state that the majority of adolescent referred to them; *"have fitted an ARMS as opposed*

to being full blown psychotic" (PP3, 17). Either way any agreed guidelines should provide more consistency and clarity both from a clinician's perspective and for the young person involved (in terms of what treatment options are available to them, the service responsible for this and the likely duration of their care in the first instance).

Finally, further training appears to be required and desired by both EIP and CAMHS professionals. Training may take the form of shadowing or observing experienced clinicians during assessment and intervention sessions. In-house training such as workshops is another option. In this instance individuals from both CAMHS and EIP services could attend thus, facilitating a much closer working relationship.

6.4.3 Future Research

Since the qualitative study was designed as an initial exploratory analysis of the main issues faced by EIP mental health professionals, it would be intriguing as a next stage of research to see if these issues and debates are common across EIP services nationally. As previously discussed it is possible that some of the issues raised during this study simply reflect the current position of the TEWV EIP in terms of its evolution and development. It is clear from several surveys (223, 224) and personal correspondence with other service managers that care and provisions for under eighteens with an ARMS is highly variable. Conducting interviews or focus groups with clinicians from other services may prove useful to those wishing to develop national guidelines or those wishing to generate theories and frameworks for the ARMS concept.

The perception of social inclusion and peer support as being a highly effective, yet informal intervention strategy could also be worthy of further investigation. A mixed method quantitative and qualitative pilot study looking at the efficacy, acceptability and feasibility of a formalised and structured social inclusion programme would be interesting given that most therapeutic work previously has focussed on the use of low dose medication and structured psychological therapies such as CBT or family therapy.

Further research in terms of the survey could also focus on assessing the generalisability of these findings and whether any training interventions improve competence as well as confidence in relation to detection of the ARMS in young people. A short audit directly accessing future training needs within CAMHS and EIP would be beneficial at this time. Finally an interesting casenote audit could investigate whether the interventions endorsed by professionals are presently offered to young people within routine clinical practice.

6.4.4 Conclusions

Mental health professionals working with adolescents suspected of having an ARMS hold mixed views as to the clinical utility and helpfulness of the ARMS label and concept. Identification in this age group is perceived to be extremely difficult for a variety of reasons making professionals hesitant to present young people with the ARMS label. Confidence in identifying an ARMS is influenced by professional background and clinical contact with this patient group with psychiatrists appearing to be well prepared for the possible inclusion of the psychosis risk syndrome in DSM-V.

The majority of professionals believe that interventions should be offered to this patient group but this should not initially be in the form of low dose antipsychotic medication. Monitoring, psycho-education and psychological therapies that promote social inclusion are widely supported and are perceived to potentially reduce transition rates. Further training however is required by some mental health professionals, possibly PMHWs because of their limited familiarity, previous clinical contact and role in mental health screening.

7 Discussion

This chapter is an overarching discussion of the results and data collected from the FARMS and PAARMS research projects, intended to supplement the specific discussions at the end of each of the respective sections. The chapter will start with a discussion of the scientific implications of the studies, going into a summary of the study results, contemplating whether the results are consistent with other studies and debating what they tell us about adolescents with ARMS. Secondly the clinical implications arising from the data are presented and discussed. The discussion is concluded with potential policy implications, limitations and future research opportunities.

7.1 Scientific Implications

7.1.1 What was the purpose of the scientific investigation?

This thesis primarily aimed to examine the characteristics and short term outcomes of adolescents presenting to mental health services with an At-Risk Mental State for Psychosis. The secondary aims were to understand how young people experience an ARMS and identify the major issues faced by mental health professionals who potentially come into contact with this patient group.

The need to conduct this research was based on the lack of adolescent specific research published to date and the perception that this patient group may potentially represent an opportunity to prevent transition to psychosis, reduce distress and improve functioning. The concept of early intervention is especially important for young people since those who develop psychosis in their teenage years, experience worse illness outcomes when compared to working age adults (27, 202). The need to investigate is also highlighted by the possible inclusion of the psychosis risk syndrome in the impending Diagnostic and Statistical Manual for Mental Disorders

version five (DSM-V; 86, 87). The validity and utility of the ARMS construct is far from universally accepted and it is unclear how this concept is understood and perceived by specialist and non-specialist mental health professionals. Opponents of the concept suggest it may create stigma and expose young people to potentially harmful and unnecessary treatments (183, 340). This therefore makes any research related to the identification and management of adolescents, potentially at-risk of psychosis a high stakes issue.

7.1.2 Summary of study results

Study 1 of the FARMS project initially characterised and followed up 30 adolescents with an ARMS over a six month period. All 30 participants initially presented with sub-threshold psychotic symptoms, with the vast majority reporting auditory changes (27/30), bizarre ideas (20/30), visual changes (20/30) and suspiciousness/persecutory ideas (18/30). Of these symptoms perceptual abnormalities in general were rated as being the most intense and distressing symptoms. A mean C-GAS rating of 53.03 indicates substantial functional impairment within the cohort. In terms of co-morbidity depressive illness (13/30), anxiety disorders (6/30) and pervasive developmental disorders (5/30) were particularly common. Not surprisingly given the high level of depressive illness and severe symptomology the proportion of individuals having attempted suicide (9/30) and engaged in significant self-harm (16/30) within the previous six months was remarkably high. The results also suggest elevated levels of perceived family dysfunction and negative metacognitive beliefs. In terms of six month follow up outcomes, only one individual had made the transition to psychosis whilst several participants (around 24%) demonstrated some form of symptom or functional remission. Psycho-social functioning at baseline assessment was significantly associated with six month outcome.

Study 2 of the FARMS project interviewed six of the thirty adolescents initially identified as having an ARMS. The interview findings indicate that young people are keen to know about their condition and respect clinicians who inform them about this. Although hostility and stigma were feared by young people in relation to

their condition most young people reported no major changes in how they were perceived by their family and friends and therefore appeared able to deal with any hostility that was forthcoming. Finally, in terms of treatment and support it appears that young people found the opportunity just to talk to a mental health professional beneficial rather than any specific medical or psychological therapy.

Findings from the qualitative study embedded within the PAARMS project indicate that there are four major themes that are important to mental health clinicians who regularly work with adolescents suspected of having an ARMS. Firstly clinicians experience mixed reactions from young people when presenting them with the ARMS label. Possibly with these reactions in mind, clinicians tend to rephrase and at times actively avoid using the full term At-Risk Mental State for Psychosis with their patients. In terms of treatment practices, the use of anti-psychotic medication for treating a suspected ARMS is perceived as a 'last resort' and a decision that is viewed as having ethical implications. The use of social inclusion and group work was seen as more effective in challenging and normalising young people's psychotic like experiences. Finally, the observation of particularly low transition rates in this patient group were perceived as being a successful outcome of the treatment and support offered by the clinicians. Despite relatively high levels of prior experience working with adolescents and those with an ARMS, clinicians all reported difficulties and complexities associated with identification and assessment practices associated with this age group. Developmental as well as maturational process and the significance of peers were just some of the perceived complexities of assessing and working with young people. Finally, all participants talked about possible ways to improve clinical services and the standard of care offered to all young people with a potential ARMS indicating that clear guidelines and additional training was required in both Early Intervention in Psychosis and Child and Adolescent Mental Health services in the identification and management of the condition.

The second study within the PAARMS project evaluated the current knowledge and attitudes of child and adolescent mental health clinicians in relation to the ARMS concept. Only around half of the clinicians surveyed reported confidence in identifying an ARMS. The findings indicate that psychiatrists usually have the most

contact and confidence in identifying individuals suspected of having an ARMS. The overall consensus amongst the sample of clinicians was that psychosocial interventions, rather than medication, should be offered to young people. When asked whether the ARMS label was helpful or harmful there was a general consensus that the term was 'helpful' in some way.

7.1.3 Are the study results consistent with other findings?

How do individuals initially present with an At-Risk Mental State

In terms of how adolescents with ARMS initially present to services the findings are in most cases consistent with the predominately working-age adult populations previously investigated and the handful of adolescent specific studies that exist. Like their adult counterparts, adolescents were found to present with substantial functional impairments (69, 88-90), obtaining baseline functioning scores that fall within the range of scores observed elsewhere (60, 92, 93, 95). This finding is unsurprising given that the Melbourne criteria requires chronically poor or declining functioning by definition.

As for co-morbidity the study's finding that 70% of participants fulfilled the criteria for one or more Axis I disorders is in keeping with several other reports of figures between 60-80% (69, 103, 119). The high levels of depressive and anxiety disorders observed are also in keeping with the previous literature (69, 88, 89, 103, 116). As too is the great difficulty in identifying and assessing adolescents with a potential ARMS given that a high proportion also report sub-threshold symptoms for several different disorders (209, 210). The finding that a substantial proportion of participants fulfilled the criteria for a Pervasive Developmental Disorder is also consistent with literature from areas of childhood onset schizophrenia (129, 213, 214), genetic high risk studies (215) and other ARMS studies (90, 117, 216).

However, a major inconsistency between this study and those utilising adult samples is the infrequent reporting of substance abuse disorders which are usually the most prevalent co-morbidities after depressive and anxiety disorders. (88, 89). At this

stage it is unclear why this group of adolescents demonstrated relatively low levels of substance abuse but this finding is in keeping with the adolescent specific studies that currently exist (110, 209-211).

The observation that 30% of participants had reported a suicide attempt whilst 53% had engaged in significant self-harm within the previous six months is potentially understandable given the high level of impairment and depression within the cohort. Research suggests that risk of suicide is particularly higher during the early phases of psychosis (131) but figures obtained from adult ARMS studies (131, 132) indicate much lower rates of attempted suicide (9-14%) than those observed here. In terms of trauma experiences the number of individuals reporting significant traumatic experiences during their lifetime is slightly below that recorded elsewhere (133, 134). The reliability and validity of trauma reporting however is controversial and questionable (135).

As for demographic factors our findings are consistent with those studies reporting relatively equal proportions of males and females (60, 62, 93). This finding could be interpreted as somewhat surprising given the age of our sample and observations that males are more likely to develop psychosis at a much earlier age (318). The data is also inconsistent with the small number of adolescent specific studies that exist that report a predominance of males (110, 209-211). In terms of ethnicity our solely white British cohort reflects the geographical area in which the research was conducted although the vast majority of other studies also report no significant ethnic trends in those presenting and fulfilling ARMS criteria. The finding that the majority of participants were from lower socio-economic backgrounds (when compared to local census data) is in line with emerging findings elsewhere (69, 106).

In terms of intake criteria at baseline assessment the finding that all participants fulfilled the ‘attenuated’ or Group 2 criterion is at odds with previous studies using the Melbourne criteria (60, 69, 93) that also identified individuals fulfilling the ‘BLIPS’ criterion. Based on the previous research we would have expected the vast

majority of participants within this study to fulfil the 'attenuated' criterion (which occurred) but also observed a handful of cases having experienced a BLIP.

As for the prevalence of specific attenuated positive symptoms at baseline assessment, our findings, like Miller et al., (95) demonstrate that perceptual abnormalities, suspiciousness and bizarre ideas are the most commonly reported symptoms. However the high rate of disorganised speech (48%) observed in Miller et al. was not replicated within our findings and may represent a genuine difference in how adolescents present with the ARMS. The same assumption could also be made in relation to the measured severity, frequency and distress of attenuated positive symptoms. Unlike the findings from EDIE-2 (71) this study demonstrates that perceptual abnormalities, as opposed to non-bizarre ideas, are rated as the most distressing and intense symptoms by ARMS adolescents. Support for this finding may come from another adolescent specific cohort who observed that perceptual abnormalities and hallucinations were the most frequently reported positive symptoms (209).

Attempts by previous studies to accurately estimate duration of untreated illness (DUI) have been difficult given limitations in patient recall (48), the vague nature of a definitive definition for DUI and that studies report durations as short as one week till several years (60). Therefore our average of 32 weeks should be interpreted with caution but does represent a significant lower time frame compared to research centres presenting time frames between 13 and 22 months (103, 110, 111).

The finding that adolescents with ARMS appear to use more maladaptive and unhelpful metacognitive beliefs is in keeping with previous research using adult samples (136). Poor perceptions of family functioning reported by participants within this study was also expected given the previous literature (137-139).

Follow-up studies and predictors

The transition rate observed in this study at six month follow-up is in line with the recent trend of declining transition rates (62). However the observed transition of

3.4% after six months is below figures observed in adult studies that have used the Melbourne Ultra High Risk criteria (16%; 62) and figures obtained within an NHS clinical setting (10%; 69). A recent meta-analysis of transition and outcome (published after the literature review for this thesis was completed) presents a two year transition rate of 27.4% (CI 95%, 24.6%-30.4%) for published studies that have adopted the CAARMS/ARMS criteria (343). The figure of 3.4% is more in line with rates observed in the most recent follow up study in Australia where only 5% of ARMS patients were found to make a transition to psychosis after a six month monitoring period (141). Although the findings of this study are comparable to those observed at the FARMS clinic, a major criticism of this study is the poor follow-up practices described given that the status of at least a third of participants could not be accurately obtained and was therefore assumed based on limited information ('Not Psychotic' was the default assumption when information was lacking). For the FARMS study, the mental health status of only one individual was unobtainable.

Although the findings are not surprising to some experienced clinicians who were interviewed during the PAARMS project, the observed figure is below that recorded in the only prospective adolescent studies to be conducted so far. Two studies published by Ziermans and colleagues (217, 344; the latter published after the literature review for this thesis was completed) indicate a transition rate of around 14-15% for this age group after a follow up period of 18 months to two years. Researchers have also stated that adolescent cohorts should demonstrate relatively high rates given that adolescents with ARMS (15-19 year olds) are at a significantly greater risk of becoming psychotic (153).

Reasons for these differences may reflect an over inclusion of false positives given the non-specific nature of prodromal symptoms (48), the potential masking or mimicking of prodromal symptoms by co-morbid conditions and the neuro-maturational and psychological changes that naturally occur during adolescence (73, 174). As previously stated some clinicians believe it is almost impossible to distinguish between the psychosis prodrome and depression (126) and this may explain why a high proportion of individuals were diagnosed with an affective

disorder within the FARMS cohort. Yung et al. (141) have speculated that many referrals within their previous studies experience psychotic-like symptoms that are 'clinical noise' around a non-psychotic syndrome. Based on personal clinical experience this is a possibility given that for individuals with a co-morbid Pervasive Developmental Disorder, the psychotic-like symptoms observed have reflected unusual and maladaptive thinking styles and belief systems associated with the condition. Again from clinical experience and discussion with colleagues it is also likely that several of the individuals within the FARMS cohort will be diagnosed as having personality disorders rather than psychosis upon nearing their eighteenth birthday. In such cases ideational and perceptual disturbance could be conceptualised as secondary to a wider disruption to the developing personality and associated sense of self.

Selection bias due to the study's recruitment strategy is a possibility since it has already been observed that the FARMS clinic received no referrals of individuals experiencing a BLIP or substance precipitated psychotic symptoms. Young people experiencing a BLIP may not be referred to specialist mental health services since by the time they present to a GP their symptoms have significantly remitted and they are discharged back into the community. Given the difficulties of identifying a potential prodrome and the findings from the PAARMS study that many Child and Adolescent mental health professionals are not confident in its identification it is likely that failure to refer genuine 'at risk' cases may partially explain the low transition rate observed. Modifying our recruitment practices so that potential eligible participants are identified at an earlier stage within primary care settings (therefore reducing the potential bias created by CAMHS professionals) is likely to generate an even lower transition rate however given that psychotic like experiences are common in 'normal' adolescent populations (205).

Another explanation may relate to the care and 'active' treatment received by participants within the FARMS study given that a review of medical notes indicated the use of medication, cognitive behavioural therapy and other potentially preventative interventions during the six month follow-up period. This was therefore not a true monitoring study since previous studies have shown that targeted

interventions have the potential to delay the onset of psychosis (161, 162). It is possible that individuals and especially teenagers are more amenable to non-specific treatments at the early stages of a prodrome, a notion which is supported by experienced clinicians (as observed during the PAARMS project) and elsewhere (141). As demonstrated by Study 2 of the FARMS project adolescents reflect positively on talking to mental health professionals and being informed about their condition and these experiences may have been protective.

Other potential explanations may consider a lead time or sample age bias. A lead time bias explanation suggests that many transitions may occur later (after the six month follow up) and this notion is potentially supported by the fact that the highest transition rates have been observed in studies with follow up periods lasting for several years (79). It may be that adolescents experience a longer symptomatic prodromal period compared to adults. Alternatively, due to support from parents, many may seek help much earlier than their adult counterparts. This suggestion would be supported by evidence that adolescents with psychosis have been found to present to services with a shorter DUP (345) whilst estimates of DUI within the FARMS cohort are substantially lower than those recorded elsewhere (103, 110, 111). If treatment can therefore delay transition and individuals are presenting earlier to services, more transitions will occur at a later stage. A counter argument to this line of reasoning is that several studies have suggested that the period of maximum risk of transition is usually within the first six months after identification (60, 62).

The low transition rates within this study therefore did not allow for an investigation into the possible predictors of transition to psychosis. Previous research using adult populations indicates that functioning at baseline (60, 92, 93, 148, 149), intake criteria (145, 152), Axis I co-morbidity (116) and specific positive and negative symptoms (60, 65, 93, 145, 149) are just some of the factors that predict transition. These findings therefore still require verification in an adolescent specific sample.

Detailed follow up data on a subsample of the FARMS cohort demonstrates a high level of symptom and functional remission. The findings of Simon and Umbricht

(106) suggest that around 60% of individuals initially identified as having an ARMS no longer fulfil criteria after a twelve month follow up period although data from another study by Lemos-Giraldez et al. (111) presents a much lower percentage of 15%. Data from a recently published study of adolescents (344; the only one to the author's knowledge to have investigated criteria remission in this age group) reports that only 35% of participants remained 'at-risk' after two years. Analysing data from a subsample of the FARMS cohort demonstrates that around 29% of participants no longer fulfilled baseline ARMS criteria six months after initial identification. Data from this analysis also indicated that overall levels of psycho-social functioning had increased significantly whilst the presence, severity and frequency of several positive psychotic-like experiences had decreased. Findings from the Jorvi service in Finland also discovered that ARMS adolescents experienced significant improvements in functioning, quality of life, anxiety and depression after around 6 months of care (222). Another relevant adult ARMS study demonstrates that many individuals at eight months follow-up show improvements in social and role functioning (147).

The lived experience of the At-Risk Mental State

The finding that young people want to be told about their condition or 'risk status' goes against research conducted in genetic testing for conditions such as Huntington's disease and breast cancer (177). Unlike receiving a diagnosis of psychosis (178) the presentation of the ARMS label is not perceived as being negative. In line with advocates of the ARMS concept the label, rather than increasing apprehension, appears to open the door for new optimism that treatment is forthcoming (146, 177). Observations from the PACE clinic that individuals experience relief and tend to feel 'better', possibly because they are not currently psychotic (179) are supported. These findings are similar to the reactions of adolescents diagnosed with depression who report relief when hearing about the diagnosis as it confirmed that their distress had a name and they were not the only person to experience these symptoms (181).The notion that some ARMS individuals demonstrate concern, scepticism and denial to the news (159) is not confirmed.

Although adolescents categorised as having the ARMS fear the subsequent reactions of family, friends and those in the community, the discrimination and hostility reported by individuals at risk for other conditions was not forthcoming (1). Although several young people were reluctant to initially share their condition with their friends all described continued acceptance when information became public. The proposed hypothesis that the ARMS label will interfere with a patient's ability to communicate with others, leading them to withdraw and experience a loss of contact with friends they have prior to their illness (198) was not observed. This acceptance is at odds with findings that young people particularly endorse the view that children who obtain mental health treatment are likely to be outsiders at school. Adolescents perceptions of peers with psychosis are also extremely negative with the majority endorsing attitudes that suggest those with the condition are more violent, suicidal and academically poor (1). However, research relating to prejudice suggests that when situations are personalised (e.g. by close contact with a member of the discriminated group) earlier voiced attitudes are not usually enacted (346).

The reaction of parents and family members is also positive given that family dynamics is a factor associated with short term outcomes (137, 138). For example it has been observed that young people at risk of psychosis living in a critical family environment have significantly worse positive symptoms at six month follow up (187) demonstrating that parents and their reactions have an important role in the recovery process. Family members and partners of those with psychosis are seen to influence the explanations and beliefs held by the young person and therefore come to reinforce either a helpful or unhelpful explanation (188). The positive reactions observed may have been the result of the ARMS label offering parents a way to deal with the negative feelings they had experienced towards their child (190).

The finding that young people find it beneficial to talk to a mental health professional about their condition is supported by other early intervention studies. In one study first episode psychosis patients spoke positively about their experiences of psychological 'talking' therapies that helped them explore and understand their experiences. Such therapy addressed their psychological needs and meant they were better able to deal with their personal difficulties (171). Another study of adults with

ARMS discovered that those involved with services appreciated the value of being able to communicate their psychological distress which reduced levels of anxiety and confusion, improved their ability to cope with symptoms and improved mood and social ability (172).

Young people's desire to talk to peers with similar symptoms is possibly in line with the theory that people discriminate between safe and unsafe people in terms of talking about their condition (188). Wanting to talk to peers who understand and have experienced the condition themselves may be a way of young people trying to negate the perceived loss of contact with friends once they disclose their condition (198). The latter study highlights that psychosocial engagement programmes that encourage activities typical of young adults but also allow opportunities to meet with people who have similar experiences are desired and essential to the recovery process.

Professional attitudes towards ARMS

Given the lack of previous research in this area it is hard to establish whether the findings are in line with expectations. The consensus amongst our sample of child and adolescent clinicians was that psychosocial interventions, rather than medication, should be offered to young people with ARMS. This is in contrast to the findings of Tor and Lee (11) who reported that the majority of psychiatrists surveyed expressed a preference for the use of antipsychotic medication. Our method of sampling professionals from a variety of disciplines, a focus on CAMHS (in contrast to adult-based services) as well as cultural issues may account for these disparities. After all it has been established that adolescents are prone to neuroleptic side effects (204) and most alarming that little is also known about the effect that antipsychotic medication may have on the developing adolescent brain (113). Therefore it is not at all surprising that the clinicians surveyed and interviewed endorse potentially less damaging and controversial treatment options.

The finding that many clinicians find it particularly difficult and are not confident in identifying ARMS in adolescents is not surprising either given the difficulties

previously outlined (48, 73, 174). Previous literature indicates that it is also difficult to ascertain which behaviours are parts of normal development given that certain characteristics typical of adolescence such as conflicted family relationships, grandiosity, egocentrism and magical ideation bear a close resemblance to psychotic features (174). Findings from a recent survey also indicated that child psychiatrists were less confident in dealing with psychosis when compared to their adult counterparts (208). The findings of this study potentially indicated that child and adolescent clinicians lack experience and are ill equipped to assess and treat an adult type disorder like psychosis.

In terms of informing individuals about their condition and presenting someone with the ARMS label, this is something that clinicians voiced reluctance and discomfort in relation to. Again, this finding appears consistent with existing research relating to providing a diagnosis of psychosis (226). A separate survey of psychiatrists in Singapore found that many have problems with the ARMS name itself (103) and the rephrasing of the term adopted by some clinicians in the PAARMS study seems to confirm this discomfort with the label. The high proportion of CAMHS clinicians stating that the ARMS label has the potential for positive and negative connotations is consistent with the international debates currently taking place. Proponents of labelling state that that those presenting to services are already ill and the label helps individuals understand their symptoms and is indicative that help is forthcoming (146, 177, 184). Opponents of the label suggest that those who never make the transition to full blown psychosis may experience a lasting sense of fragility which may alter their future life goals and exposure to unnecessary stigma and treatment (1).

Finally, given the lack of official treatment guidelines and potentially a high degree of variability in resources allocated to the identification and management of adolescents with ARMS (223, 224) it is not surprising that clinicians clamoured for more training and locally agreed identification and management guidelines across CAMHS and EIP services.

7.1.4 What do the results and previous findings tell us about adolescents with ARMS?

The findings from the studies reported in this thesis confirm that adolescents with ARMS present to mental health services with significantly poor levels of psychosocial functioning. In terms of symptomatology they also experience intense and distressing psychotic like symptoms and co-morbidities. The high level of threshold and sub-threshold symptoms of depression and anxiety as well as elevated metacognitive beliefs and family perceptions (which are elevated beyond the norm when compared to non-help seeking populations) suggest that these may have an important role to play in the development and maintenance of psychotic-like symptoms and the presentation of young people to mental health services.

It is the author's opinion that these findings support the creation of a new diagnostic category in order to capture the distress and disability demonstrated by those with an 'At-Risk Mental State' for psychosis. Indeed the levels of self-harm and suicide attempts (which can be interpreted as the breaking of residual social, moral and legal rules and norms) are also justification that these behaviours go beyond normal adolescent behaviour simply relating to a period of natural 'storm and stress'. Additional support for making the ARMS concept an official diagnosis is the finding that the young people within this study identified personal difficulties and changes themselves before accessing mental health services. It also appears that they wanted to be informed about their 'condition' and respected clinicians who provided them with this information. This supports previous arguments that the ARMS label, rather than increasing apprehension (as is often the case with a diagnosis of psychosis), may open the door for new optimism that outweighs any anxiety as symptomatic patients know that some form of treatment is forthcoming (177). A label in this instance also helps young people to validate their distress and reassure them that they were not the only person to experience these symptoms (181). Additional support for this viewpoint is also forthcoming from the PAARMS survey of CAMHS professionals within this thesis.

It has been suggested that many ARMS labelled individuals would go on to experience discrimination and hostility from employers, family members, peers and health care professionals and would respond by withdrawing or limiting their social contact to those accepting of their condition (1). Our findings do not provide support for this view. The studies within this thesis have so far demonstrated that these negatives aspects may not be as significant as some fear.

Reviewing the initial arguments put forward to support any 'at-risk' diagnosis; early identification at this stage could potentially prevent or delay the onset of a full first episode of psychosis (which would have significant implications from a personal and society perspective in terms of quality of life, employment and treatment costs to name but a few key areas). Prompt and effective treatment in this potentially critical time period may preserve functioning and improve short to long term outcomes via a reduction in DUP (1). If identification is not made (especially in adolescents where long term outcomes associated with psychosis are worse; 26, 27, 201, 202) this could represent a significant missed opportunity. Although the vast majority of individuals who are identified do not make any transition within the first few years they are by no means asymptomatic. Engagement and support from services (due to identification) may help to shed light on the various presenting symptoms (distressing psychotic like symptoms, depression, anxiety and other common co-morbidities; 146).

However as with the creation of any new diagnosis within the medical profession there is always the possibility of overdiagnosis (347). Moynihan and colleagues point to the possibilities of wasting resources on unnecessary treatments and generating anxiety and adverse effects in patients when this occurs. Changing diagnostic criteria may dramatically increase the number of individuals defined as 'sick' causing a significant proportion of a population to be suddenly classed as 'ill' thus creating a massive strain on resources and services expected to treat the condition. In these instances important qualifiers must be included in the diagnostic definition. Finally the avoidance of litigation and regret are another concern as professionals may fear punishment for missing the early signs of a disease but are unlikely to face sanctions for overdiagnosis. All these fears appear valid should the

ARMS become an official diagnosis. In countering these arguments resources are already in place to identify and treat ARMS individuals as many EIP, CAMHS and stand-alone 'at-risk' teams nationally already undertake these activities. Secondly the financial benefits of potentially preventing psychosis in a handful of individuals (thus reducing future medication costs, inpatient bed days, welfare benefits etc) are far more likely to outweigh the cost of identifying and treating those with a suspected ARMS (although this argument requires further qualification and investigation). Since many adolescents experience sub-threshold psychotic experiences within the normal population (205) it is essential that any criteria includes relevant qualifiers that are strictly adhered to during diagnosis, otherwise a vast proportion of adolescents will suddenly and unnecessarily be deemed 'ill' under any new proposal. These qualifiers should include chronic or declining psychosocial functioning, associated distress and a help seeking nature. Both of these factors however maybe more difficult to establish in children and adolescents given that this life stage is associated with a natural period of 'storm and stress' whilst referrals to services may come from parents, youth offending services and/or educational establishments for example rather than the young person themselves. Resources may therefore have to be specifically set aside for training relating to assessment and identification purposes.

However in advocating any diagnosis, it is important to acknowledge at this stage that the widely used terms of At-Risk Mental State for psychosis or Psychosis Risk Syndrome as proposed by DSM-V (87) are not in the author's view ideal. Firstly they do not necessarily reflect the observed illness course associated with the symptoms observed nor do they match the views of front line mental health practitioners. For example the PAARMS study has already demonstrated the avoidance of using the full term At-Risk Mental State for psychosis by clinicians in 'real world' settings and this appears sensible since short to medium term assessments have demonstrated particularly low and declining psychosis transition rates. In fact many individuals make the transition to another psychiatric condition instead (60, 62, 106, 141, 145). Indeed, it is not clear at this stage what additional risk of impending psychosis, if any, adolescents fulfilling the ARMS criteria may have compared to peers in contact with CAMHS generally. In fact the data in this

thesis and from elsewhere indicates that the majority of ARMS individuals are not all predestined to a path of cognitive and functional decline (unlike the majority of their peers who develop psychosis at this age) with many no longer reaching the threshold or being perceived as 'at-risk' after just one or two years follow up (106). Therefore there are major questions regarding the ARMS utility as a predictive concept and the author agrees with those who believe that the inclusion of a Psychosis Risk Syndrome is too premature at this time. This belief appears to be the general consensus within the academic community given that the proposed inclusion has subsequently been dropped by the DSM working group committee within the last few months (348).

Therefore, a more appropriate label could be utilised such as 'Brief attenuated psychosis syndrome' since the name itself conceptualises the symptoms, distress and course of the illness more accurately than ARMS. The author acknowledges that this term is far from ideal and also has the potential to generate stigma and criticism from within patient and academic communities. Indeed the use of the term attenuated (or sub threshold) in any diagnosis in order to describe symptomatology is highly controversial and once again opens up the debate as to when we should categorise symptoms and experiences as 'abnormal' behaviour.

Opponents of what the author is proposing here may argue that no agreed aetiology or illness course exists for this 'Brief attenuated psychosis syndrome'; an important factor in the assignment of any diagnosis. The argument that a diagnostic category must have a clear aetiology however is not necessarily valid given that psychosis itself as outlined in Chapter III has numerous competing genetic, bio-chemical and psychological explanations. The natural course of this 'illness' clearly requires further study but can be achieved over time. Indeed, follow up studies assessing remission and symptom change are in their infancy but already exist whilst longitudinal narrative accounts of those so identified could be obtained using various methodologies (diary studies and regular prospective and retrospective interviews, with patients, clinicians and family members). Opponents may also question; 'What are the additional benefits of this diagnosis when many of these young people will already reach criteria for depression, anxiety or another

disorder'? In response to this it has already been demonstrated that young people desire something that validates their psychotic-like experiences. This term offers this without the potential anxiety and connotations of being labelled 'at-risk'. In terms of an agreed treatment approach although guidelines and an evidence base at this time are limited, a possible consensus has emerged between patient and clinician during this thesis. Monitoring, psycho-education and relatively 'simple' psychological therapies (that allow young people to discuss their symptoms with professionals and others with similar experiences) are preferred. From a professionals point of view this may reflect the understanding that young people are particularly susceptible to the side effects of anti-psychotic medication or the fact that identification in this age group is particularly difficult and complex. What does appear to be clear is that the majority of individuals benefit from identification (in terms of symptomatology and functioning over the short to medium term) and some form of support from services. As discussed previously support may be relatively simple (basic reassurance or some psycho-education) but enough to allay fears and normalise psychotic-like experiences (e.g. social groups). This argument is sensible when we consider that the recently published results from the EDIE-2 trial demonstrated few if any benefits of CBT above treatment as usual (349). The generation of any diagnosis therefore has the potential to increase research in this area in order to truly identify the most effective element or type of therapy offered to these individuals.

7.2 Clinical Implications

The findings from the FARMS project indicate that adolescents with ARMS present to services as a highly symptomatic patient group in need of identification and support. Such individuals experience significant levels of impairment and report a variety of affective, anxiety and psychotic-like symptoms. However this presentation (i.e. not experiencing a first episode of psychosis and experiencing a multitude of non-specific symptoms) means that it is often unclear, especially in the absence of official guidelines, whether CAMHS or EIP services are best placed to work with adolescents with ARMS. Since the core business of child psychiatry has traditionally focused on developmental disorders it means that child and adolescent

clinicians may have limited experience and are often ill-equipped to assess and treat an adult-type disorder such as psychosis (207). However, it could also be argued that EIP services are not ideal since they were initially configured to work with first episode psychotic patients (34) and may generate more anxiety and stigmatisation than generic CAMHS services. Therefore there is a clear argument for the establishment of either; a stand-alone At-Risk Mental State service solely responsible for the assessment and management of this patient group or an integrated service working seamlessly between EIP and CAMHS (as described by Tiffin & Hudson; 70). Based on the views of the clinicians interviewed during the PAARMS project such a service would receive plenty of referrals given that the majority of adolescents currently referred to EIP; "*have fitted an ARMS as opposed to being full blown psychotic"* (PP3, 17).

In terms of outcomes, an ARMS service may contemplate moving away from transition rates as an indicator of success given the low figures observed in this thesis and elsewhere. Focus should therefore be placed on reviewing improvements in functioning, quality of life, remission of symptoms and associated distress. Young people should be informed of these targets and aims at the outset.

In terms of diagnosis and psycho-education, it is clear that young people want to be informed about their condition. However, the present findings do not necessarily provide specific indications on how best to proceed with these processes. Providing plenty of time, information and allowing young people and their families to ask questions appears to be the most appropriate strategy at this stage. Direct feedback and experience from the FARMS clinic do provide some pointers for good practice though. The author found that emphasising the positives aspects of ARMS identification was well received. (i.e. *'It is good that we have identified this early which means that it should be easier to make things better'; 'You are not psychotic'; 'Most individuals with ARMS do not become psychotic over the short term'*). Providing individuals with information about their condition is such an important issue given that it has been demonstrated that people with psychosis who are more informed about their condition are more likely to engage with services, adhere to medical interventions and have better long term outcomes (197).

Despite the absence of official treatment guidelines, the findings reported in this thesis indicate that both professionals and young people themselves strongly advocate the use of psychological therapies, psycho-education, monitoring and social inclusion. According to clinicians, service users and the cognitive model of psychosis, social groups for example appear to be beneficial as they facilitate contact with peers and challenge psychotic appraisals by increasing access to normalizing or alternative explanations (278). Facilitating social contact between young people with ARMS is desired and may lead to a sharing of useful management strategies and help young people normalise their experiences. Possible ideas include the establishment of regular social groups (i.e. playing football, going to the cinema etc.) or arranging one to one sessions between young people supported and observed by a clinician. Indirectly these practices may improve levels of social functioning and promote friendships. Given the acceptability of psychological therapies that promote social inclusion, novel interventions such as Behavioural Activation therapy (which has also demonstrated significant reductions in depressive symptomatology; 350) should be considered. However, more effort is required to ensure the standardisation of psychological interventions currently offered to all ARMS patients, given the variety and non-specific nature of support currently provided. The findings of this thesis (in relation to the possible mechanisms involved in the development of symptoms) may also support the use of family therapy to alter negative family perceptions and cognitive therapy to challenge maladaptive metacognitive beliefs in routine clinical care.

Finally, further training and supervision appears to be required by both EIP and CAMHS professionals because of the difficulties of working with this patient group. Training may take the form of shadowing or observing experienced clinicians during assessment and intervention sessions or involve more formalised programmes such as obtaining professional qualifications that focus upon child development and developmental psychopathology. By characterising how adolescents with ARMS present to services this should positively inform training relating to identification.

7.3 Policy Implications

Both the mental health policy implementation guide (34) and Early Psychosis Declaration (351) were written for the establishment of services providing care for individuals experiencing a first episode of psychosis. They explicitly outline required staffing levels, treatment options and the professional skills required by Early Intervention teams. Although they both promote earlier identification of the illness and prevention as a primary objective neither provide clear guidance for working with individuals with ARMS.

This thesis will significantly inform the generation of any new guidelines (both locally and nationally) which may in turn lead to the establishment of a stand-alone ARMS service within Tees, Esk and Wear Valleys NHS Foundation trust. By characterising how young people present to services it will be easier for senior managers to determine and allocate resources appropriately. Clearer guidelines and care pathways as outlined by Tiffin and Hudson (70) are desired by mental health professionals who are regularly experiencing difficulties because of their absence. Discussions are already taking place to develop locally agreed guidelines to ensure a seamless and consistent standard of care. Such pathways should consider and contemplate the following key areas:

- Detection- A strategy for raising awareness about the ARMS condition (e.g. providing information, training and guidance about when to make a referral to schools, colleges, GPs, CAMHS etc.) in order to reduce DUI.
- Assessment practices- Agreement on the measures used (CAARMS, SIPS/SOPS, PANSS, DAWBA) and the duration of the assessment process (given the difficulties of working with this age group).
- Outcomes- For those with ARMS explicitly outlining the duration of care in the first instance (i.e. initially six months and needs reviewed at this stage) and the service responsible for care co-ordination; EIP, CAMHS or both). Psycho-educational material to be provided upon identification. First line treatment options available (monitoring, psychological therapies, social

groups) and when to consider the use of medication (low dose anti-psychotic or anti-depressants).

- Training and supervision- Agreement on the levels of training and supervision (one to one, peer, group) required by professionals working regularly with this patient group.

7.4 Strengths

There are several strengths to this thesis which require acknowledgement. Firstly the thesis attempts to conceptualise the concept of the ARMS from alternative perspectives using a variety of different methodological approaches. These have included first person qualitative accounts from various key stakeholders (i.e. service users and front line clinicians) as well the collection of prospective quantitative clinical data. On reflection, obtaining the personal accounts of service users and clinicians has been highly informative but a novel approach given the lack of qualitative research conducted so far (185, 186). The methods used and data collected not only have the potential to improve patient care in the short term (as outlined by some of the clinical implications above) but have also initiated the process of examining and understanding some of the theoretical models and mechanisms behind the development and maintenance of psychotic-like symptoms. By developing our knowledge in these areas, future intervention packages targeting these mechanisms maybe developed.

The concept of ARMS within the context of adolescence is also an important clinical issue that warranted further examination. The argument for this has been made previously, that identification within this age group potentially represents one of the earliest stages of psychosis identification and prevention (‘early’ early intervention) but is fraught with many difficulties (normal maturational processes, false positives, labelling, stigmatization etc.).

Finally, this thesis establishes capacities for future research, not only from the perspective of conducting research within adolescent ARMS patient groups but also within the sponsoring NHS trust and supporting academic institution. The ability to

recruit individuals for research can be a difficult task but funding opportunities may depend on researchers being able to demonstrate a track record of recruitment and patient and public involvement (PPI) in their work. This thesis demonstrates both aspects. Personal correspondence with individuals involved in the EDIE-2 project indicate that the recruitment of 30 ARMS participants in the stated time frame was a positive achievement. From the perspective of PPI, several of the young people initially involved in the qualitative interviews have presented themselves for further involvement (mainly consultation roles) in the development, design and execution of future research projects conducted by the academic institution within the field of child and adolescent mental health. Conducting and proposing future research projects within the locality in the future, should be met with less resistance (from service managers and clinicians) given the establishment of a research culture within some of these services. All of these factors will facilitate the processes of obtaining funding and attracting collaborators in order to conduct national multi-site research within the ARMS field.

7.5 Limitations

The major limitation of this thesis is that the results may simply reflect the experiences and practices of young people and clinicians accessing services and working for Tees, Esk and Wear Valleys NHS Foundation trust. Biases may exist in how young people were referred to the FARMS clinic for example whilst the views of clinicians may simply reflect the ethos and the current stage of the service's development. The sample size of thirty participants for the FARMS study and six participants within the qualitative studies could also be interpreted as a limitation affecting generalisation and the representativeness of the findings. However it is important to consider that the host trust covers a large and diverse geographical area covering both rural and urban areas with varying degrees of deprivation. The sample size of 30 participants is also the largest adolescent specific study to be conducted so far and should be viewed in light of its merits as a feasibility pilot study and the resources available to the overall project. In practice, a much larger sample would be required if predictors of transition to psychosis in this group were to be

estimated. For example, if 50 cases of psychosis were to be observed at six months follow-up a sample size of approximately 1000 adolescents fulfilling the ARMS criteria would be required. Whilst such samples may potentially populate statistical models of prediction (e.g. using multiple logistic regression) assembling such a large cohort, even internationally, would not appear feasible.

Although the process of identifying literature for this PhD has been outlined in Chapter 1, the opportunity to conduct a more thorough systematic review of adolescent ARMS studies was ultimately missed. A more transparent and systematic approach with a clear search protocol, explicit inclusion criteria and guidelines for the assessment of study quality would have been of greater benefit to any individual wishing to replicate this research. For example, a failure not to acknowledge studies published in non-English language journals (something which the author did not make explicit) may have missed highly relevant studies from countries that have only just begun to adopt the early intervention approach for youth mental health. A systematic review also reduces bias by removing the author's prior knowledge and preferences when constructing search terms, selecting database and other aspects of the literature identification process.

In terms of the qualitative research, the findings may have been contaminated by the views and experiences of the author since such research is open to interpretation bias which have been discussed in detail previously. Reflective diaries, regular supervision and having participants informally view the themes generated towards the end of the analysis may not be sufficient to ensure quality of the data and interpretation. The author's dual role as a researcher but also as a colleague and clinician is also a limitation but can be perceived as potential strength in that it facilitated access to both clinicians and patients as participants in the studies.

The qualitative findings may also have been subject to selection and response bias, largely reflecting the experiences of young people demonstrating positive outcomes, ignoring the sub-group of patients who eventually go on to become psychotic. Our decision not to interview individuals who had become psychotic is potentially biased as individuals who become psychotic may have significantly different

experiences to those not making a transition within the first six months. However our findings indicate that most young people do not become psychotic within the first six months and there is still the possibility that a handful of the participants interviewed will become psychotic over the coming months and years. The demographic details of those interviewed also indicate a varied and diverse group of participants in terms of age, gender and outcome at six month follow up.

In terms of follow-up data collection, the inability to conduct several full psychiatric assessments at this stage is disappointing but could not be prevented given the refusal to provide consent. The comparative analysis of symptomatology and functioning at baseline and follow up therefore only represents a small proportion of participants assessed at baseline. The assessment of outcome at six months only provides a snap shot of levels of impairment for one fixed time point and may not capture the potential fluctuations and remission of symptoms experienced by adolescents over the first few months of identification. Other studies have reviewed transition and symptomatology on a monthly basis where possible but have also struggled to follow up a number of participants beyond baseline (141). Finally, this study is unable to control for treatment effects given that on close analysis and review of medical records, participants were treated for various time frames, by various services (CAMHS and/or EIP) and using a variety of different interventions (low does medication, psychological therapies etc.).

7.6 Future Research

Future research should consider trying to replicate the FARMS project (the characterisation and follow up of ARMS adolescents) with a significantly larger cohort drawn from multiple sites. Such a study could indicate whether the findings of this thesis are representative of how ARMS adolescents present to mental health services nationally. As discussed previously, a much larger study and longer follow-up period (lasting several years) would be required to provide significant power to analyse which factors are predictive of making a transition to psychosis. Compared to other studies conducted so far this may represent a long and optimistic time frame but it is possible that adolescents, unlike their adult counterparts, experience a much

longer prodromal period. As well as collecting data relating to transition to psychosis any follow up should review levels of functioning, quality of life, remission of symptoms and associated distress. Attempting to control for potential treatment effects and adopting a true monitoring arm to any study, data of this nature would demonstrate whether young people naturally improve with time after identification or experience a series of 'peaks and troughs' in term of functioning and symptomatology during their teenage years.

As previously stated data from this thesis could be analysed further to see whether differences exist in the presentation of adolescents with ARMS in terms of age, gender and length of DUI. Plans to compare the metacognition scores (MCQ-30) with a matched sample (age, gender, socio-economic status) of non-help seeking adolescents is underway. The hypothesis of this research is that ARMS adolescents use more maladaptive and unhelpful metacognitive beliefs when compared to a matched sample of non-psychiatric adolescents. In terms of family functioning in ARMS adolescents, it would be interesting to investigate whether this is significantly impaired in comparison to non-help seekers and whether family functioning is associated with symptom severity and outcome. An exploration of these factors may identify a role for treatments that specifically targets these areas.

In terms of qualitative research, a grounded theory approach may be especially useful in investigating how young people experience the process of identification, treatment and possible stigmatisation. This time participants with an ARMS and those having gone on to develop psychosis would be interviewed in order to compare and contrast the differing experiences encountered through services and aspects of their life. The experiences of parents and siblings who live with a son/daughter/sibling with ARMS is also worthy of exploration as is a longitudinal study of personal narratives that plot the course of an ARMS.

As for future surveys, it is important to establish whether difficulties in identification, attitudes and understanding of the concept, treatment preferences and training requirements are common across EIP and CAMHS services nationally. If so it would be wise to explore whether any training interventions improve competence

as well as confidence in relation to detection of the ARMS in young people. Such data could significantly inform and support the development of any national guidelines for the identification and management of ARMS.

Although this thesis has identified and characterised how adolescents initially present to mental services and how their condition develops over the short term, the next question that requires answering is; 'How do we treat this patient group?' Within the UK the focus of research has been on trials of CBT for both adolescents and young adults with the findings of the multi-site EDIE 2 trial demonstrating limited benefits (349). Instead of CBT, other interventions such as Behavioural Activation (BA) therapy are worthy of exploration. BA although initially designed for depression has been explored in psychotic patients (352) and may suit an adolescent patient group because of its focus on behavioural work that aims to increase social contact rather than examining internal cognitive processes. A six month treatment trial of BA plus treatment as usual versus a treatment as usual only group could be conducted measuring outcomes such as transition, functioning, quality of life, symptom remission and associated distress (after feasibility and pilot work has been successfully completed).

The merits of psycho-educational group therapy also promoting social inclusion and contact with other ARMS adolescents should be considered given the desire of young people to talk to peers with similar symptoms and the benefits observed by mental health professionals when young people work together in groups. After all psycho-educational multi-family group treatment has already demonstrated improvements in symptomatology and functioning alongside acceptable levels of user satisfaction and adherence in adolescents (167). More generic psycho-educational programmes have also been piloted with significant reductions in symptomatology and improvements in quality of life being observed (168).

With appropriate field work BA and psycho-educational interventions may not only be as effective and acceptable to young people with ARMS but also delivered by services at a significantly lower cost than CBT. Evidence is already emerging to support the cost saving demonstrated by BA (353). Despite limited evidence for its

efficacy, safety and acceptability by patients and clinicians alike, both anti-psychotic and anti-depressant medication were prescribed to several participants within the FARMS cohort. These findings indicate that despite the reservations of child and adolescent mental health professionals in relation to their use, further trials are required over the coming years, to develop a safe and effective medical alternative for those not amenable or agreeable to psychological interventions.

Finally it is the responsibility of all research groups to identify factors that prevent individuals from accessing mental health services during the prodromal stage rather than waiting until they are floridly psychotic. Creative methodologies also need to be explored in order to boost the predictive power of the CAARMS and identify whether interventions have genuinely prevented or delayed an individual from becoming psychotic.

7.7 Conclusion

The results of this thesis support the notion that adolescents with ARMS present to mental health services with significant levels of symptomatology and impairment in functioning. However it appears that there are some subtle differences in how adolescents present when compared to adults with ARMS. In terms of short term six month outcomes, transition rates to psychosis are low with around a quarter of individuals demonstrating significant improvements in symptomatology and functioning. ARMS adolescents state that they wish to be told about their condition upon identification and do not appear to experience significantly negative or distressing instances of stigma as initially feared. Talking to mental health professionals and possibly peers who also experience similar symptoms, are perceived as the most beneficial support offered by services. As for child and adolescent mental health professionals it appears that medication is not a first line treatment strategy but monitoring, psycho-educational material and psychological therapies are widely endorsed. Identification and management of adolescents with ARMS is complicated and hindered by a variety of factors including maturational process and a lack of official guidelines and protocols. Future research however is required to establish whether these initial findings are representative of ARMS

adolescents and child and mental health professionals within the UK and to identify clinical and cost-effective interventions that reduce symptoms, distress and improve functioning outcomes. Finally, it is the author's belief that the findings contained in this thesis potentially support the case for creating a new diagnostic entity based loosely upon the ARMS concept (an 'attenuated psychosis syndrome').

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9 Appendix

1. Clinicians information leaflet

Tees, Esk and Wear Valleys NHS Trust

Durham University

Follow-up of the "At-Risk Mental State" for Psychosis in Adolescence

The FARMS Clinic and Research Project

A Guide for CAMHS/EIP Clinicians

INTRODUCTION

Over the last few years there have been increased efforts from Mental Health Services to assess and treat help-seeking young people who are perceived to be at an elevated risk of developing psychosis (an At-Risk Mental State). The majority of studies in this area have focused their attention on a wide range of young people aged anywhere between 14 to 35 years, but little is known about the “at-risk” adolescent population.

The FARMS Clinic and Research Project

What is it?

The FARMS clinic and research project is a collaborative venture by Durham University and Tees, Esk and Wear Valleys NHS Foundation Trust aimed at gathering more information about young people aged between 12 to 18 years old, who are at risk of developing psychosis. The projects main aims are to:

- Identify the characteristics of young people with an “At Risk Mental State” in terms of demographics, symptomology, functioning and developmental co-morbidity.
- Provide an estimate of how many adolescents make a transition to psychosis and identify characteristics associated with more favourable outcomes over the short-medium term.
- Obtain the views and experiences of young people who fulfil the ARMS criteria within our service.

What would you like me to do?

In order to make this study worthwhile we are hoping to recruit between 30-60 “at risk” adolescents between December 2009 and September 2011. We are asking all CAMHS/EIP clinicians to keep a look out for potential ARMS cases and we have provided some screening criteria to do this (see overleaf). If you or your team suspect an individual could be at an elevated risk, then we suggest that a referral is made to the specialist FARMS assessment clinic we have set up within the trust.

This clinic is led by Dr Paul Tiffin, Consultant Child and Adolescent Psychiatrist and Patrick Welsh, Assistant Psychologist, Early Intervention in Psychosis Service.

Our clinic will provide a full and comprehensive psychological assessment and provide feedback to referrers regarding our findings and recommendations. Consultation and advice to referrers will also be offered.

How do I refer to the FARMS project?

Before making a referral to the FARMS clinic we would like clinicians to explain to the young person and their carer what the FARMS project and research clinic is all about and why a referral seems appropriate. This will prepare potential participants for the possibility they may be approached to take part in a research study. To do this we have two leaflets outlining our research (one for young people themselves and one for parents/carers) which we would like clinicians to distribute before the referral is made. Only when the young person and their family have fully read and understood our leaflets should the referral be made. Referrals can be made by contacting either Paul Tiffin or Patrick Welsh using the details below.

Identifying whether some one is “at risk” (Screening Criteria)

Do you care for any young person between the ages of 12-18 years old who is **experiencing poor or deteriorating functioning** and:

Has a relative with a history of psychotic illness
Has unusual or distressing perceptual disturbance
Has delusional/bizarre/paranoid ideas
Has recently recovered from a brief psychotic episode (<7 days)

Contact us

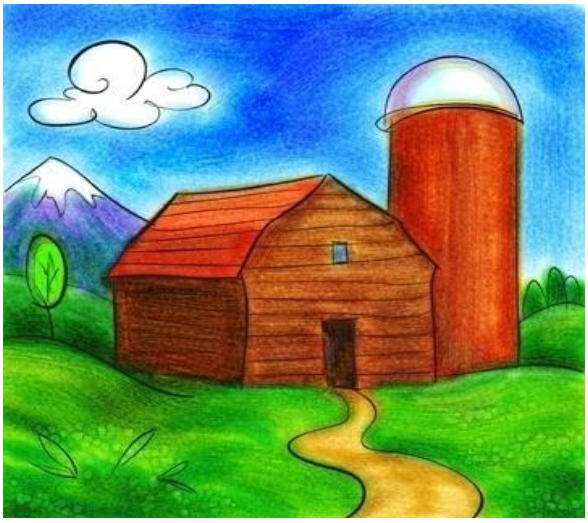
If you have any questions regarding the study or have any issues about making a referral please don’t hesitate to contact us:

2. FARMS assessment tools

The Follow-up of the “At-Risk Mental State” (FARMS) Survey

Assessment Pack

Baseline Assessment



Patient ID:

Date of Assessment:

Sex: Male ☐ Female ☐

Age: Years Months

Ethnicity:

Parental Occupation (Inc brief description):

Informants present:

What this pack contains:

1. **Background information** – family history and disorientation scale.
2. **Initial Functioning Matrix**- this estimates the client's day-to-day functioning across a number of domains, both past and present.
3. **The CAARMS** *(FARMS Version)*
4. **C-GAS** (to be completed with the aid of the functioning matrix).
5. **The Social & Communication Disorder Checklist**
6. **The Young Mania Rating Scale**
7. **The Hamilton Depression Rating Scale**
8. **The Family Perceptions Scale**
9. **Initial Substance Use Chart** *(present and recent past)*
10. **MCQ-30 and Score sheet**
11. **HoNOSCA Score sheet**
12. **PANSS Score sheet**
13. **DAWBA diagnosis**

Please note:

Although not included in this pack, the DAWBA must also be completed. It is an essential part of the FARMS assessment.

PANSS and HoNOSCA ratings also form part of a full FARMS assessment and can be derived once all the above assessments have been completed. Additional questioning of participants is therefore not required.

Background Information

Family History of psychotic illness or symptoms? (please specify relationship to client and main symptoms and any diagnoses)

Family History of non-psychotic mental health problems or symptoms including developmental disorders? (please specify relationship to client and main symptoms and any diagnoses)

Disorientation Scale

1. What is today's date? (Day/Month/Year)
   True ☐ False☐

2. Can you tell me roughly what time it is?
   Respondents answer:
   Actual time:

3. What is your name?
   True ☐ False☐

4. How old are you today (in years) and what is your date of birth?
   Age True ☐ False☐

   DOB True ☐ False☐

5. Can you tell me the name of this place?
   True ☐ False☐

6. What type of place this is?

7. What town/city are we in?.
   True ☐ False☐

DISORIENTATION– SEVERITY RATING SCALE (BASED ON PANSS ALGORITHM)

LACK OF AWARENESS OF ONE'S RELATIONSHIP TO THE MILIEU, INCLUDING PERSONS, PLACE AND TIME, WHICH MAY BE DUE TO CONFUSION OR WITHDRAWAL.

1 **Absent**	2 **Minimal**	3 **Mild**	4 **Moderate**	5 **Moderate severe**	6 **Severe**	7 **Extreme**
Well orientated. Definition does not apply.	Questionable pathology; maybe at the upper extreme of normal levels. Time estimate 15-30 minutes out OR difficulty in remembering name of location or town/ city	General orientation is adequate but there is some difficulty with specifics. For example, person confuses day of the week with an adjacent day or is unable to answer either the location name, type or town/city. Time estimate out by 30-60 minutes.	Only partial success in recognizing person, place and time. For example person is unable to answer correctly the current day or month and the location name, type or town/city. Time estimate out by 1-2 hours.	Considerable failure in recognizing person, place and time. Person only has a vague notion where they are. For example person struggles with personal information such as age or date of birth as well as current day, month and location name, type and town/city. Time estimate out by 3-5 hours.	Marked failure in recognizing person, place and time. For example, person has no knowledge about their whereabouts, confuses the date by more than one year and provides a time estimate out by 6-12 hours. Is able to answer name and/or date of birth/age correctly.	Person appears completely disorientated with regard to person, place and time. There is gross confusion or ignorance regarding name, current year and date of birth
☐	☐	☐	☐	☐	☐	☐

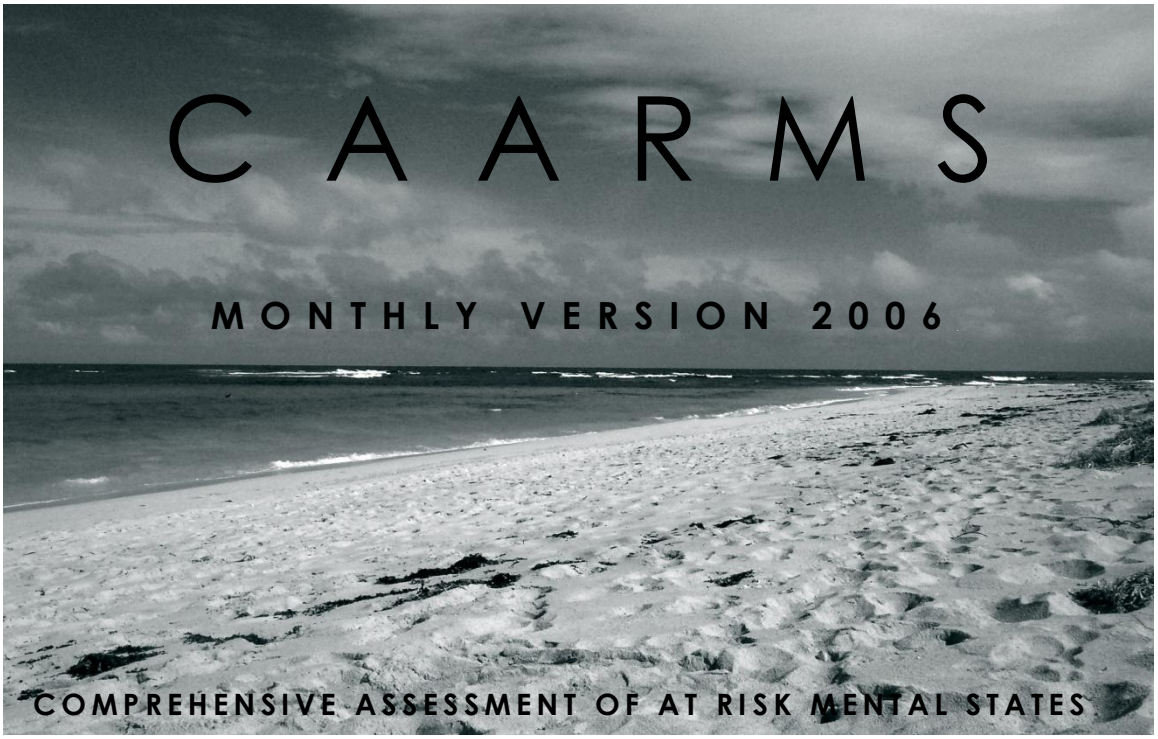
ARMS Assessment of Functioning Matrix- Baseline Form

Client ID: . Date: . Information Source (please tick): Client ☐ Carer ☐ Other (Please Specify) ☐

Area	**Time Periods**			
Educational/Occupational	**Over Last Month**	**Six Months Ago**	**Two Years Ago**	**Best Functioning Ever**
Work/college/school performance is at level expected for ability?	☐Good grades/standard of work in line with or exceeding ability ☐Struggling to maintain standards at times but generally good ☐Performance consistently less than would be expected for age/ability ☐Poor or absent achievement at work/education	☐Good grades/standard of work in line with or exceeding ability ☐Struggling to maintain standards at times but generally good ☐Performance consistently less than would be expected for age/ability ☐Poor or absent achievement at work/education	☐Good grades/standard of work in line with or exceeding ability ☐Struggling to maintain standards at times but generally good ☐Performance consistently less than would be expected for age/ability ☐Poor or absent achievement at work/education	☐Good grades/standard of work in line with or exceeding ability ☐Struggling to maintain standards at times but generally good ☐Performance consistently less than would be expected for age/ability ☐Poor or absent achievement at work/education
Attendance	☐Few or no absences (less than 5 days) ☐ >5days but less than 2 weeks missed ☐Some attendance but less than 50% of work/education time scheduled ☐No attendance during period rated	☐Few or no absences (less than 5 days) ☐ >5days but less than 2 weeks missed ☐Some attendance but less than 50% of work/education time scheduled ☐No attendance during period rated	☐Few or no absences (less than 5 days) ☐>5days but less than 2 weeks missed ☐Some attendance but less than 50% of work/education time scheduled ☐No attendance during period rated	☐Few or no absences (less than 5 days) ☐ >5days but less than 2 weeks missed ☐Some attendance but less than 50% of work/education time scheduled ☐No attendance during period rated
Conduct/Behaviour Problems	☐No conduct problems in period rated ☐Minor &/or occasional (<weekly) quarrels and oppositionality with teachers or supervisor ☐Frequent (>weekly) &/or problematic behavioural episodes ☐Problems prevent attendance at usual work/educational placement	☐No conduct problems in period rated ☐Minor &/or occasional (<weekly) quarrels and oppositionality with teachers or supervisor ☐Frequent (>weekly) &/or problematic behavioural episodes ☐Problems prevent attendance at usual work/educational placement	☐No conduct problems in period rated ☐Minor &/or occasional (<weekly) quarrels and oppositionality with teachers or supervisor ☐Frequent (>weekly) &/or problematic behavioural episodes ☐Problems prevent attendance at usual work/educational placement	☐No conduct problems in period rated ☐Minor &/or occasional (<weekly) quarrels and oppositionality with teachers or supervisor ☐Frequent (>weekly) &/or problematic behavioural episodes ☐Problems prevent attendance at usual work/educational placement

Social	Over Last Month	Six Months Ago	Two Years Ago	Best Functioning Ever
Peer Friendships	☐ Ability to make friends AND keep them over time. At least one good friend ☐ Makes friends but struggles to maintain friendships (6 months or more) ☐ Associates with peers but no close friendships made or maintained ☐ Marked isolation from peers with no friendships, close or otherwise	☐ Ability to make friends AND keep them over time. At least one good friend ☐ Makes friends but struggles to maintain friendships (6 months or more) ☐ Associates with peers but no close friendships made or maintained ☐ Marked isolation from peers with no friendships, close or otherwise	☐ Ability to make friends AND keep them over time. At least one good friend ☐ Makes friends but struggles to maintain friendships (6 months or more) ☐ Associates with peers but no close friendships made or maintained ☐ Marked isolation from peers with no friendships, close or otherwise	☐ Ability to make friends AND keep them over time. At least one good friend ☐ Makes friends but struggles to maintain friendships (6 months or more) ☐ Associates with peers but no close friendships made or maintained ☐ Marked isolation from peers with no friendships, close or otherwise
Skills	☐ Very socially able, behaving appropriately across all settings, demonstrating age-appropriate empathy ☐ Some social deficits apparent in some but not all settings (e.g. poor interaction with unfamiliar individuals) ☐ Significant deficits with awkwardness and/or some inappropriateness apparent across several settings ☐ Marked social deficits with behaviour markedly inappropriate at times and little evidence of empathic ability	☐ Very socially able, behaving appropriately across all settings, demonstrating age-appropriate empathy ☐ Some social deficits apparent in some but not all settings (e.g. poor interaction with unfamiliar individuals) ☐ Significant deficits with awkwardness and/or some inappropriateness apparent across several settings ☐ Marked social deficits with behaviour markedly inappropriate at times and little evidence of empathic ability	☐ Very socially able, behaving appropriately across all settings, demonstrating age-appropriate empathy ☐ Some social deficits apparent in some but not all settings (e.g. poor interaction with unfamiliar individuals) ☐ Significant deficits with awkwardness and/or some inappropriateness apparent across several settings ☐ Marked social deficits with behaviour markedly inappropriate at times and little evidence of empathic ability	☐ Very socially able, behaving appropriately across all settings, demonstrating age-appropriate empathy ☐ Some social deficits apparent in some but not all settings (e.g. poor interaction with unfamiliar individuals) ☐ Significant deficits with awkwardness and/or some inappropriateness apparent across several settings ☐ Marked social deficits with behaviour markedly inappropriate at times and little evidence of empathic ability
Activities	☐ Two or more regular (weekly+) social activities engaged in (e.g. sport, cinema, clubs etc) ☐ At least one regular social activity engaged in at least monthly in company of other/s ☐ Infrequent social activities (less than monthly) or mainly web-based contact ☐ Almost no social activity outside of home OR only web-based contact	☐ Two or more regular (weekly+) social activities engaged in (e.g. sport, cinema, clubs etc) ☐ At least one regular social activity engaged in at least monthly in company of other/s ☐ Infrequent social activities (less than monthly) or mainly web-based contact ☐ Almost no social activity outside of home OR only web-based contact	☐ Two or more regular (weekly+) social activities engaged in (e.g. sport, cinema, clubs etc) ☐ At least one regular social activity engaged in at least monthly in company of other/s ☐ Infrequent social activities (less than monthly) or mainly web-based contact ☐ Almost no social activity outside of home OR only web-based contact	☐ Two or more regular (weekly+) social activities engaged in (e.g. sport, cinema, clubs etc) ☐ At least one regular social activity engaged in at least monthly in company of other/s ☐ Infrequent social activities (less than monthly) or mainly web-based contact ☐ Almost no social activity outside of home OR only web-based contact
Romantic Attachments	☐ Age-appropriate relationships initiated and maintained to some extent ☐ At least short-lived romantic relationships during period rated ☐ Some interest in relationships but no appropriate attempts at initiation ☐ No age-appropriate interest expressed in such relationships	☐ Age-appropriate relationships initiated and maintained to some extent ☐ At least short-lived romantic relationships during period rated ☐ Some interest in relationships but no appropriate attempts at initiation ☐ No age-appropriate interest	☐ Age-appropriate relationships initiated and maintained to some extent ☐ At least short-lived romantic relationships during period rated ☐ Some interest in relationships but no appropriate attempts at initiation ☐ No age-appropriate interest	☐ Age-appropriate relationships initiated and maintained to some extent ☐ At least short-lived romantic relationships during period rated ☐ Some interest in relationships but no appropriate attempts at initiation ☐ No age-appropriate interest

Practical	Over Last Month	Six Months Ago	Two Years Ago	Best Functioning Ever
Self-care	☐Good self-care with little/no prompting ☐Generally good with some prompting required at times ☐Self-care only maintained with external support/prompting OR some self-neglect apparent at times ☐Basic self-care neglected even with frequent prompting and support offered	☐Good self-care with little/no prompting ☐Generally good with prompting required at times ☐Self-care only maintained with external support/prompting OR some self-neglect apparent at times ☐Basic self-care neglected even with frequent prompting and support offered	☐Good self-care with little/no prompting ☐Generally good with prompting required at times ☐Self-care only maintained with external support/prompting OR some self-neglect apparent at times ☐Basic self-care neglected even with frequent prompting and support offered	☐Good self-care with little/no prompting ☐Generally good with prompting required at times ☐Self-care only maintained with external support/prompting OR some self-neglect apparent at times ☐Basic self-care neglected even with frequent prompting and support offered
Independence	☐Age appropriate use of transport and can confidently stay away from carer when appropriate (e.g. school trips, college accommodation etc) ☐Generally has ability to get around but can lack confidence in some situations (e.g. long trips, overnight stays) ☐Generally dependent on carer/s presence but can demonstrate independence when strongly encouraged ☐Highly dependent on carer/s with little evidence of independence	☐Age appropriate use of transport and can confidently stay away from carer when appropriate (e.g. school trips, college accommodation etc) ☐Generally has ability to get around but can lack confidence in some situations (e.g. long trips, overnight stays) ☐Generally dependent on carer/s presence but can demonstrate independence when strongly encouraged ☐Highly dependent on carer/s with little evidence of independence	☐Age appropriate use of transport and can confidently stay away from carer when appropriate (e.g. school trips, college accommodation etc) ☐Generally has ability to get around but can lack confidence in some situations (e.g. long trips, overnight stays) ☐Generally dependent on carer/s presence but can demonstrate independence when strongly encouraged ☐Highly dependent on carer/s with little evidence of independence	☐Age appropriate use of transport and can confidently stay away from carer when appropriate (e.g. school trips, college accommodation etc) ☐Generally has ability to get around but can lack confidence in some situations (e.g. long trips, overnight stays) ☐Generally dependent on carer/s presence but can demonstrate independence when strongly encouraged ☐Highly dependent on carer/s with little evidence of independence
Vulnerability	☐Exercises good judgement to stay safe and is appropriately assertive ☐Generally stays safe and is sensible but struggles with assertiveness and can be occasionally led into trouble by peers ☐Occasionally exploited by others and some vulnerability to negative peer pressure and poor judgements ☐Prone to exploitation by others/bullying and repeatedly places themselves at risk through poor choices (exclude self-harm)	☐Exercises good judgement to stay safe and is appropriately assertive ☐Generally stays safe and is sensible but struggles with assertiveness and can be occasionally led into trouble by peers ☐Occasionally exploited by others and some vulnerability to negative peer pressure and poor judgements ☐Prone to exploitation by others/bullying and repeatedly places themselves at risk through poor choices (exclude self-harm)	☐Exercises good judgement to stay safe and is appropriately assertive ☐Generally stays safe and is sensible but struggles with assertiveness and can be occasionally led into trouble by peers ☐Occasionally exploited by others and some vulnerability to negative peer pressure and poor judgements ☐Prone to exploitation by others/bullying and repeatedly places themselves at risk through poor choices (exclude self-harm)	☐Exercises good judgement to stay safe and is appropriately assertive ☐Generally stays safe and is sensible but struggles with assertiveness and can be occasionally led into trouble by peers ☐Occasionally exploited by others and some vulnerability to negative peer pressure and poor judgements ☐Prone to exploitation by others/bullying and repeatedly places themselves at risk through poor choices (exclude self-harm)



A. Yung, L. Phillips, M.B. Simmons, J. Ward, K. Thompson, P. French, P. McGorry

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The PACE Clinic

Department of Psychiatry

The University of Melbourne, Australia

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:

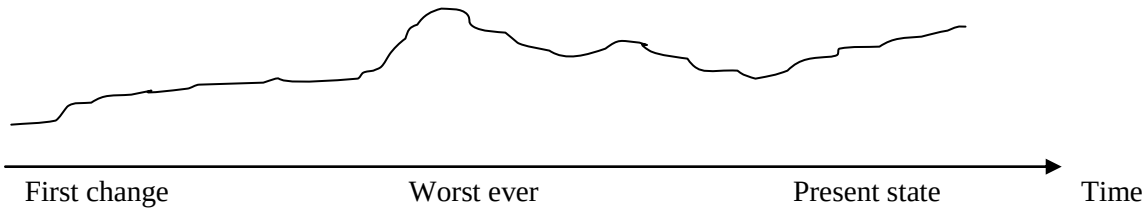
- At the first interview (not follow-up interviews), the CAARMS aims to obtain a general overview of the history of change from the premorbid state in the respondent. All available information should be used.
- Record the **time of first noted change** - date and age of respondent in years:

  Date:
  Age:

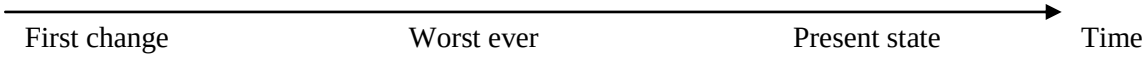
- Note first ever symptoms or signs:

- **Duration of untreated illness** (weeks):

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



- Current time line:



INDEX

1: POSITIVE SYMPTOMS

1.1 UNUSUAL 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?

Ideas of Reference

- 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?

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 thoughts 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 thoughts 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?

UNUSUAL THOUGHT CONTENT- GLOBAL RATING SCALE

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic and Severe**
No unusual 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.	Referential ideas that certain events, objects or people have a particular and unusual significance. Feeling that experience may be coming from outside the self. Belief not held with conviction, subject able to question. Does not result in change in behaviour.	Unusual thoughts that contain completely original and highly improbable material. Subject can 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.
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
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 noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use
☐	☐	☐

Level of Distress (In Relation to Symptoms)

0 **100**

1.2 NON-BIZARRE IDEAS

Non-Bizarre Ideas ('Crystallized Ideas')

- 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?

Non-Bizarre Ideas - Global Rating Scale

0 **Never, absent**	1 **Questionable**	2 **Mild**	3 **Moderate**	4 **Moderately severe**	5 **Severe**	6 **Psychotic and Severe**
No non-bizarre ideas.	Subtle changes that could be reality based. Eg. Very self-conscious.	Increased self-consciousness . Eg. Feeling that others look at the subject, or talk about the subject. Or feeling of increased self-importance. Subject able to question.	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.	Clearly idiosyncratic beliefs, which although 'possible' have arisen without logical evidence. Less evidence than rating of 3. Eg. Thoughts that others wish the subject harm, which can be easily dismissed. Thoughts of having special powers, which can be easily dismissed.	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.
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
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 and at other times as well	Noted only in relation to substance use
☐	☐	☐

Level of Distress (In Relation to Symptoms)

0 **100**

1.3 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, etc. Subject unsure of nature of experiences. Able to dismiss. Not distressing. Derealisation	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
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
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 noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use
☐	☐	☐

Level of Distress (In Relation to Symptoms)

0 **100**

1.4 DISORGANISED SPEECH

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.
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
Onset date: ***Offset date*:**

Frequency and Duration

0	1	2	3	4	5	6
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☐	☐	☐	☐	☐	☐	☐

Pattern of Symptoms

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

Level of Distress (In Relation to Symptoms)

0 **100**

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:

- 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:

- 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.
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
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 noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use
☐	☐	☐

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.
☐	☐	☐	☐	☐	☐	☐

2.3 ABSTRACT THINKING

Similarities:

I'm going to say a pair of words and I'd like you to tell me in what important way they're alike. Let's start, for example, with the words "apple" and "banana". How are they alike – what do they have in common?

IF THE RESPONSE IS THAT "THEY'RE BOTH FRUIT" THEN SAY: Good. Now what about ….? (Select three other items from the list at varying levels of difficulty).

IF AN ANSWER IS GIVEN THAT IS CONCRETE, TANGENITAL OR IDIOSYNCRATIC (E.G. "THEY BOTH HAVE SKINS", "YOU CAN EAT THEM", "MONKEYS LIKE THEM", then say: OK, but they're both fruit. Now how about …and…: how are these alike? (Select three other items from the list at varying levels of difficulty).

Similarities List:

1. *How are a ball and an orange alike?*
2. *Apple and Banana?*
3. *Pencil and pen?*

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4. *Table and Chair?*
5. *Tiger and elephant?*
6. *Hat and shirt?*
7. *Bus and Train?*

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8. *Arm and leg?*
9. *Rose and Tulip?*
10. *Uncle and Cousin?*
11. *The sun and the moon?*

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12. *Painting and poem?*
13. *Hilltop and Valley?*
14. *Air and water?*
15. *Peace and prosperity?*

ABSTRACT THINKING– SEVERITY RATING SCALE (BASED ON PANSS ALGORITHM)

IMPAIRMENT IN THE USE OF THE ABSTRACT SYMBOLIC MODE OF THINKING AS EVIDENCED BY DIFFICULTY IN CLASSIFICATION, FORMING GENERALIZATIONS, AND PROCEEDING BEYOND CONCRETE OR EGOCENTRIC THINKING IN PROBLEM SOLVING TASKS.

1 **Absent**	**2** **Minimal**	**3** **Mild**	**4** **Moderate**	**5** **Moderate severe**	**6** **Severe**	**7** **Extreme**
Definition does not apply.	Questionable pathology; may be at the upper extreme of normal limits.	Some problems with concepts that are fairly abstract and remotely related. Difficulty with the hardest similarities task.	Often utilizes a concrete mode. Tends to be distracted by functional aspects and salient features.	Deals primarily in a concrete mode, exhibiting difficulty with most categories.	Can formulate classifications for only the most simple of similarities. Thinking is locked into functional aspects and salient features.	Can only use concrete modes of thinking. Salient and functional attributes do not serve as a basis for classification.
☐	☐	☐	☐	☐	☐	☐

3: GENERAL PSYCHOPATHOLOGY

3.1 MANIA

- 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.
☐	☐	☐	☐	☐	☐	☐

Basis of Rating?
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 noted	Occurs in relation to substance use and at other times as well	Noted only in relation to substance use
☐	☐	☐

4: 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 C-GAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR C-GAS score of 50 or less** for past 12 months or longer	☐	☐
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:		
• **Global Rating Scale Score of 3-5** on *Unusual Thought Content* subscale, **3-5** on *Non-Bizarre Ideas* 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 *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS for **at least a week** • **OR Frequency Scale Score of 2** on *Unusual Thought Content, Non-Bizarre Ideas, 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:		
• **Global Rating Scale Score of 6** on *Unusual Thought Conten*t, **6** on Non-Bizarre Ideas, **5-6** on *Perceptual Abnormalities* **and/or 6** on *Disorganised Speech* subscales of the CAARMS		
PLUS		
• **Frequency Scale Score of 3** on *Unusual Thought Content, Non-Bizarre Ideas, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales of the CAARMS	☐	☐
PLUS (for both categories)		
• **Symptoms present in past year**	☐	☐
PLUS (for both categories)		
• **30% drop in C-GAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR C-GAS score of 50 or less** for past 12 months or longer	☐	☐
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 that resolved spontaneously (without antipsychotic medication) within one week.

	YES	NO
• **Global Rating Scale Score of 6** on *Unusual Thought Content* subscale, **6** on *Non-Bizarre Ideas*, **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 *Unusual Thought Content, Non-Bizarre Ideas, 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**	☐	☐
PLUS		
• **30% drop in C-GAS** score from premorbid level, sustained for a month, occurred within past 12 months **OR C-GAS score of 50 or less** for past 12 months or longer	☐	☐
CRITERION MET FOR GROUP 3 – BLIPS Group	☐	☐

5: PSYCHOSIS THRESHOLD /ANTI-PSYCHOTIC TREATMENT THRESHOLD

	YES	NO
• **Severity Scale Score of 6** on *Unusual Thought Content* subscale, **6** on *Non-Bizarre Ideas*, **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 *Unusual Thought Content*, *Non-Bizarre Ideas, Perceptual Abnormalities* **and/or** *Disorganised Speech* subscales	☐	☐
PLUS		
• Symptoms present for **longer than one week**	☐	☐
PSYCHOSIS THRESHOLD CRITERION MET	☐	☐

Children’s Global Assessment Scale (C-GAS)

C-GAS Score

Please use the data collected from the functioning matrix to calculate the young person’s current C-GAS score.

100-91	**Superior functioning** in all areas (at home, at school and with peers), involved in a range or activities and has many interests (e.g., has hobbies or participates in extracurricular activities or belongs to an organized group such as Scouts, etc.). Likable, confident, "everyday" worries never get out of hand. Doing well in school, no symptoms
90-81	**Good functioning in all areas.** Secure in family, school and with peers. There may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam, occasional "blow ups" with siblings, parents or peers).
80-71	**No more than slight impairment in functioning** at home, at school, or with peers. Some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g., parental separations, deaths, births of a sib) but these are brief and interference with functioning is transient. Such children are only minimally disturbing to others who are not considered deviant by those who know them.
70-61	**Some difficulty in a single area, but generally functioning pretty well**, (e.g., sporadic or isolated antisocial acts, such as occasionally playing hooky or petty theft; consistent minor difficulties with school work, mood changes of brief duration; fears and anxieties which do not lead to gross avoidance behaviour; self doubts). Has some meaningful interpersonal relationships. Most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern.
60-51	**Variable functioning with sporadic difficulties or symptoms** in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not those who see the child in other settings.

50-41	**Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area**, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.
40-31	**Major impairment in functioning in several areas and unable to function in one of these areas,** i.e.**,** disturbed at home, at school, with peers, or in the society at large, e.g., persistent aggression without clear instigation; markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal intent. Such children are likely to require special schooling and/or hospitalization or withdrawal from school (but this is not a sufficient criterion for inclusion in this category).
30-21	**Unable to function in almost all areas,** e.g., stays at home, in ward or in bed all day without taking part in social activities OR severe impairment in reality testing OR serious impairment in communication (e.g., sometimes incoherent or inappropriate).
20-11	**Needs considerable supervision** to prevent hurting other or self, e.g., frequently violent, repeated suicide attempts OR to maintain personal hygiene OR gross impairment in all forms of communication, e.g., severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.
10-1	**Needs constant supervision** (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect, or personal hygiene.

Social and Communication Checklist

REQUIRES INFORMANT: Please specify (Relationship to client):

For each item, please mark the box that best describes the young person's behaviour at around the age of 10:

1. **Not aware of other people's feelings**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

2. **Did not realise when others were upset or angry**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

3. **Did not notice the effect of his/her behaviour on other members of the family**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

4. **Behaviour often disrupted family life**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

5. **Very demanding of other people's time**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

6. **Difficult to reason with when upset**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

7. **Did not seem to understand social skills (e.g. persistently interrupted conversations)**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

8. **Did not pick up on body language**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

9. **Did not appear to understand how to behave when out (e.g. in shops, or other people's homes)**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

10. **Did not realise if he/she offended people with his/her behaviour**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

11. **Did not respond when told to do something**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

12. **Couldn't follow a command unless it was carefully worded**
Not true ☐ *Sometimes True* ☐ *Very or often true* ☐

Total Score

Was there any other comments or concerns about the young person's behaviour at around this age? (If yes please describe):

Young Mania Rating Scale **(clinician administered)**

Warning: ONLY COMPLETE IF THE YOUNG PERSON SCORES 2 OR MORE ON THE CAARMS MANIA SEVERITY RATING SCALE.

For each item, write the correct number on the line next to the item. (Only one response per item)

1.Elevated Mood
0. Absent
1. Mildly or possibly increased on questioning
2. Definite subjective elevation; optimistic, self-confident; cheerful; appropriate to content
3. Elevated, inappropriate to content; humorous
4. Euphoric; inappropriate laughter; singing

2.Increased Motor Activity - Energy
0. Absent
1. Subjectively increased
2. Animated; gestures increased
3. Excessive energy; hyperactive at times; restless (can be calmed)
4. Motor excitement; continuous hyperactivity (cannot be calmed)

3.Sexual Interest
0. Normal; not increased
1. Mildly or possibly increased
2. Definite subjective increase on questioning
3. Spontaneous sexual content; elaborates on sexual matters; hypersexual by self-report
4. Overt sexual acts (towards patients, staff or interviewer)

4.Sleep
0. Reports no decrease in sleep
1. Sleeping less than normal amount by up to one hour
2. Sleeping less than normal by more than one hour
3. Reports decreased need for sleep
4. Denies need for sleep

5.Irritability
0. Absent
2. Subjectively increased
4. Irritable at times during interview; recent episodes of anger or annoyance on ward
6. Frequently irritable during interview; short, curt throughout
8. Hostile, unco-operative, interview impossible

6.Speech (Rate and Amount)
0. No increase
2. Feels talkative
4. Increased rate or amount at times; verbose at times
6. Push; consistently increased rate and amount; difficult to interpret
8. Pressured; uninterruptible, continuous speech

7. Language – Thought Disorder
0. Absent
1. Circumstantial; mild distractibility; quick thoughts
2. Distractible; loses goal of thought; changes topics frequently; racing thoughts
3. Flight of ideas; tangentiality; difficult to follow; rhyming; echolalia
4. Incoherent; communication impossible

8.Content
0. Normal
2. Questionable plans, new interests
4. Special project(s); hyper-religious
6. Grandiose or paranoid ideas; ideas of reference
8. Delusions; hallucinations

9.Disruptive – Aggressive Behaviour
0. Absent, co-operative
2. Sarcastic; loud at times, guarded
4. Demanding; threats on ward
6. Threatens interviewer; shouting; interview difficult
8. Assaultive; destructive; interview impossible

10.Appearance
0. Appropriate dress and grooming
1. Minimally unkempt
2. Poorly groomed; moderately dishevelled; overdressed
3. Dishevelled; partly clothed; garish make-up
4. Completely unkempt; decorated; bizarre garb

11.Insight
0. Present; admits illness; agrees with need for treatment
1. Possibly ill
2. Admits behaviour change, but denies illness
3. Admits possible change in behaviour, but denies illness
4. Denies any behaviour change

Total Score

The Hamilton Rating Scale for Depression (clinician administered)

Warning: ONLY COMPLTE IF THE YOUNG PERSON ANSWERS "YES" TO QUESTIONS H1, H7 OR H13 ON THE DAWBA.

To rate the severity of depression in patients who are already diagnosed as depressed, administer this questionnaire. The higher the score, the more severe the depression.

For each item, write the correct number on the line next to the item. (Only one response per item)

---

1 DEPRESSED MOOD (Sadness, hopeless, helpless, worthless)
_____ 0= Absent
1= These feeling states indicated only on questioning
2= These feeling states spontaneously reported
3= Communicates feeling states non-verbally—i.e., through facial expression, posture, voice, and tendency to weep
4= Patient reports VIRTUALLY ONLY these feeling states in his spontaneous verbal and non-verbal communication

2 FEELINGS OF GUILT
_____ 0= Absent
1= Self reproach, feels he has let people down
2= Ideas of guilt or rumination over past errors or sinful deeds
3= Present illness is a punishment. Delusions of guilt
4= Hears accusatory or denunciatory voices and/or experiences threatening visual hallucinations

3 SUICIDE
_____ 0= Absent
1= Feels life is not worth living
2= Wishes he were dead or any thoughts of possible death to self
3= Suicidal ideas or gesture
4= Attempts at suicide (any serious attempt rates 4)

4 INSOMNIA EARLY
_____ 0= No difficulty falling asleep
1= Complains of occasional difficulty falling asleep—i.e., more than ½ hour
2= Complains of nightly difficulty falling asleep

5 INSOMNIA MIDDLE
_____ 0= No difficulty
1= patient complains of being restless and disturbed during the night
2= Waking during the night—any getting out of bed rates 2 (except for purposes of voiding)

6 INSOMNIA LATE
_____ 0= No difficulty
1= Waking in early hours of the morning but goes back to sleep
2= Unable to fall asleep again if he gets out of bed

7 WORK AND ACTIVITIES
_____ 0= No difficulty
1= Thoughts and feeling of incapacity, fatigue or weakness related to activities; work or hobbies
2= Lost of interest in activity; hobbies or work—either directly reported by patient, or indirect in listlessness, indecision and vacillation (feels he has to push self to work or activities)
3= Decrease in actual time spent in activities or decrease in productivity
4= Stop working because of present illness

8 RETARDATION: PSYCHOMOTOR (Slowness of thought and speech; impaired ability to concentrate; decreased motor activity)
_____ 0= Normal speech and thought
1= Slight retardation at interview
2= Obvious retardation at interview
3= Interview difficult
4= Complete stupor

9 AGITATION
0= None
_____ 1= Fidgetiness
2= Playing with hands, hair, etc.
3= Moving about, can't sit still
4= Hand wringing, nail biting, hair-pulling, biting of lips

10 ANXIETY (PSYCHOLOGICAL)
0= No difficulty
_____ 1= subjective tension and irritability
2= worrying about minor matters
3= Apprehensive attitude apparent in face or speech
4= Fears expressed without questioning

11 ANXIETY SOMATIC: Physiological concomitants of anxiety, (i.e., effects of autonomic overactivity, "butterflies," indigestion, stomach cramps, belching, diarrhea, palpitations, hyperventilation, paresthesia, sweating, flushing, tremor,
_____ headache, urinary frequency).
Avoid asking about possible medication side effects (i.e., dry mouth, constipation)
0= Absent
1= Mild
2= Moderate
3= Severe
4= Incapacitating

12 SOMATIC SYMPTOMS (GASTROINTESTINAL)
0= None
_____ 1= Loss of appetite but eating without encouragement from others. Food intake about normal
2= Difficulty eating without urging from others. Marked reduction of appetite and food intake

13 SOMATIC SYMPTOMS GENERAL
0= None
_____ 1= Heaviness in limbs, back or head. Backaches, headache, muscle aches. Loss of energy and fatigability
2= Any clear-cut symptom rates 2

14 GENITAL SYMPTOMS (Symptoms such as: loss of libido; impaired sexual performance; menstrual disturbances)
0= Absent
_____ 1= Mild
2= Severe

15 HYPOCHONDRIASIS
0= Not present
_____ 1= Self-absorption (bodily)
2= Preoccupation with health
3= Frequent complaints, requests for help, ect.
4= Hypochondriacal delusions

16 LOSS OF WEIGHT
A. When rating by history:
_____ 0= No weight loss
1= Probably weight loss associated with present illness
2= Definite (according to patient) weight loss
3= Not assessed

17 INSIGHT

____ 0= Acknowledges being depressed and ill

1= Acknowledges illness but attributes cause to bad food, climate, overwork, virus, need for rest, etc.

2= Denies being ill at all

Total Score

The Family Perceptions Scale (Respondent to complete)

This questionnaire looks at how a young person sees their family life at the moment. It should take around 5-10 minutes to complete. Please answer all the questions, even if you are not absolutely sure what to put in some cases.

Please answer ALL the questions, indicating whether you feel that the statement applies to your family *almost always*, *usually*, *sometimes* or *rarely*.

When answering, try to refer to your family overall, rather than focussing on individuals. For example, if you feel item 24 ("*People show their affection for each other*") applies to most of your family you may wish to respond by circling *usually*. If it applies to all of your family you should circle *almost always*. If you spend time in more than one family please answer for the one you spend most time with.

Try not to think about each question for too long before answering.

In my Family:

1	**People make time for each other** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
2	**We all have our usual bedtimes and tend to stick to them** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
3	**Money is spent carefully** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
4	**Voices are raised** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
5	**People stick to rules about mealtimes** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
6	**We each have particular jobs around the home** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
7	**Worries are properly listened to** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
8	**We cope well with unexpected emergencies** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
9	**We criticise each other** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
10	**When somebody breaks a rule they are dealt with** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
11	**It is difficult to understand each others behaviour** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
12	**We feel cared for** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
13	**Arguments are settled fairly** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
14	**People are encouraged to live a healthy lifestyle** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
15	**Discussions quickly get heated** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
16	**We all help out with jobs** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely

Please Turn the Page Over⟶

In my Family:

17	**Disputes are settled quickly** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
18	**It is easy to understand why people say the things they do** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
19	**High standards of behaviour are expected** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
20	**Hurtful things are said** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
21	**Planned activities actually happen** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
22	**It is difficult for people to have space** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
23	**Jobs are spread out equally** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
24	**People talk to each other face-to-face when they want to say something** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
25	**We all get our say when big decisions are taken** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
26	**We understand why we have particular rules** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
27	**There is someone to turn to if you are upset** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
28	**As a family we are good at sorting out problems** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely
29	**We are encouraged to make our own choices** ☐ Almost Always ☐ Usually ☐ Sometimes ☐ Rarely

Finished! Thank You for Completing this Questionnaire

Substance use Record- Baseline Assessment

Current	1 month ago	6 months ago	Most intense ever
Cigarette use (av per day):	**Cigarette use** (av per day):	**Cigarette use** (av per day):	**Cigarette use** (av per day):
Alcohol use: (units per week approx): "**Binge Drinking***" present? YES☐ NO☐	**Alcohol use:** (units per week approx): **"Binge Drinking***" present? YES☐ NO☐	**Alcohol use:** (units per week approx): "**Binge Drinking***" present? YES☐ NO☐	**Alcohol use:** (units per week approx): "**Binge Drinking***" present? YES☐NO☐
Cannabis Use: **Type** generally consumed (e.g. resin, "skunk", "homegrown" etc): **Mode** of taking (e.g. spliffs, buckets etc): **Amount** consumed (£ worth/week on average):	**Cannabis Use**: **Type** generally consumed (e.g. resin, "skunk", "homegrown" etc): **Mode** of taking (e.g. spliffs, buckets etc): **Amount** consumed (£ worth/week on average):	**Cannabis Use**: **Type** generally consumed (e.g. resin, "skunk", "homegrown" etc): **Mode** of taking (e.g. spliffs, buckets etc): **Amount** consumed (£ worth/week on average):	**Cannabis Use**: **Type** generally consumed (e.g. resin, "skunk", "homegrown" etc): **Mode** of taking (e.g. spliffs, buckets etc): **Amount** consumed (£ worth/week on average):
Stimulants and Hallucinogens: **Type** (e.g. Amphetamines, Ecstasy, Cocaine, LSD, Ketamine, 'shrooms etc): **Frequency** used (on av per month):	**Stimulants and Hallucinogens:** **Type** (e.g. Amphetamines, Ecstasy, Cocaine, LSD, Ketamine, 'shrooms etc): **Frequency** used (on av per month):	**Stimulants and Hallucinogens:** **Type** (e.g. Amphetamines, Ecstasy, Cocaine, LSD, Ketamine, 'shrooms etc): **Frequency** used (on av per month):	**Stimulants and Hallucinogens:** **Type** (e.g. Amphetamines, Ecstasy, Cocaine, LSD, Ketamine, 'shrooms etc): **Frequency** used (on av per month):
Other: **Type:** (include solvent misuse, iv /smoked opioids,abuse of prescription meds, benzos etc): **Frequency** of use:	**Other:** **Type:** (include solvent misuse, iv /smoked opioids,abuse of prescription meds, benzos etc): **Frequency** of use:	**Other:** **Type:** (include solvent misuse, iv /smoked opioids,abuse of prescription meds, benzos etc): **Frequency** of use:	**Other:** **Type:** (include solvent misuse, iv /smoked opioids,abuse of prescription meds, benzos etc): **Frequency** of use:

* Defined as "more than 5 drinks over a 2 hour session if male, 4 if female"; occurring on average at least once every two weeks

MCQ- 30

Adrian Wells & Samantha Cartwright-Hatton (1999)

This questionnaire is concerned with beliefs people have about their thinking.
Listed below are a number of beliefs that people have expressed. Please read each item and say how much you <u>generally</u> agree with it by <u>circling</u> the appropriate number.
Please respond to all the items, there are no right or wrong answers.

		Do not agree	*Agree slightly*	*Agree moderately*	*Agree very much*
1.	**Worrying helps me to avoid problems in the future**	☐	☐	☐	☐
2.	**My worrying is dangerous for me**	☐	☐	☐	☐
3.	**I think a lot about my thoughts**	☐	☐	☐	☐
4.	**I could make myself sick with worrying**	☐	☐	☐	☐
5.	**I am aware of the way my mind works when I am thinking through a problem**	☐	☐	☐	☐
6.	**If I did not control a worrying thought, and then it happened, it would be my fault**	☐	☐	☐	☐
7.	**I need to worry in order to remain organised**	☐	☐	☐	☐
8.	**I have little confidence in my memory for words and names**	☐	☐	☐	☐
9.	**My worrying thoughts persist, no matter how I try to stop them**	☐	☐	☐	☐
10	**Worrying helps me to get things sorted out in my mind**	☐	☐	☐	☐
11.	**I cannot ignore my worrying thoughts**	☐	☐	☐	☐

12.	**I monitor my thoughts**	☐	☐	☐	☐
13.	**I should be in control of my thoughts all of the time**	☐	☐	☐	☐
14.	**My memory can mislead me at times**	☐	☐	☐	☐
15.	**My worrying could make me go mad**	☐	☐	☐	☐
16.	**I am constantly aware of my thinking**	☐	☐	☐	☐
17.	**I have a poor memory**	☐	☐	☐	☐
18.	**I pay close attention to the way my mind works**	☐	☐	☐	☐
19.	**Worrying helps me cope**	☐	☐	☐	☐
20.	**Not being able to control my thoughts is a sign of weakness**	☐	☐	☐	☐
21.	**When I start worrying, I cannot stop**	☐	☐	☐	☐
22.	**I will be punished for not controlling certain thoughts**	☐	☐	☐	☐
23.	**Worrying help me to solve problems**	☐	☐	☐	☐
24.	**I have little confidence in my memory for places**	☐	☐	☐	☐
25.	**It is bad to think certain thoughts**	☐	☐	☐	☐
26.	**I do not trust my memory**	☐	☐	☐	☐
27.	**If I could not control my thoughts, I would not be able to function**	☐	☐	☐	☐
28.	**I need to worry, in order to work well**	☐	☐	☐	☐

29.	**I have little confidence in my memory for actions**	☐	☐	☐	☐
30.	**I constantly examine my thoughts**	☐	☐	☐	☐

Please ensure that you have responded to all items
Thank You.

MCQ-30 scoring

Positive beliefs

Sum: 1, 7, 10, 19, 23, 28

Negative beliefs: uncontrollability and danger

Sum: 2, 4, 9, 11, 15, 21

Cognitive Confidence

Sum: 8, 14, 17, 24, 26, 29

Need for control

Sum: 6, 13, 20, 22, 25, 27

Cognitive Self-consciousness

Sum: 3, 5, 12, 16, 18, 30

Total MCQ

Sum: 1-30

HoNOSCA
Score Sheet

Scale 0 - 4 **Rate 9 if not known**

Section A

1. Disruptive, antisocial or aggressive behaviour
2. Overactivity attention and concentration
3. Non accidental self injury
4. Alcohol, substance/solvent misuse
5. Scholastic or language skills
6. Physical illness or disability problems
7. Hallucinations and delusions
8. Non-organic somatic symptoms
9. Emotional and related symptoms
10. Peer relationships
11. Self care and independence
12. Family life and relationships
13. Poor school attendance

SECTION A TOTAL SCORE

14. Lack of knowledge - nature of difficulties

15. Lack of information - services/management

DAWBA diagnosis

Click here to enter text.

Trauma Screen (Section E2-PTSD)

0=No **1=Yes/Once** **2=Yes/>Once**

A) Serious accident
B) Fire
C) Other disaster
D) Severe attack/threat
E) Physical abuse
F) Sexual abuse
G) Rape
H) Domestic violence
I) Family/friend attacked
J) Death/suicide/overdose etc
K) Other severe trauma

Total Score

Self Harm & Suicide (section H18L & H23)

	Yes	No
H18L) Suicide Attempt (ever):	☐	☐
Within last twelve months	☐	☐
H23) Self Harm (within last six months):	☐	☐

Administering Client-Rated HoNOSCA's

The client-rated version of HoNOSCA has been developed using the 13 scales in Section A of the clinician-rated HoNOSCA. This consists of an administered questionnaire based on the main statement for each scale worded in the form of a question. For example, scale 1 of the clinician-rated HoNOSCA "Disruptive, anti-social or aggressive behaviour" became "Have you been troubled by your disruptive behaviour, physical or verbal aggression?"

The client-rated HoNOSCA is completed with minimal assistance from an independent person (i.e. not clinician). This assistant explains the purpose of HoNOSCA (i.e. to measure outcome) and gives a few brief guidelines, which consist of -

-Answer questions with last two weeks in mind.
-Try to be honest
-Try to answer all 13 questions
-Please tick one box for each question
-Try to rate the most severe difficulty mentioned in a question
-Take as long as necessary to answer questions

The client then completes the questionnaire with the assistant still present, so that help can be given in answering the questions if difficulties arise.

If it is not possible for an assistant to be available to administer the questionnaire, the client is given a "guidance sheet", which consists of the brief guidelines given above as well as an example which goes through a specific question and possible responses.

The client-rated HoNOSCA should be administered every time a clinician-rated HoNOSCA is completed, to act as a comparison. This would usually be at assessment, six-weekly review and discharge.

HoNOSCA SELF ASSESSMENT.

IN THE LAST TWO WEEKS:-

1. Have you been troubled by your disruptive behaviour, physical or verbal aggression?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

2. Have you suffered from lack of concentration or restlessness?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

3. Have you done anything to injure or harm yourself on purpose?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

4. Have you had problems as a result of your use of Alcohol, Drugs or Solvents?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

5. Have you experienced difficulties keeping up with your usual educational abilities?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

6. Has any physical illness or disability restricted your activities?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

7. Have you been troubled by hearing voices, seeing things, suspicious or abnormal thoughts?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

8. Have you suffered from self-induced vomiting, head/stomach aches with no physical cause, bedwetting or soiling?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

9. Have you been feeling in a low or anxious mood, or troubled by fears, obsessions or rituals?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

10. Have you been troubled by a lack of satisfactory friendships or bullying?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

11. Have you found it difficult to look after yourself or take responsibility for your independence?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

12. Have you been troubled by relationships in your family or substitute home?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

13. Have you stopped attending your education sessions?

□ Not at all □ Insignificantly □ Mild but definitely □ Moderately □ Severely

HoNOSCA

Parent's Assessment

The idea of this Assessment is to find out your views regarding the difficulties your son/daughter has been experiencing recently. The results are used to regularly monitor your son/daughter's progress, in conjunction with ratings by the clinical team and your son/daughter's own ratings.

1. Think back carefully and please try to be as accurate and as truthful as you can.

2. Only consider the last two weeks.

3. Please answer all 13 questions.

4. Please read all the choices before you tick the box.

5. Please tick one of the five boxes for each question.

6. If you think your son/daughter has experienced more than one of the difficulties listed in a question during the last two weeks, only give a rating for the most severe.

Thank you very much for your help.

HoNOSCA PARENT'S ASSESSMENT (V1).

IN THE LAST TWO WEEKS, DO YOU THINK THAT:-

1. Your son/daughter has been troubled by disruptive behaviour, physical or verbal aggression ☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

2. Your son/daughter has suffered from lack of concentration or restlessness?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

3. Your son/daughter has done anything to injure or harm him/herself on purpose?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

4. Your son/daughter has had problems as a result of the use of Alcohol, Drugs or Solvents?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

5. Your son/daughter has experienced difficulties keeping up with his/her usual educational abilities?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

6. Your son/daughter has any physical illness or disability that restricts his/her activities?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

7. Your son/daughter has been troubled by hearing voices, seeing things, suspicious or abnormal thoughts?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

8. Your son/daughter has suffered from self-induced vomiting, head/stomach aches with no physical cause, bedwetting or soiling?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

9. Your son/daughter been feeling in a low or anxious mood, or troubled by fears, obsessions or rituals?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

10. Your son/daughter has been troubled by a lack of satisfactory friendships or bullying?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

11. Your son/daughter found it difficult to look after him/herself or take responsibility for his/her independence?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

12. Your son/daughter has been troubled by relationships in your family or substitute home?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

13. Your son/daughter stopped attending his/her education sessions?

☐ ☐ ☐ ☐ ☐

Not at all Insignificantly Mild but definitely Moderately Severely

3. Ethical Approval

Durham University

Wolfson Research Institute
Improving health and well-being

Rebecca Perrett
Research and Development Manager, Wolfson Research Institute
Acting Chair, School of Medicine and Health Ethics Committee

Tel: 0191 334 0425
Email: Rebecca.Perrett@durham.ac.uk

Patrick Welsh
School of Medicine and Health
The Wolfson Research Institute
Durham University Queen's Campus
Stockton-on-Tees
TS17 6BH
United Kingdom

5th August 2009

Dear Patrick,

RE: Follow up of the At-Risk Mental State for Psychosis in Adolescence: The FARMS Project
Ref: ESC2/2009/07 Patrick Welsh

Thank you for your letter and the updated information which was sent in response to the queries of the School for Medicine and Health Ethics Committee.

These have been reviewed and I am satisfied that the changes made are acceptable to the committee, therefore, I am now able to grant you ethical approval for the study.

Please do not hesitate to contact me should you have any further questions. I hope that the study goes well.

With best wishes

R H Perrett.

Rebecca Perrett

National Research Ethics Service

County Durham & Tees Valley 2 Research Ethics Committee
The Tatchell Centre
University Hospital of North Tees
Piperknowle Road
Stockton-on-Tees
TS19 8PE

Telephone: 01642 624164
Facsimile: 01642 624164

21 October 2009

Mr Welsh
Durham University
Wolfson Research Institute
Queens Campus, Stockton-on-Tees
TS17 6BH

Dear Mr Welsh

Study Title:	**Follow-up of the At-Risk Mental State for Psychosis in Adolescence: The FARMS project**
REC reference number:	**09/H0908/63**
Protocol number:	**1**

Thank you for your letter of 07 October 2009, responding to the Committee's request for further information on the above research and submitting revised documentation

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

Guide for Parents & Carers

There are some grammatical errors throughout the document. Please proof read carefully and amend where necessary.

Under 'Why is the research needed?' - amend the last sentence to 'Improve the support and treatment that you and others are currently offered'.

Under 'If they do want to take part what will they have to do?' - 3rd and 4th paragraph - it should be made clear that further contact at six months, one year and two years later will be made face to face.

Guide for Young Persons

There are some grammatical errors throughout the document. Please proof read carefully and amend where necessary.

Under 'If I do take part what will happen to me?' - 3rd and 4th paragraph - it should be made clear that further contact at six months, one year and two years later will be made face to face.

Young Persons Consent Form

Statement 4 - The terminology is too complex. Please rewrite in a way which could be easily understood by potential participants.

Statement 10 - please add the words 'from the study' immediately after '.....I will be withdrawn'.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
REC application	IRAS 2.2	04 August 2009
Protocol	1	05 August 2009
Investigator CV	1	05 August 2009
GP/Consultant Information Sheets	1	05 August 2009
Referees or other scientific critique report		05 August 2009
Questionnaire: The Development & Well Being Assessment	Validated	
Questionnaire: HoNOSCA	Validated	
CV for Academic Supervisor - Paul Tiffin	1	05 August 2009

Covering Letter		
Iras Form Page 25 Completed		13 August 2009
Covering letter with correct sponsor signature (page 25 of application form)		13 August 2009
Participant Information Sheet: Young Persons Guide	2	01 October 2009
Participant Information Sheet: Parent & Carers Guide	2	01 October 2009
Participant Consent Form: Young Person	2	01 October 2009
Participant Consent Form: Young Person - Interview group	1	01 October 2009
Interview Schedules/Topic Guides	1	
Assessment Pack Six Month Follow Up	1	01 November 2009
Assessment Pack Twelve Month Follow Up	1	01 November 2009
Assessment Pack Twenty Four Month Follow Up	1	01 November 2009
Response to Request for Further Information		07 October 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0908/63	**Please quote this number on all correspondence**

Yours sincerely

Rachel Duncan
Chair

Tees, Esk and Wear Valleys NHS
NHS Foundation Trust

Research & Development Dept
The TAD Centre
Ormesby Rd
Berwick Hills
Middlesbrough
Cleveland
TS3 7SF
01642 516984
j.g.reilly@tewv.nhs.uk

Our Ref: JGR/vh

30 October 2009

Mr Patrick Welsh
Durham University
Wolfson Research Institute
Queens Campus
Stockton on Tees
TS17 6BH

Dear Mr Welsh

Title: Follow-up of the At-Risk Mental State of Psychosis in Adolescent: The FARMS Project
REC: 09/H0908/63

I am pleased to inform you that you have successfully gained research governance approval from the TEWV NHS Foundation Trust to conduct this study. All local checks are met and we have received a favourable ethical opinion. You may therefore commence this study in this Trust.

This research must be conducted in accordance with Tees, Esk and Wear Valleys NHS Foundation Trust policies and procedures, which are available to you on request. We require a report within three months of completion of the project outlining key findings for dissemination to clinicians, service users and carers as appropriate. We also encourage you to inform us of any publications which result from the project.

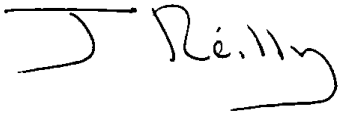
You must inform the R&D Office of any significant events or amendments in the course of the study, including:

- Change of Principal Investigator
- Early termination of the study, or continuation beyond the stated end date
- Significant adverse events
- Significant amendments to the study protocol

The Trust R&D Office conducts a yearly audit of research governance compliance, and you will be informed in advance if this study is due to be audited.

I would like to take this opportunity to wish you every success with your research. If there is any way that we can assist you in the future please contact us.

Yours sincerely



Professor Joe Reilly
Clinical Director for R&D

4. Young person's information leaflet

Tees, Esk and Wear Valleys NHS
NHS Trust

Durham University

Follow-up of the "At-Risk Mental State" for Psychosis in Adolescence

The FARMS Research Project

Young Person's Guide

INTRODUCTION

Over the last few years Mental Health Services have tried to get help to people early, rather than waiting until things get really bad. Some scientists and doctors now think we can spot the early signs of some mental health problems in people “at risk” of illness. By offering help to those who may be having early problems we may get them better more quickly.

This leaflet will tell you about a research project. Before you decide if you want to take part, it is important to understand why we are doing this research and what it will mean for you. Please read this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

The FARMS Research Project

What is it?

The FARMS research project is a study by Durham University and Tees, Esk and Wear Valleys NHS Foundation Trust. The aim is to collect information about young people who maybe “at risk” of developing certain mental health problems.

Why is the research needed?

Research is needed since there is very little information about young people, who have similar problems to you. It is hoped that by talking and listening to what you have to say we will be able to:

- Provide a better understanding of you current problems and concerns
- Improve the support and treatment that yourself and others are currently offered.

What are the benefits of taking part in the research?

- Although our findings might not benefit you directly they should help to improve the assessment and treatment of young people in the future.

Who is being asked to take part?

All young people who are seen at the FARMS clinic will be asked to take part in our research.

Do I have to take part?

No, it's your choice and you do not have to give a reason if you don't want to. This will not affect the care you receive. If you do want to take part, you will be asked to sign a form to show you understand what will happen (this is known as giving your consent). You are free to stop taking part at any time during the research without giving a reason. If you decide to stop all the information we have collected so far will still be used for our research. If during the study you lose the ability to show us you understand what is going on (we call this "capacity") we will take you out of the study straight away. We will still use the information you have already given us.

If I do take part what will happen to me?

The first thing we will ask you to do is come and see us at the FARMS clinic. Here a member of the research team will ask you and your family about your mental health. This should take 1 to 2 hours but you will be able to have breaks during this. Together, we may decide to spread the chat over two appointments.

After this is finished we will tell you what we have found. If **we don't think you are "at risk**" of developing a mental health problem, we will use all the information you have given us for our research. This information is to help us understand why some of your problems made us think you were "at risk" when you were not. Six months later we will get in touch with you to see how you are doing. Here we will ask you some questions (this should only take 20-30 minutes and will be done face to face).

For those of you who **are "at risk**", we will use all the information you have given us for our research. Six months later we will get in touch with you to see how you are doing. Here we will ask you some questions (this should only take 20-30 minutes and will be done face to face). If you are feeling well we may ask you to take part in an interview. This is so that we can find out what you think about the help and support you have been given and how you reacted to being told you were at risk. People who do take part will be given a gift voucher to spend at a high street music store. This is not to encourage you to take part but to recognise the time and effort needed to complete the interview. It is your choice if you want to take part in the interview and all you have to do is say "No" if you don't want to.

After this six month check up we will contact you again when you have been part of the study for a year and again a year later. The questions we will ask you at this stage will be the same as before, taking around 20-30 minutes to complete and will be done face to face.

For a summary explaining what taking part in our research involves please see the flow chart on page 6.

What will you do with my answers?

Firstly, the information you give us will be placed in your medical notes. All personal information (such as your name, contact details etc) will be stored on a secure NHS computer.

Some of the information we collect during the research will be stored away from an NHS computer at Durham University. All information will be kept safe using a password. Your name, address and date of birth will not be on this information, reducing the chances of someone identifying you. Where paper or audio copies of your answers are used these will be stored within a locked cabinet within Durham University. Only individuals from the research team will have access to this cabinet.

We will use this information for our research by grouping it together with the answers given by other participants. The information we collect will be used to write reports describing our results. This is so that people understand what we have found and what changes need to be made. Within these reports it will be impossible for others to realise you have taken part in the study and identify the answers you gave. You will never be named in any of our findings. At the end of the study we will write or email you a summary of what we found.

All the information you give to us during the research will remain confidential (not shared with anyone outside the research or care team) **unless** there are **special circumstances**. Special circumstances often means the information you have given is linked to a crime (past or present) or that you intend to hurt yourself or others. If this takes place, someone from the research or care team will discuss with you why this information must be shared with others. This is part of NHS safeguarding practices and takes place to keep you safe.

If you become upset or unhappy with our research?

If you become upset or unhappy with our research you should ask to speak to one of the research team first. They will do their best to answer your questions. If you would like to talk to someone else the best person maybe your Child and Adolescent Mental Health care-coordinator. If you are upset and these people are not available please contact your GP or NHS Direct.

In the unlikely event that you are harmed during the research and this is someone else's fault, you may have grounds for a legal action for compensation against Tees, Esk and Wear Valleys NHS Foundation Trust or Durham University (but you may have to pay your legal costs). If you wish to complain formally, you can do this by contacting either:

To protect your safety, rights, wellbeing and dignity, this study has been reviewed and given favourable opinion by County Durham & Tees Valley 2 Research Ethics Committee.

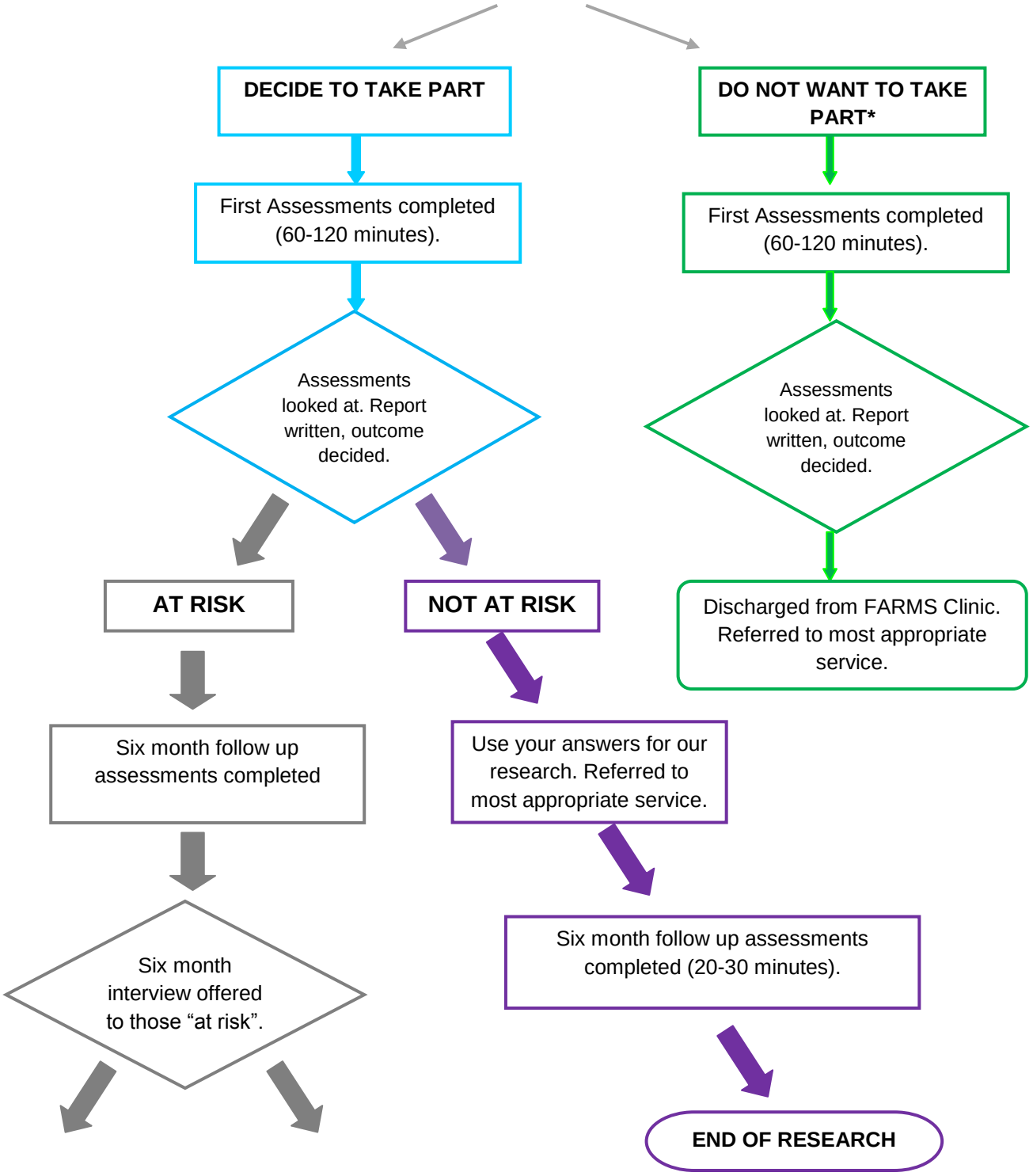
Want more Information?

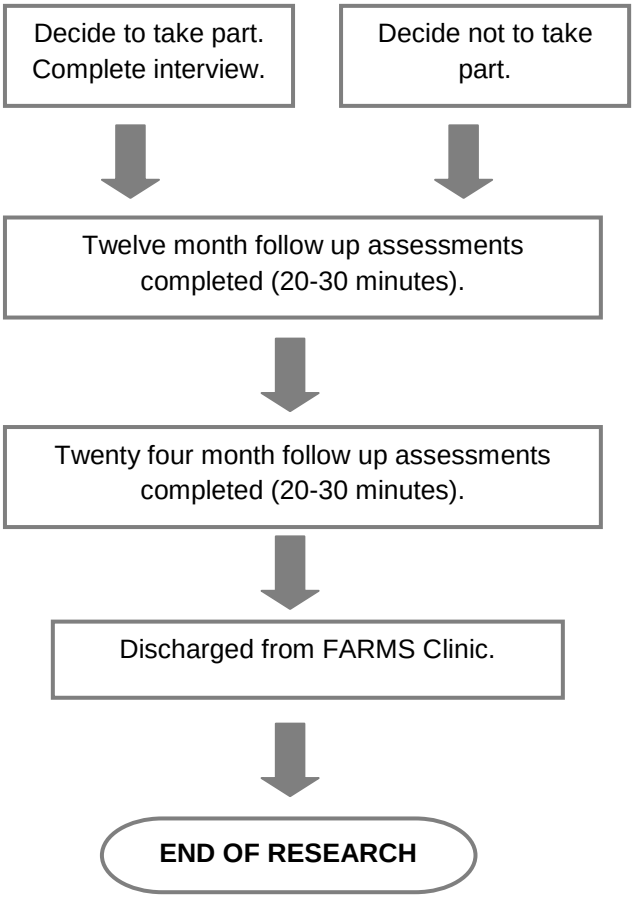
If you have any questions or would like to talk to someone about the project in private, please contact:

Flow Chart of what is involved

STEP 1 Come to see us at the FARMS Clinic

STEP 2 Clinic and research explained.
Consent to take part in the research taken.





* If you do not want to take part in our research that is fine, it is your decision. You will still receive the same NHS care as those taking part in our research.

5. Sample size determination

TABLE I

Sample sizes required per group at the two sided 5% significance level for different values of d and power (d=expected mean difference/ standard deviation)

	Power (1-beta)				
d	**99**	**95**	**90**	**80**	**50**
0.10	3676	2600	2103	1571	770
0.20	920	651	527	394	194
0.30	410	290	235	176	87
0.40	231	164	133	100	49
0.50	148	105	86	64	32
0.60	104	74	60	45	23
0.70	76	54	44	33	17
0.80	59	42	34	26	13
0.90	47	34	27	21	11
1.00	38	27	22	17	9
1.10	32	23	19	14	8
1.20	27	20	16	12	7
1.30	23	17	14	11	6
1.40	20	15	12	9	5
1.50	18	13	11	8	5

Taken from: Campbell MJ, Julious SA, Altman, DG. Estimating sample sizes for binary, ordered categorical and continuous outcomes in two group comparisons. *BMJ* 1995;311:1145

The parameters used for this example are:

- The desired statistical power of the trial. In this instance 0.8
- Cohen's d based upon *FPS total score* data (40.7-45.7)/(16.5+18.7/2)=0.28 or 0.3

Based on these parameters a sample size of 176 is required for each group.

6. Six month interview schedule

Six month Interview Schedule

Introduction

Thank you for taking part in this interview for the FARMS project. Today I am going to ask you about some of your thoughts and experiences regarding the At Risk Mental State. As I have explained before there are no right or wrong answers. I will be taping the interview so that I can remember your answers and these will be stored safely and anonymously after we have finished.

Experiencing ARMS

- Could you describe in your own words what the At Risk Mental State means?
- Could you describe your thoughts about being labelled as having an At Risk Mental State?
- Could you describe your feelings about being labelled as having an At Risk Mental State?
- Do you think being labelled At Risk has changed the way you see or feel about yourself as a person?
- What about the way other people see you: members of your family/friends? Has this changed?
- Did you find the label helpful/unhelpful?
- What are your thoughts and feelings about the future?

Support/treatment

- What did you think about the assessments conducted at the FARMS clinic?
- Did you find the feedback made you more anxious/less anxious/neither?
- Did these feelings affect your symptoms/experiences or ability to get things done in life?
- Could you tell me about the treatment you received?
- What was it for?
- What, if anything, did you find the most useful?
- What other help might you think would be useful to other young people like yourself with similar difficulties?

7. Free textual analysis and the identification of emergent themes of Transcript AA (FARMS project)

Emergent themes	Original Transcript	Exploratory comments
	INT: Thank you for taking part in this interview for the FARMS project. I'm going to ask you some questions about your thoughts and experiences regarding the At Risk Mental State, we're going to talk through things like that. As I explained before, there's no right or wrong answers and as you can see I'm taping the interview so I can remember the things you've said and these will be stored safely and anonymously after we've finished. Ok. So just to start things off, I want you to try and think about six months ago, it was in this building that you first came to see me and (a colleague) as well and we asked you a couple of questions and stuff like that and we did what we call an assessment and then we gave you a bit of a booklet and said that some of the experiences you were having, it, it was known as like having an At Risk Mental State sort of thing for psychosis. I'm just wondering, could you describe in your own words what, what do you think the At Risk Mental State means?	
I am not ill.	***PP: It's a way of, kind of categorising people*** *bureaucratically* ***so that people who've had similar experiences can be kept in the same group and it also kind of means that you don't have a mental illness but….***	*The ARMS is not a mental illness.* Relief? I am not ill.
	INT: You're on the right lines …	
Understanding	***PP: You maybe show mild symptoms or experiences that***	

	may develop if unnoticed or untreated.	*A mild condition.* Things could be worse if left.
	INT: OK. Yeah, Yeah, that's a good explanation, definitely along the right lines there. So when we gave you that booklet and went through, and said you're at risk, and obviously a lot of things won't have sank in at the time because well you've been giving us a lot of questions and stuff like that, a lot of answers when you did our assessment. I'm just wondering what your thoughts were or your reaction or feelings were when you were told you had this this At Risk Mental State?	
Relief **What is wrong with me** **Validation**	***PP: I didn't really have much of a reaction, it was more if anything it was kind of a relief kind of thing because I knew there was obviously something wrong and the fact that somebody acknowledged that, and I'd been seen and everything and I kind of had something to go away with that I knew somebody else had already noticed, then I could work with that.***	*Positive/relief reaction. Knew something was wrong and good that it has been identified.* Importance that experiences/condition indentified and validated by others. Worried before the assessment? What is wrong with me?
	INT: Was it, so you're saying you felt relief, did you think it, did you also feel relieved that many things were maybe worse, if that makes sense. Did you come here thinking the worst or I'm going to be labelled or something	
Perception **Knowing what I want**	***PP: Yeah, that was something that I didn't want to happen, I didn't want to come and think and have somebody think that I was maybe had a full blown mental illness. I thought it was maybe more, just a case of therapy or something like that. Just to deal with the symptoms rather than a course of medication or anything like that.***	*Scared that might be seen as really ill.* I am ill but not that ill. *An idea about what sort of treatment they would/would not like.* Preconceptions about possible treatment.
	INT: So are you saying you might have been that when you	

Help forthcoming **Reducing uncertainty** **It has a name** **Information**	first came here, you might have been quite worried about being put on medication? ***PP: Yeah***. INT: Any particular reason why? ***PP: Just because I've been on lots of different medications before for migraines and things and generally I'm not very for medication whether its routines or side effects or anything like that, I'm not very good with it.*** INT: So as you've started working through things with R and stuff like that, after you'd had the assessment with us we told you that you were at risk, given you the booklet, and then you started working with R again. Again would you, do you think that that's been told, and I suppose, it's not being labelled, but I suppose to us you might have been slightly labelled as having this At Risk Mental State. Do you think it affected you in anyway in terms of how you saw yourself or thinking about the future? ***PP: Not really, I think it was, it maybe helped rather than it hindered because I knew that at least something was going to be done, at least that I was going to like, see R and everything and if I would have left and I hadn't been given anything then I might have been more worried about the future and stuff because I didn't know what was going on. With, given the At Risk Mental State kind of label thing it was helpful cause then I could read up and I knew how it was going to be dealt with and everything like that***.	*Explanation why not keen on medication use.* *The ARMS label was positive because I knew what was wrong. It had a name, could search for information.* Action. Need/desire for someone to validate their experience. Identify something is wrong and help is forthcoming. Reducing uncertainty.

	INT: Yeah. OK and in terms of reading up, I am just wondering what sort of things were you able to, did you find anything?	
Limited information	***PP: Booklets and things and there was a few websites, not many***	*Limited info available.* Desire for information.
	INT: I was concerned, because I don't think there are many but if you did come across some then that's quite interesting. OK. And so as you were reading things again, was there anything in particular that you read that particularly scared you or got you more not scared but worked up or like I said was again it was all sort of feelings of relief and its going to be ok?	
Stress Understanding Not looking after self.	***PP: Yeah, I think, because I was reading so much at the time I was quite busy with a lot of things, I don't really think I took a lot of it in. But I just think, it all made sense, nothing was sensationalised or anything like that. I think it was clear and concise.***	*Didn't take in a lot at the time but did understand and was not afraid by the info given.* Too stressed to fully understand everything. Stressful time.
	INT: So did things become more clear then after you started working with R because he said you were busy at the start of things, so maybe things didn't sink in at first but did things maybe start becoming more understandable when you started working with	
Understanding Anxiety Reduction	***PP: Yeah. He kind of, it explained everything, he made sure I understood and it helped me to maybe calm down a bit with the understanding because I hadn't really, nothing had sunk in, I didn't really understand the mental state and that kind of thing.***	*Hard concept to fully understand at first. Understanding led to relief. Importance of support to help people understand concept and themselves.*

Sharing info **Telling others** **Those who are close to me.**	INT: It is quite a hard thing to understand it has to be said, so, but it's a very interesting point. So we've said whether this sort of label of being labelled at risk is going to change the way you feel yourself. Has it changed the way you see or feel yourself as a person? ***PP: Not really, no***. INT: Not really. Did you ever let, well actually has it changed, did you sort of share that information with anyone else in your family cause obviously your mam was here at the time? ***PP: Yeah. I think most of family know*** INT: But what have you told them or what do they make of it? ***PP: I don't think I've really told them much. They knew I was being seen, coming here, but other than that I don't think they really knew or what. I think it was only my mam and dad who knew anything detailed. It wasn't like kept from them, deliberately, it wasn't like hiding things round the house, that kind of thing it was just a*** INT: And I'm just wondering obviously with your parents and obviously like you mam was in when we were talking things through with her. Would you say that the way they behaved towards you in the past changed or not? ***PP: No not really.***	*No need to tell other people in detail but not scared or ashamed about this.* Only close people told, given exact info. I don't want to share?

Limited detail	INT: Not that you noticed? ***PP: No.*** INT: OK. Again that's a good thing. I guess sort of sum up what you've talked about this before, would you say you found we are going to call it a label this At Risk Mental State label helpful or unhelpful? ***PP: Like I said, I think I found it more of a help than a hindrance just because I knew what's going on I knew that something was going to be done so*** INT: OK... Have you ever mentioned anything about it to your friends as well? ***PP: I think I did, when I first came, I don't think the At Risk Mental State came up.*** INT: Yeah, so I was going to say so what did you really tell your friends about it? ***PP: Just I think the first time I came it was during school time, so when I got back to school I said where I'd been and everything and I didn't think it was much of a problem to tell them where I'd been so basically all they knew was that I was being seen by psychologists and things and that was really all I told them.*** INT: And what was their reaction to that or did they just get on with things?	*Describes that help is forthcoming.* *Told friends but not in detail.*

Concern/Worry **No Change** **Reaction** **Some stigma** **Its expected**	***PP: It was, they were just I think worry was some of the things, they were worried….but there was no real change.*** INT: It's good that people worry about you ***PP. There are a few aren't really friends who are like are you a nutcase or whatever but that's just really*** INT: Yes they might, as you said they are not really friends, they're just yeah. Ok then. I think moving on from this then so moving on what we have said about how you sort of reacted to the news. I mean actually the finally point about that sort of thing that going aback to the assessment and when we said you had an At Risk Mental State. Can you, its really hard, but can you describe maybe what your first reaction or feeling was or just can you not really remember? ***PP: I can't really remember… just no, carn't.*** INT: No, so I suppose we can take from that, we didn't completely shock you or was it maybe things as you said that it didn't sink in because you had that much going on ***PP: I think it didn't sink in really very well. Even once they had, it was more relief because I knew I was being seen so.*** INT: Is there any way we can maybe, again these are quite hard questions so you're doing well, but is there anyway we could maybe improved things so things, might have sunk in sooner? If that makes sense?	*Friends concerned/worried, no negative changes.* Not bothered, nothing has changed. *Some stigma reported by peers.* It's expected.

Stress **Not looking after myself**	***PP: I don't think so mainly because it was my GCSEs that were the problem, making me, maybe think less about the situation and maybe distracted me from it a bit. So I don't think there was anything really that could have been done.*** INT: And, so going back to the assessment, we actually had two sort of times when we saw you about six months ago to gather our information and stuff like that and give you feedback. Do you have any comments about the assessment you did, and again thinking back, was there anything you didn't really like, or anything that? ***PP: Not really.*** INT: No? We've said about the feedback and stuff like that. I'm just trying to think, I guess talking about the booklet we gave you, how did you, how did you find that?	*Things were busy and stressful and that's why information was not "sinking in" or understood.* School work and time of life very stressful. Too much going on.
	PP It was ok, I thought maybe it was a bit long a bit long winded really, but still if it explains everything then it's necessary really. INT: Was there any particular parts in that that you found that were helpful or not cause if we were thinking about shortening, it was maybe a bit long what are the key bits? Or the key bits you remembered really cause that could answer it?	*Information too much at first.*
Simple Info **Being concise**	***PP: I think mainly just a basic explanation would be good and then the follow up what's goes from now and a part that would be the best bit but I think most of it was probably necessary anyway even though I didn't take much of it in***	Information given needs to be more basic/relevant/concise initially?

	and that might be probably why I don't remember a lot of it. INT: Not necessarily, it maybe that there's some scope for us to as you said, maybe have a summary page at first and if all you read is that well at least then …ok. So the way we are going here as well with questions is thinking about treatment, so, I actually don't know an awful lot what R did end up working with you through in the end but can you tell me a bit about the treatment, we'll call it treatment but the work you did with R, what sort of things you did.	
Someone there for me **Talking things through**	***PP: It was mainly about a kind of working a kind of week by week and every time he seen me he would ask me if there was anything happening, if anything had stressed me out and if anything like that. And if anything had, he would work through he would say, how do you cope with that better, could it have been worse, that kind of thing. It was mainly just talking things through.*** INT: Yes… Did you ever do, so there was talking things through but did you do any I don't know write things down in any diaries?	*Describes anxiety management and talking things through during weekly monitoring*. <u>It is important to talk things through, someone to listen, someone is around.</u>
Looking after self	***PP: There was one thing, I'm not sure I did it. I'm not sure if I completed it because I was busy at the time, but it was just a kind of log of the things that had happened and how they made me feel and just kind of see how regular the things were and how stressful.*** INT: So was that as you said was that monitoring looking at your sort of feelings and stress?	*Description of a mood diary but not completed*. <u>Not helpful? Too busy to look after self. Shows it hasn't stopped them living?</u>

	PP: It was based on like what I would do when this, whatever happened, based on the stress… but I think by then I nothing was really going on so I'd didn't really complete it because I didn't have anything to fill in. INT: Yeah, so did things for you would you say got better quite quickly then do you think? ***PP: Yes, I think so, I think that*** INT: I know that's a hard question why things maybe got better as well but can you think about maybe what was it that really helped?	
Someone is there for me **Listening**	***PP: I think it was probably just knowing that somebody was helping was probably the biggest help, just knowing that someone was there and they were writing it down or whatever, they were actively trying to help, probably made me feel better.*** INT: I think that makes a lot of sense actually. Its there anything of the stuff that R do with you, I know you said that was the most important thing knowing that maybe R was there to explain things and maybe help you cope and stuff like that. Was there anything particularly that Richard advised that you found most useful?	*Fact that someone was available to talk was good.* Active element of support/treatment. Validation and understanding of experience.
Thinking about thinking **Helpful**	***PP: I think it was probably to think more about like attitudes and feeling and how they changed depending on behaviour and stuff like that and how behaviour changed depending on feelings and how it can relates I think that helped quite a lot, just thinking about it more helped change***	*Looking at how they think about things.* Thinking about things was useful.

Anger **Letting me down**	***what I might do when something happened.*** INT: Ok. Again saying things that we've said what were the most useful. Was there anything in particular that again wasn't very good or again was there something that you might have liked to have had help with or? ***PP: I don't think so, not really… There were a few maybe group sessions that he suggested, that I never really got kind of feedback about I was told that they would be fun and that kind of thing but it never was offered.*** INT: Right Ok, so would you have been interested in doing those groups? ***PP: Yeah.*** INT: Yeah, I think the thing was they didn't actually ended up coming off if you know what I mean so we didn't start them. So some group stuff with I take it would have been with other people your age would have been quite good? ***PP: Yes.*** INT: OK that's interesting. Ok… So you've said that would have been helpful. What other helps, so this is maybe bringing the lot together, what other help might you think would be useful to other young people like yourself with similar difficulties?	Happy with support offered but then angry, annoyed that group work had not been offered.
Groups **Peers**	***PP: Probably a kind of group situation as well as a kind of separate help, a group situation might help as well but all***	*Social groups may be helpful but it depends on the person.*

Others have it **Support** **Real experience**	***depends on the person.*** INT: And what is it, this is again an odd question and you are doing superbly, what is it about the group I was just wondering that would be? ***PP: I think it's probably more that you know somebody else who is going through the same thing. I think that helps quite a lot just in your own min, just maybe put you at ease a bit.*** INT: OK. Yeah. So final summary for that then, this is the last sort of chance, is there anything else that you though was good about your help or anything that really needed changing? ***PP: Not really*** INT: So we did ok then? Ok? Do you have anything else to say?	*Important to know someone else with ARMS.* Social groups useful as others understand what you are going through/advice/techniques. Others have this condition.

8. List of emergent themes from Transcript AA (FARMS project)

Themes	Page/line
I am not ill	1.13
Understanding	1.18 3.75 3.83
Relief	1.26
What is wrong with me	1.26
Validation	1.26
Perception	2.35
Knowing what I want	2.35
Help forthcoming	2.58
Reducing uncertainty/anxiety	2.58 3.83
It has a name	2.61
Information	2.61 2.68 6.182
Stress	3.75 6.161
Not looking after self	3.75 6.161 7.200

Sharing information	4.100
Telling others	4.100
Those who are close to me	4.100
Limited detail	4.128
Concern/worry	5.135
No change (reactions)	5.135
Some stigma	5.140
Its expected	5.140
Someone is there for me	6.192 7.217
Talking things through	6.192
Thinking about thinking	8.226
Helpful	8.226
Anger (letting me down)	8.235
Groups/peers/support	8.253

Others have it	9.259
Real experience	9.259

9. The process of abstraction for Transcript AA (FARMS project)

Abstraction and contextualisation leading to the development of a super-ordinate theme (Participant AA)

Themes	page/line	key words/phrases
The reaction of others		
Sharing information	4.100	"*I don't think I've really told them much"*
Limited detail	4.128	"*All they knew was that I was being seen by psychologists and things and that was really all I told them"*
Concern/worry	5.135	*"They were worried"*
No change	5.135	*"There was no real change"*
Some stigma	5.140	*"Are you a nutcase"*

10. Master Table of IPA themes (FARMS project)

Master table of themes for the group

"How others would take me"

Perceived consequences of their condition

BB: "I don't go mentioning it to anybody cos I'm scared of what they think of me" Line 95.

CC: "They are going to look at us and think what's wrong with her" Line 139.

The actual responses of peers

BB: "She didn't exactly think I was completely crazy" Line 100.

AA: "There are a few aren't really friends who are like are you a nutcase or whatever" Line 140.

FF: "If there was anything they could do to help" Line 120.

CC: "Just my best friend knows but she's fine about it… she is there for me". Line 122.

BB: "[A] few people who take the mick out of me but then I have my close friends" Line 114.

The actual responses of family members

EE: "They seem quite supportive… no drastic changes or anything" Line 73.

CC: "They were supportive and they understood …, just me brother who worked me" Line 112.

BB: "So she felt like sorry for me basically" Line 62

11. PAARMS Interview Schedule

Professional Attitudes towards the At Risk Mental State (PAARMS): Interview Schedule

Introduction

Thank you for agreeing to take part in this interview. Today I am going to ask you about some of your thoughts and experiences regarding the At Risk Mental State and how people are currently assessed and treated within Early Intervention in Psychosis and CAMHS services. As I have explained before there are no right or wrong answers and your responses will remain anonymous. I will be taping the interview so that I can remember your answers and these will be stored safely and anonymously after we have finished.

- Could you start by telling me about your experience to date with the At Risk Mental State? (Prompts: training, number of cases seen).

- What treatment do you offer or think should be offered to individuals with an At Risk Mental State?

- Do you think there are any major training needs for services in relation to the At Risk Mental State? (Prompts: confidence in identification, treatment, training others).

- In your experience do you think the At Risk Mental State label has been useful for the young person you have been working with?

- What experience do you have of the FARMS clinic?

- What do you think are the strengths and weaknesses of the clinic?

12. CAMHS questionnaire (PAARMS project)

CAMHS "At Risk Mental State" for psychosis Clinician's Survey:

We are currently evaluating the views of CAMHS clinicians in relation to the "At Risk Mental State" (ARMS) concept for psychosis and are very keen to hear about your opinions and experiences. Don't worry if you feel that you know very little about this concept (this is one of the reasons why we are undertaking this audit to inform future training needs). We appreciate you are very busy and so this questionnaire is designed to be as straightforward and brief as possible, taking around 5-10 minutes to complete. This questionnaire has been distributed across all CAMHS teams across the trust.

Which CAMHS Team do you currently work for (please tick/highlight):

Darlington ☐	Derwentside ☐	Sedgefield ☐	Durham Dales ☐	Redcar & Cleveland ☐	Durham & CLS ☐
Middlesbrough ☐	Easington ☐	Stockton ☐	Hartlepool ☐	Scarborough ☐	Tier4 ☐

Your current job title (e.g. PHHW, Consultant Psychiatrist/Psychologist etc.):

.....

1. Have you ever worked alongside a clinician from the Early Intervention in Psychosis (EIP) service in the assessment or treatment of any of your clinical cases?

   Yes ☐ *No* ☐

2. I am familiar with the concept of the "At Risk Mental State" for psychosis

Strongly Agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly Disagree* ☐

3. Over the past 12 months I have worked with young people who has been confirmed as having an At Risk Mental State for psychosis:

   Yes ☐ *No* ☐

4. The "ARMS" concept constitutes a meaningful clinical syndrome:

Strongly Agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly Disagree* ☐

5. I feel confident in identifying a young person with the At Risk Mental State

Strongly Agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly Disagree* ☐

6. Describing an individual as experiencing an "ARMS" can be:

Helpful ☐ *Harmful* ☐ *Both* ☐

Please explain your views……..

……

7. This group of individuals should receive some support from health services:

Strongly Agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly Disagree* ☐

8. The services better placed to provide this support are (please tick all that apply):

Primary Care ☐
Generic psychiatric services ☐
EIP Services ☐
Psychosis Services ☐
Voluntary Services ☐
CAMHS ☐
None ☐
Other……

9. I think young people with an At Risk Mental State should be offered the following treatment (please tick all that apply)

Watchful waiting/monitoring for possible changes in mental state ☐
Psychological interventions (e.g. CBT, anxiety management) ☐
Low dose antipsychotic medication ☐
Psychoeducation ☐
Omega-3 fatty acids/fish oils ☐
None of the above ☐
Other……

10. Which three of the following symptoms do you think are key to applying a label of the “At-Risk Mental State”? [Please tick three boxes in any order]:

Perceptual distortions	☐
Anxiety	☐
Social withdrawal	☐
Ideas of reference	☐
Loss of energy	☐
Sleep disturbance	☐
Unusual ideation (e.g. paranoia)	☐
Difficulties with concentration	☐
Visual hallucinations	☐
Poor or declining functioning	☐
Disorganised thinking/speech	☐
Depression/low mood	☐

11. Any other comments you would like to make? (i.e. possible training needs, previous experience with this client group)

Thank you for completing the following audit.

If you have any questions about this audit or would prefer to complete it electronically please email: Patrick Welsh, Assistant Psychologist, Early Intervention in Psychosis Service.

13 Free textual analysis and the identification of emergent themes for PP4 (PAARMS project)

Emergent themes	Original Transcript	Exploratory comments
	INT: Thank you for agreeing to take part in this short interview. I'm going to ask you about some of your thoughts and experiences around the At Risk Mental State and how people are currently maybe assessed and treated within Early Intervention in Psychosis services and possibly maybe experiences with CAMHS and how they work with cases and stuff like that. Just to say there are certainly no right or wrong answers and your responses will remain anonymous and stored securely. As you can see I am taping the interview so I can really remember what you've said. So, just to start things off could you sort of tell me about your experiences to date with the At Risk Mental State so maybe what training you've had, how long you have been working in this area anything like that.	
EXPERIENCE	***PP: I've been working in with EIP for about 2 years. I had no kind of formal training in At Risk Mental State, I think it is something that although I have had kind of psychosocial kind of intervention type training which covers a lot of the At Risk Mental State and the prodromal side of psychosis and things like that. I suppose my training has been on the job really and kind of working with other colleagues and picking it up of how they can assess people and what they look out for and what kind of our criteria is really so it's more through experience then it is through specific training opportunities.***	*No formal training* *Learning and training through experience and peer supervision.* *Training strategies*

STANDARDISATION	INT: Okay then, I mean yeah. I suppose talking about training then cos we have touched on that first, would you say you have any personal training around this area or and if so what are they but if not or another question what about service training needs. ***PP: I think yeah it would be nice for everyone to be kind of singing off the same kind of hymn sheet really, I suppose knowing exactly what an At Risk Mental State is for every clinician cos I think it does vary and maybes just some kind of training that might standardise that so everybody knows exactly what the definition is and what that means and how to assess that and how manage and treat people that present with an At Risk Mental State. Yeah it would be helpful.***	*Standard procedure and understanding of the concept is possibly required.* *Can be achieved through training.*
	INT: Is that across services would you say ***PP: Yeah I would say so. CAMHS and EIP sorry yes.***	*Across CAMHS and EIP for training a standardisation of practice.*
TRAINING NEEDS	INT: As I said any personal needs would you say that? ***PP: Training wise, I am quite comfortable working with people with an At Risk Mental State, I suppose more kind of any kind of training that relates to treatment around people with At Risk Mental State so what kind of psychological therapies work best, what approaches work best, things like that might be helpful I think.*** INT: Yeah so as you said you feel quite confident or comfortable working with these people.	*Feels comfortable with ARMS cases.* *Training that relates to treatment is a personal priority (specific training need).*

	PP: Oh yeah definitely. Yeah. INT: Good to hear. Thinking about treatment then, I just want you to talk about and tell me what sort of treatment you offer to people and what sort of stands out and maybe how long you worked with them and if this is slightly different could you maybe think about maybe what treatment should be offered if that makes sense. ***PP: Yeah I think when we are looking at kind of people who kind of present with an At Risk Mental State rather than someone who is kind of truly unwell or presenting with positive or lots of negative symptoms of psychosis. Its about us not stepping in too early with any kind of medical model using medication, its more kind of talking therapies, normalisation I think in reducing I think people hold a lot of stigmas around kind of mental health and get worried you know a lot of people kind of say that they are worried about going crazy or going you know kind of developing some serious mental health problem so its about kind of making people aware that just because they are presenting that way just because they are getting support from secondary services doesn't mean that that person will then be in secondary services for a long time and will develop anything that is serious in relation to their mental health. So its about kind of its about obviously what we do is lots of assessment to find out exactly what is going on and to look at maybe stresses and we work on the stress vulnerability model to see kinda what's impacting on their life, socialisation things we get them out we do the football projects, sports projects, walking groups things like that, lots of people who present***	
MEDICATION		*Psychological therapies before medication.*
STIGMA		*People worry about stigma and services*
INFORMATION GIVING		*Working through stigma and reducing anxiety by suggesting things are not long term.*
SOCIAL ISOLATION		*Stress vulnerability, normalisation treatment approach.*

	with an At Risk Mental State might be isolating themselves, withdrawing from society so its about getting them back into the swing of things really but not label them with a mental health problem more just looking at what their difficulties are and how we can solve them and using the kinda problem solving approach I suppose	*Social isolation is a problem and must be overcome.*
SOCIAL ANXIETY	INT: You have covered some interesting areas there and something I want to go back to. So on a you've mentioned quite in detail some of the things you sort of do but so would you say that you usually offer that sort of anxiety management, stress vulnerability sort of for everyone you work with, every At Risk sort of ***PP: Yes definitely its offering like graded exposure to anxiety and you get a lot of people that are very socially anxious which they could cross over into you know paranoid and delusional beliefs so its about yeah offering not offering too intensive support***	*Social anxiety as a symptom in ARMS cases. Social factors are important.*
MEDICATION	INT: And you think on medication ***PP: Yeah its always something that we only consider if its massively necessary. I think its important that we steer away from that as much as we can I suppose.***	*Medication as a last resort. Avoidance.*
	INT: That's interesting in terms of again working with these young people then I know every case is different how long you would usually ***PP: Generally with At Risk Mental State it would be six months, so we would pick them up and we would***	*Current care pathway description.*

CARE PATHWAY	***obviously tell them that its for six months and that its for a short period of work to help and support so they know exactly how long they have got and then obviously after them six months it would be reviewed with the hope that you know those difficulties will be reduced and that they don't present with a need that needs kinda supporting through secondary services and obviously what we try and do at that point is then maybes refer them back to Primary Care and offer some support through them looking at things that the IAPT service or just monitoring from the GP really. So the ideal is six months, obviously we take people for longer if needs be.*** INT: Okay you mentioned before this is going back to a things you said a couple of minutes ago you said about labelling and stigma and stuff like that it's a really interesting point, I'm just wondering in your experience do you think the At Risk Mental State that label so to speak so its not a diagnosis has been useful for the young person you have been working with or how do you go about explaining it them sort of issues	*Assessment, support and review process/cycle over a six month period.*
FEAR	***PP: I don't think the term At Risk I think would send fear through a lot of people I think, they present that way because a lot of people don't even consider themselves to be developing any serious mental health problem they just know that they have particular anxieties and that they are struggling at the minute. I think if you kinda present it and say well you know you might be at risk of developing a psychosis I think that can increase the stress for that person it could make things worse really so its about how you put it across it's the words that you use and its looking***	*ARMS label creates fear.* *People aware they have problems but not considering they have a mental health problem.* *Avoidance being cautious of using the ARMS term by rephrasing*

AVOIDANCE/ REPHRASING	***at obviously our service kind of and the way we approach people saying that we are here to offer you support and looking at things like the stress vulnerability bucket is a good way of describing to say look we are looking at reducing your stress and that will hopefully reduce the symptoms or the difficulties that you've got now over a short term rather than saying look we are catching you now because you might be at risk of developing something really serious later on. I think that kinda thing can sometimes be counter-productive.*** INT: Yeah, so from a personal point of view have, do you actually tell people though that they might have an At Risk Mental State. ***PP: No*** INT: That's fine, and if so how would people react to that but go on	*things.*
AVOIDANCE	***PP: No I've never said At Risk Mental State I think I just explore their experiences and their difficulties and explain that you know, if I think personally that they are At Risk then I will explain that this is how long we are going to work with you and its possibly up to six months and this is what we are going to work through. I think just using the term that you have an At Risk Mental State is I think is a label and it carries a stigma***	*Avoidance of term.*
STIGMA		*Negative views about the term possibly from personal experience?*
	INT: So you wouldn't say you really use it, you are sort of re-framing it, you don't say I think you have the At Risk Mental State for Psychosis but as you said you re-frame it, I	

REPHRASING	think that sits more does that sit more comfortably. ***PP: Yeah it does I think although we have a responsibility to say where we are from I think that any new assessment you obviously say you are from the Early Intervention in Psychosis Team that we work with people that have psychosis and explain what that means but also that we work with people that maybe kind of At Risk but you word it differently basically and say that you know generally everybody at some point could be At Risk of developing a serious mental health problem and that again that is about normalising things a little bit for them I suppose. So yeah.***	*Although participant doesn't like the label sees it could be used to normalise things. Everyone can be at risk at times.*
COMPLEXITY	INT: Okay. Just thinking about the younger age group cos that's what we are looking at so working with sort of adolescents with the At Risk Mental State, would you say there is any difference maybe, I know you might not have, but any difference between the younger age group and the older age group in terms of doing assessments and treatment complexity or anything like that. ***PP: I think, from my experience working within EIP and working with younger people its always younger people that are within their teenage years, don't work with any younger, so there is always you've got a person's difficulties on top of what a teenager will experience things you know kind of emotional regulation and hormonal kinda problems and I think they are still developing so there is all that kind of difficulty to take into account I suppose. It's approaching things differently, you know you will offer different things to young people than***	*Additional complexities of working with teenagers/adolescents.*
WORKING WITH YOUNG PEOPLE		*Approaching assessments and interventions differently.*

	you would to kind of adults, younger people might want to be more social, they obviously have things through school that you could offer them, so yeah the approach would be a lot different I think from younger people to working with older people.	
	INT: Yeah, just a couple more questions, I'm just thinking about any joint sort of working experience working with CAMHS I just want to know what your views are in terms of whether what your experiences of working with them with any cases of the At Risk Mental State or is that not really happened.	
	PP: I think it has yeah, so far fine really, I've used the CAMHS Consultants when medication has been introduced for young people. I think what I've always said is when I take someone that has maybe been assessed in CAMHS as an At Risk Mental State and they have come to us also that we work with them for a short period of time then we will review it and if needs be then they would maybe go back into CAMHS for whatever support or then discharged but at least keep them in the loop and understand that that person is not coming to us. They still sit under the CAMHS umbrella and still if needs be still have a CAMHS Consultant.	*Experience of working with CAMHS.*
	INT: If you have worked with them since and there is no specific symptoms and they	
	PP: I had no problem working with CAMHS and they are quite supportive.	*Positive experience.*

BEING CAUTIOUS	INT: The final lot of questions is just what you're experiences are with or what do you think some of the strengths and weaknesses are of this sort of research clinic we set up, the FARMS clinic I know you haven't necessarily had lots of experience with me as such but again just any general points on that, again it doesn't matter if you don't and it doesn't matter if it's all weaknesses or problems ***PP: No let me think… I suppose cos the At Risk Mental State is open to so much interpretation I think whenever you do any assessment it depends how the difficulties that person having is there a clinical need then for that person to come in or is it a question of you saying well no that person needs to stay in Primary Care and doesn't need to, so there is that balance of is bringing a person into secondary services productive or counter productive and I think sometimes if they were certain issues that she was going on that you would say they are At Risk bringing them in would sometimes make those things worse, sometimes young people can latch on to services*** INT: So again it is possibly that issue about labelling again ***PP: Yeah the labelling and kinda of obviously having to go into individual sessions and what that means and what do their friends know about that and you know getting support from mental health services. So yeah I have not got any major concerns [laughter].***	*Being cautious about bringing cases into services.*

	INT: Okay I'm just trying to think if I have covered everything. I suppose just the general question is there anything else I know we have covered quite a bit but is there anything else you want to say about the At Risk Mental State that I haven't sort of covered with these questions or any issues you have working with these cases. ***PP: I think it needs to be, we need to look at supporting people who are At Risk Mental State, there are other countries that do it a lot better than we do, I think they are always quite far ahead of us, I think their DUP, duration of untreated psychosis is quite low its about three weeks where ours is 3 years so its about catching people early enough and its about supporting people early enough but obviously no coming in with that kind of horrible stigma of we are a mental health service and you have got a mental health problem. A lot of the time people need just that little bit of support and then they are on the way. And you will never ever know whether that person will have ever developed a psychosis or not, but if you have supported them then you have done your job I suppose. I do see it as a positive but you have to be careful who you bring in. Definitely.*** INT: Okay I think that's everything.	*Improvement is needed.* *Early intervention is key.* *You have to be careful who you identify as being at risk. Cautious.*

14. List of emergent themes from transcript PP4 (PAARMS project)

Themes	Page/line
Experience	1.13
Standardisation	1.22
Training Needs	1.34
Medication	2.50 3.77
Stigma	2.51 4.121
Information Giving	2.57
Social Isolation	2.59
Social Anxiety	2.71
Care Pathway	3.83
Fear	3.98
Avoidance/rephrasing	3.103 4.118 4.131
Complexity	4.141
Working with young people	4.144
Being Cautious	5.173

15. Table of initial super-ordinate themes and themes for all transcripts (PAARMS project)

THEMES

The At Risk Mental State label

Avoidance/rephrasing (1,4,5)
Information giving (4)
Stigma (4)
Understanding (1)
Fear/scary (4,5)
Confirmation (2)
A useful explanation (6)
Not as scary (1)
A vague label (6)
Being cautious (6)
First reaction (3)
Less stigmatising (3)
Relief (3)

Working with Adolescents

Young versus old (4)
Things take time (1)
Complexity (3,4)
Being cautious (1,3,4,5)
Working with young people (4,6)
Young people are receptive (2)
What is normal adolescent behaviour (1,5,6)
Most referrals have an At Risk Mental State (1,3,5)
Becoming an adolescent (6)
Difficulty (2)
Common experience (3)

Treatment: What do we offer

Psychological therapies (1,2,5,6)
No medication (5)
Medication as a sign of psychosis (1)
Medication is a big decision (6)
Medication (2,3,4)
Medication for the worst symptoms (6)
Medication as a last resort (1)
Uncertainty of medication (6)
Monitoring (1,2)
Treatment (3)

Treatment: What works

Social inclusion is important/successful (1,5,6)
Social isolation (4)
Importance of peers (6)
Getting back to normal life (1)

Are we successful?

Outcomes (1,3,5,6)
Helped (2)

Current guidelines

Standardisation (4)
Uncertainty (2)
What do we do with cases (6)
Consistency (2)
Guidelines (2)
Caseload management (5)
Current pathway of care (2,4)
Service development (3)

Training

Experience (1,3,4,5)
Assessment training (5)
Training for all services (1)
Training opportunities/needs (2,4)
Working with young people/comfortable (1)
Limited training opportunities (6)

Miscellaneous

Anxiety (2)
When to use the CAARMS (6)
The CAARMS (5)
Social Anxiety (4)
Making a judgement (1)
Working with adults (2)
Vague concept (3)
The best place (3)

(…) brackets and numbering represent the corresponding participant/transcript

16. Table of super-ordinate themes and sub themes for all transcripts (PAARMS project).

THEMES

1. The At Risk Mental State label

Acceptability
Understanding (1)
A useful explanation (6)
Less stigmatising (3)
Relief (3)
Confirmation (2)
Not as scary (1)

Negativity
First reaction (3)
Fear/scary (4,5)
A vague label (6)

Avoidance and Rephrasing
Avoidance/rephrasing (1,4,5)
Information giving (4)
Being cautious (6)

2. Treatment Practices

Medication is a big decision
Medication (2,3,4)
No medication (5)
Medication as a sign of psychosis (1)
Medication is a big decision (6)
Medication for the worst symptoms (6)
Medication as a last resort (1)
Uncertainty of medication (6)

The importance of social inclusion
Social inclusion is important/successful (1,5,6)
Social isolation (4)
Importance of peers (6)
Getting back to normal life (1)

Are we successful?
Outcomes (1,3,5,6)
Helped (2)
Young people are receptive (2)
Experience (1)

3. Working with Adolescents

Is it just normal adolescent behaviour?
What is normal adolescent behaviour (1,5,6)
Complexity (3,4)

Associated complexities of working with this client group.
Young versus old (4)
Being cautious (1,3,5)
Becoming an adolescent (6)
Working with young people (6)
Difficulty (2)
Experience (1,3,4,5)

4. Service Development

Consensus and Guidelines
Standardisation (4)
Uncertainty (2)
What do we do with cases (6)
Consistency (2)
Guidelines (2)
Caseload management (5)
Current pathway of care (4)
Service development (3)

Training
Experience (1,3,4,5)
Assessment training (5)
Training for all services (1)
Training opportunities/needs (2,4)
Limited training opportunities (6)

(…) brackets and numbering represent the corresponding participant/transcript