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## **Abstract**

### **Aim**

Evidence from meta-analyses of randomised clinical trials show interventions for young people at ultra high risk (UHR) of developing psychosis are effective both clinically and economically. While research evidence has begun to be integrated into clinical guidelines, there is a lack of research on the implementation of these guidelines. This paper examines service provision for UHR individuals in accordance with current clinical guidelines within the National Health Service (NHS) in England.

### **Method**

A self-report online survey was completed by clinical leaders of Early Intervention in Psychosis (EIP) teams (N=50) within the NHS across the UK.

### **Results**

Of the 50 EIP teams responding (from 30 NHS Trusts), 53% reported inclusion of the UHR group in their service mandate, with age range predominantly 14-35 years (81%) and service provided for at least 12 months (53%). Provision of services according to NICE clinical guidelines showed 50% of services offered cognitive behavioural therapy (CBT) for psychosis, and 42% offered family intervention. Contrary to guidelines, 50% of services offered antipsychotic medication. Around half of services provided training in assessment by CAARMS, psycho-education, CBT for psychosis, family work and treatment for anxiety and depression.

### **Conclusions**

Despite clear evidence for the benefit of early intervention in this population, current provision for UHR within EIP services in England does not match clinical guidelines. While some argue this is due to a lack of allocated funding, it is important to note the similar variable adherence to clinical guidelines in the treatment of people with established schizophrenia.

**Keywords:** ARMS, clinical guidelines, clinical high risk,

**Running head:** Implementation of UHR clinical guidelines

# **Service provision for ultra-high risk for psychosis: A survey of early intervention in psychosis services in England**

## **Introduction**

It is well established that the majority of mental health disorders begin before adulthood and persist across the lifespan (1). Surveys in the United Kingdom estimate the incidence of psychosis at five per 1000 adults (2), with the diagnosis of schizophrenia accounting for around 30% of adult mental health and social care monetary budgets (3). Schizophrenia disrupts social and family relationships, resulting in severe educational and occupational impairment, lost productivity, unemployment, physical illness, and premature mortality (4).

The onset of psychosis is invariably preceded by early symptom development characterised by a range of non-specific behavioural and psychological symptoms, as well as functional deterioration, and has been conceptualised as an ultra-high risk (UHR) mental state (5). Yung et al. (1998) developed criteria proposed to predict the onset of a psychotic disorder, specifically: low intensity/frequency psychotic symptoms, brief limited psychotic symptoms and/or genetic risk in the presence of functional decline (6). Among people identified as UHR for psychosis, around 22% transition to a psychotic disorder within 12 months and 36% after three years (7-9). Long term follow up studies have shown ongoing mental health problems for UHR individuals who have not transitioned to psychosis (10, 11). A six year follow up of UHR individuals who had not transitioned found 28.3% reported attenuated psychotic symptoms and for 61.5% of those with comorbid disorders at baseline these comorbidities were still present (12).

Interventions that delay or prevent transition to psychosis are considered valuable at both economic and individual levels (13, 14). A recent meta-analysis of psychological, pharmacological or nutritional interventions to prevent or delay transition to psychotic

disorders for UHR individuals found cognitive behavioural therapy effective in reducing transition to psychosis at 12 months (risk ratio 0.54, 95% confidence interval 0.34 to 0.86). The meta-analysis also showed that omega-3 fatty acids and integrated psychotherapy interventions were associated with reductions in transition to psychosis at 12 months (15). However, limitations regarding evidence quality were highlighted. The results of five trials examining CBT within a meta-analysis of interventions for UHR for psychosis, found the number needed to treat (NNT) for one person to avoid transition to psychosis was 11 (13). A further meta-analysis of only CBT interventions for prevention of psychosis identified six randomised trials (16). The results of this meta-analysis indicated that CBT interventions were associated with a reduced rate of transition to psychosis at six, 12 and 18–24 months after treatment, in comparison to monitoring or non-specific supportive therapy.

Clinical guidelines for psychosis have been derived from research evidence to provide recommendations to clinicians for best practice. For established schizophrenia, one systematic review identified and compared 24 guidelines from 18 countries (17). The review showed that the recommendations for pharmacotherapy were similar internationally, but that there was great variability in the guidelines for psycho-social interventions for people with schizophrenia.

Recommendations for the treatment of UHR individuals have also been developed from research evidence. For example, the International Early Psychosis Association (IEPA) recommended: 1) regular monitoring; 2) interventions aimed at specific difficulties (i.e. anxiety, depression, substance misuse); 3) help with interpersonal, vocational and family stress; 4) support to develop coping skills for sub-threshold symptoms and; 5) individual/family psycho-education (18). The IEPA recommends that these interventions are provided flexibly and in low stigmatising environments (i.e. home, primary care or youth-

based settings). Clinical Practice Guidelines have been developed in the United Kingdom (19, 20), Australia (18) and Canada (21) (see Table 1).

[INSERT TABLE 1 AROUND HERE]

Based on evidence from naturalistic cohort studies (e.g., (22, 23), NICE (2013) acknowledges that current clinical practice is likely to be highly variable, due to local resources and service configurations, clinician attitudes and awareness of clinical guidelines (19). For example, recent estimates for the implementation of CBT and Family Intervention (FI) as per NICE guidance for schizophrenia reported rates of implementation of 5.3% for CBT and 1.1% for FI (24). Further challenges to the implementation of guidelines were highlighted in an audit investigating early intervention in psychosis service development, whereby there exists inconsistencies between service models, resources and delivery such as age of clients accepted to the service and the length of care provided (25).

While the research evidence for interventions for UHR individuals is growing and has begun to be integrated into a range of clinical guidelines across countries, there is a lack of research on the implementation of clinical guidelines for this population. Therefore, the aim of this paper is to examine service provision for UHR individuals in accordance with current clinical guidelines (e.g., NICE) and within the National Health Service (NHS) in England.

## **Method**

A survey of early intervention for psychosis (EIP) teams within the NHS across England was conducted using a self-report online survey. Only dedicated EIP services were recruited and thus the sample did not include generic early intervention services in the community. The survey was developed based on current clinical guidelines in UK, Australia and Canada, and included the following domains: service provision for UHR (such as service inclusion criteria, duration of inclusion), screening, assessment and interventions for UHR,

and training provision for staff working with UHR individuals within EIP teams. The survey comprised multiple choice and free form questions and was piloted with three clinicians (Nurse, Psychologist, Psychiatrist) working in EIP teams. Feedback was provided and incorporated to ensure clarity of understanding and interpretation. Early intervention teams were identified through the Initiative to Reduce the Impact of Schizophrenia (IRIS) Network (26). The network is drawn from the key national leads, regional leads and EIP practitioners working in services. The network identified EIP team leaders in the NHS in England who were then sent an email with a link to the online survey (Bristol Online Survey). A snowball method was employed, whereby service leaders were asked to forward the survey to leaders of other EIP services in order to achieve a comprehensive coverage. The survey controlled for multiple entries from services by asking participants to name their service. Data were collected between April and August 2014. At the time of data collection there were 150 EIP services in England. Analysis was undertaken using IBM Statistical Package for the Social Sciences version 20 for Windows to provide descriptive statistics of the data-set.

## **Results**

Fifty EIP service teams covering 30 National Health Service Trusts in England responded to the survey. Fifty three percent of these services reported including provision of services for UHR for psychosis. The following data are drawn from this subset of the main sample, namely, services that provided for UHR individuals. See Table 2 for descriptive data.

### *Inclusion and assessment*

The majority of EIP services that reported including UHR individuals, provided 12 months or more of service for UHR (65%). Predominantly EIP services included UHR individuals between the ages of 14-35 years (81%) and meeting criteria using an assessment tool such as the Structured Interview for Prodromal Symptoms / Scale of Prodromal

Symptoms (SIPS/SOPS) (9), or Comprehensive Assessment of At Risk Mental States (CAARMS) (69%). For services that included a screen for UHR, there was much variability in the tools employed, with the CAARMS and the Prodromal Questionnaire (27) more prevalent, 15% and 11% respectively. The assessment of UHR individuals was principally conducted utilising the CAARMS or SIPS/SOPS (50%).

[INSERT TABLE 2 AROUND HERE]

### *Intervention*

Interventions predominantly employed by EIP services for UHR individuals were psycho-education (96%), monitoring of mental state / “watchful waiting” (88%), treatment for anxiety (77%), cognitive behavioural informed interventions (73%), and family work (61%). The recommended NICE standard interventions, namely, CBT for psychosis and family intervention were reported as provided by 50% and 42% of services respectively. Antipsychotic medication was utilised by 50% of services and 4% of services offered Omega-3 fatty acids/fish oils as a treatment. Comorbidity was addressed by 23-58% of services.

[INSERT TABLE 3 AROUND HERE]

### *Training*

Training of staff on UHR status core assessment instruments such as CAARMS and SIPS/SOPS was provided by 46% and 11% of EIP services respectively. The most common staff training for interventions focussed on psycho-education (64% of services). Many services provided training on interventions for comorbidity such as anxiety (58%), depression



(46%) and substance misuse (38%). Training for the NICE recommended interventions of CBT for psychosis and family therapy were provided by 46% and 34% of services respectively.

## **Discussion**

Research shows that young people who are at UHR for psychosis can be reliably detected [27, 28] and classified [29], with treatment such as cognitive behavioural intervention directed at normalising the subclinical symptoms, unusual experiences, salience and perceptual aberrations demonstrating efficacy for preventing the number of transitions to psychotic disorder by about half (13, 28). However, early intervention in psychosis services remain predominantly focussed on intervention for first episode psychosis (FEP) rather than prevention of psychotic disorder by intervening in the prodromal stage, namely the UHR for psychosis group. As evidenced by our data just over half of EIP services reported inclusion of the UHR group in their service mandate. These findings contrast with robust research evidence demonstrating the effectiveness of early intervention in the UHR group (13, 15, 16) and the subsequent cost savings for the health services (14). When services include UHR individuals, there appears to be a general consensus about the target population. For example, the majority of EIP services set inclusion criteria for 14-35 year olds and provided service for a period of 12 months or more.

Concordance with clinical guidelines for intervention in UHR for psychosis showed only half of services provided CBT for psychosis and less than half (42%) provided family intervention. NICE standard CBT is the recommended first line of treatment for the UHR population and yet less than 50% of services are providing training on CBT. Therefore, it is not surprising that less than half of services are providing this first line treatment. Despite the body of evidence for the efficacy and cost effectiveness of CBT (13, 14) in the UHR

population, our data indicate that resources are not being allocated for the training of EIP teams.

The majority of services provided non psychosis specific interventions targeting comorbidity or adopting a wait and see approach. The NICE guidelines recommend monitoring of symptoms but this should not be in the absence of active psychotherapies such as CBT. Monitoring of mental state was conducted by 88% of services and 64% provided psycho-education, with both approaches essential for the UHR individual in gaining understanding and management of their mental health problems. Our data did not allow an examination of whether monitoring was used in the absence of other interventions. Treatment for comorbidity such as anxiety, depression and substance use was provided by three quarters of the services.

NICE guidelines recommend that antipsychotic medication should not routinely be used with UHR individuals. In addition, the Australian and New Zealand Early Intervention clinical guidelines, advocate that antipsychotic medication should not be utilised unless (i) at least one week of frank positive psychotic symptoms has been sustained; or (ii) a rapid worsening of psychotic symptoms accompanied by significant functional decline and elevated risk to self or others (15). In the current study antipsychotic medication was an intervention provided for UHR in at least half of the services. One plausible interpretation is that a lack of follow up on assessments may lead to a lack of clarity in respect to diagnostic status such that some of these people may have transitioned to psychosis or that prescribing is for other reasons such as bipolar disorder or sleep disturbance. Alternatively, this finding may reflect a more fundamental problem, namely that recommended guidelines are not being implemented as evidenced in the treatment of people with schizophrenia (3, 24).

The rates of training provision for staff were relatively consistent with the proportion of services delivering specific assessments (CAARMS, SIP/SOPS) and interventions (CBT for psychosis, NICE family therapy). Around half of services provided training in assessment by CAARMS, psycho-education, NICE CBT for psychosis, general family work and treatment for anxiety and depression. Interestingly, while 88% of services adopted a monitoring of mental state approach, only 34% reported receiving training for this.

### *Strengths and limitations*

Few studies have examined the degree of inclusion of UHR populations within public mental health services. Most studies have focused on specialist UHR services such as Headspace (29) and Headstrong (30). Our study sampled 54% of NHS Trusts (i.e., public mental health services) across England and thus represents a wide geographical spread. A strength of the current study is that it provides a broad overview regarding the implementation of recommended guidelines across England. However, this broad focus on service level alone, means that it is unclear at the individual patient level how guidelines are being implemented such as what combination of interventions are provided and within what time frame. Future studies would benefit from undertaking a more in-depth examination of staff training. Given that staff skills are fundamental to the implementation, there is a need to delineate current barriers, such as staff knowledge of guidelines, the quality of training provision and the availability of training for staff within teams.

The majority of EIP services in England do not receive allocated funding for the UHR population and there are few stand alone services specifically commissioned for the UHR population nationally. For most services, the UHR service is provided as an adjunct to the FEP service. The UHR population would not have been included in the original commissioning or funding of services as this occurred prior to the release of NICE guidance

for this clinical population. Thus, for many services the provision of a UHR service is contingent on capacity within the FEP service. UHR was included in the UK clinical guidelines for psychosis and schizophrenia for the first time in 2013. A new Access & Waiting Time target was introduced nationally in the UK from April 2016 in which providers will be mandated to complete an assessment within two weeks of referral for both FEP and UHR individuals, followed by a NICE concordant care package for first episode psychosis. A national investment in funding will support this initiative to increase the availability of UHR interventions across the UK, thus it will be important to continue to monitor the implementation of guidelines as changes are implemented.

### *Conclusions*

The results of this study are very timely given the proposed introduction in 2016 of a national directive for UK services to provide NICE concordant care for people at UHR for psychosis (NHS England, 2016). Our findings show limited provision of NICE recommended treatment for UHR for psychosis and that in relation to use of antipsychotic medication some services are providing interventions contrary to guidelines. While the lack of adherence to guidelines may be due in part to lack of dedicated funding and staff training, it mirrors the poor concordance of clinical guidelines in the treatment of schizophrenia (24, 25). It is of concern that a national UK directive is proposed for concordance with UHR clinical guidelines when our study (i) is the first to examine rates of concordance and (ii) shows a lack of staff training and resources.

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Table 1: Clinical guidelines for the treatment of UHR for psychosis

Recommendation	United Kingdom (NICE)	Canada (CPA)	Australia &NZ (RANZCP)
Early assessment and monitoring of symptoms	✓	✓	✓
Individual CBT for psychotic symptoms	✓		✓
Treatment for co-morbid mental health problems (eg anxiety, depression)	✓	✓	✓
Supportive therapy		✓	✓
Omega -3 fatty acids			✓
Family therapy	✓		
Antipsychotic medication <i>should not</i> be used as a first treatment option	✓		✓

Table 2: Services provided for UHR in EIP services

<b>Service Provision for UHR</b>	<b>EIP services % (N)</b>
Duration of service provision	
3-6 months	34 (9)
12 months	19 (5)
> 12 months	46 (12)
Criteria for UHR inclusion	
<i>Age (years)</i>	
14-35	81 (21)
14-65	4 (1)
16-25	8(2)
16-35	4 (1)
18-35	4 (1)
<i>Clinical status (SIPS/SOPS, CAARMS)</i>	69 (18)
Not meeting criteria for PANNS	27 (7)
Directorate for UHR service	
Child and Adolescent Services	19 (5)
Adult Services	69 (18)
Both	4 (1)
Not known	8(2)
Assertive Engagement	
Yes	77 (20)
No	23 (6)
<b>Assessment and Screening for UHR</b>	
Screening Employed (yes)	50 (13)
<i>Screening Instrument</i>	
CAARMS	15 (4)
SIPS/SOPS	8 (2)
Prodromal Questionnaire	11 (3)
Psychosis Checklist	4 (1)
SCID-II	4 (1)
SPI-A	4 (1)
Comprehensive Core Assessment	4 (1)
Pre morbid adjustment Scale	4 (1)
<i>Assessment Instrument</i>	
CAARMS	31 (8)
SIPS/SOPS	19 (5)
PANNS	11 (3)
Combination of the above	23 (7)
<b>Intervention for UHR</b>	
Psycho-education	96 (25)
NICE standard CBT for psychosis	50(13)
Cognitive Behavioural informed interventions	73 (19)
NICE standard family therapy	42 (11)
Family work	61 (16)
Group work	42 (11)
Omega-3 fatty acids /fish oils	4 (1)
Monitoring of mental state/ watchful waiting	88 (23)
Antipsychotic medication	50 (13)
Comorbid Disorders	73(19)



<b>Training for staff</b>	
<i>Assessments</i>	
CAARMS	46(12)
PANNS	19 (5)
SIPS/SOPS	11 (3)
KGV psychosis scale	8 (2)
Modelling/ Observation	8 (2)
SPI-A	4 (1)
<i>Intervention</i>	
Psycho-education	64 (17)
NICE standard CBT for psychosis	46 (12)
Cognitive Behavioural informed interventions	42 (11)
NICE standard family therapy	34 (9)
Family work	46 (12)
Group work	19 (5)
Omega-3 fatty acids /fish oils	-
Monitoring of mental state/ watchful waiting	34 (9)
Antipsychotic medication	31 (8)
Comorbid Disorders	61(16)

Table 3: Service delivery and training compared to UK clinical guidelines (NICE)

NICE Guideline	Percentage of EIP services		
	United Kingdom	Service delivered	Training delivered
Early assessment and monitoring of symptoms	✓	88% (monitoring)	34-46%
Individual CBT for psychotic symptoms	✓	50%	46%
Treatment for co-morbid mental health problems (eg anxiety, depression)	✓	31-77%	23-58%
Family intervention	✓	42%	34%
Antipsychotic medication <i>should not</i> be used as a first treatment option	✓	50%	31%