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## Are current labeling terms suitable for people who are at risk of psychosis?

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### ABSTRACT

Inclusion of 'attenuated psychosis syndrome (APS)' in the DSM-5 has been hotly debated because of the concern about stigmatising young patients with a 'psychosis risk' label. This study aimed to investigate whether current labeling terms such as 'at risk mental state', 'ultra-high risk' (UHR) and 'APS' are suitable for people who are at risk of psychosis. This study included 105 subjects (55 patients aged 15–25 years who used an early intervention service to prevent psychosis and 50 professionals who worked with them). A questionnaire regarding their opinions about the stigma associated with the above labels and the Mental Health Consumers' Experience of Stigma scale were administered. The patients were less likely than the professionals to agree that there was stigma associated with the terms 'UHR' and 'APS'. Significantly more patients with a family history of psychosis and those who had transitioned to psychosis agreed that there was stigma associated with the term 'UHR' and/or that this term should be changed. Patients who agreed with the negative attitude items for the three labeling terms and the need to change the terms 'UHR' and 'schizophrenia' showed significantly higher scores on the Stigma scale. In conclusion, patients at risk of psychosis may experience less stigma related to labels than expected by professionals, suggesting that mental health professionals may not be able to help patients unless they listen to their views on nosological and treatment issues rather than make assumptions. Previous stigmatising experiences may have strengthened the stigma attached to this label.

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### 1. Introduction

Since the mid-1990s, the retrospective concept of the 'prodrome' was changed to a prospective one to effectively identify and prevent people who may be at risk of developing psychotic disorder. Prodrome was replaced to newly developed term, 'at risk mental state' (ARMS) or 'ultra-high risk' (UHR) for psychosis (Yung et al., 1996). The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), includes 'attenuated psychosis syndrome' (APS) as a new diagnosis in Section 3, which is the section for conditions requiring further research (American Psychiatric Association, 2013). The proposal to include this condition as a possible diagnosis in DSM-5 prompted much debate in the build up to the publication of DSM-5. While some argued that the introduction of this diagnosis could help promote early detection and treatment, others were concerned about potential stigma generated

by its inclusion (Brummitt and Addington, 2013; Mittal et al., 2015; Shrivastava et al., 2011; Tsuang et al., 2013; Yang et al., 2010).

Patients with established psychotic disorder have high levels of self-perceived stigma, which frequently prevents successful treatment (Link et al., 2001; Yoo et al., 2015). This negative stigmatising effect of mental health has been observed even in the pre-psychotic phase. Stigma-related stress in youth at risk of psychosis has been associated with reduced well-being and increased anxiety, depression, suicidality and the risk of transitioning to psychotic disorder (Rüsch et al., 2014, 2015; Xu et al., 2016; Yang et al., 2015). Self-perceived stigma in patients in the prodromal phase may develop due to various reasons, including psychosis-like symptoms, awareness of the illness and labeling (Yang et al., 2015). In particular, labeling terms themselves may lead to direct negative stigmatization by activating a 'set of pre-existing conceptions' concerning mental illness (Kim et al., 2012; Link et al., 1987, 1989; Yang et al., 2010).

A diagnosis can be a powerful tool to share information with professionals, but providing a label to patients carries the potential for stigma, and information about a disorder can occasionally be "too much for the patient" (Mittal et al., 2015). The term 'schizophrenia' has been changed

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in some Asian countries to reduce the prejudice and stigma related to this label (Chiu et al., 2010; Kim et al., 2012; Lee et al., 2013; Sartorius et al., 2014; Sato, 2006). In addition, a new term to replace 'schizophrenia' has also been proposed in Western countries for improving scientific validity and possibly being less stigmatising (Kapur, 2003; Tranulis et al., 2013; van Os, 2009). Consistent with this, it seems important to consider the way those terms are used in individuals at high risk of psychosis in order to minimize potential stigma. Following the introduction of 'APS' in the DSM-5 research section, investigation is needed to evaluate the possible harmful effects and benefits that might be associated with the APS diagnosis. This should include assessing any perceived stigma associated with this new diagnosis (Yung et al., 2012). However, only a few studies have investigated the perspectives of people at high risk for psychosis regarding their condition (Welsh and Tiffin, 2012). Furthermore, no study has directly investigated and compared the opinions of patients and mental health professionals regarding the proposed APS diagnosis and other related terms (Corcoran, 2016). This study aimed to investigate whether current labeling terms are suitable for people who are at risk of psychosis by surveying the opinions of patients and professionals regarding the potential stigma associated with the labels.

## 2. Methods

### 2.1. Participants

This study included young people who were enrolled in an early intervention service to prevent or treat the occurrence of a first psychotic episode and the professionals who worked with them. The patients were enrolled at the Personal Assessment and Crisis Evaluation (PACE) clinic of Orygen Youth Health in Melbourne, Australia. The PACE clinic provides clinical services and care for young people at high risk of schizophrenia and other psychotic disorders. Professionals among the mental health practitioners employed at Orygen Youth Health who had worked with UHR patients were enrolled. The patients' inclusion criteria were as follows: (a) fulfilled one or more of the three operationally defined UHR criteria (Nelson et al., 2013) as assessed by the Comprehensive Assessment of At-Risk Mental States (Yung et al., 2005); (b) aged 15–25 years and (c) completed three or more clinical sessions with a mental health practitioner at the PACE clinic. A written information sheet for this study was provided to eligible participants and written consent was obtained from all participants. This study was approved by the Melbourne Health Human Research Ethics Committee.

### 2.2. Questionnaire and data

A questionnaire developed by the researchers regarding the labels 'ARMS', 'UHR' and 'APS' was administered to the patients and professionals. An initial trial was performed with selected patients and professionals to determine whether the questionnaire was understandable. They were asked whether they understood all the questions and what could be clarified for future use. After revising the questionnaire based on this feedback, we initiated the data-collection process. It was composed of a total of 12 items with the same four questions for each three labeling terms as follows: (a) There is stigma (e.g., prejudice and discrimination from others) as a result of this term; (b) People are afraid and ashamed as a result of receiving this label; (c) The use of this term is helpful in preventing the development of psychosis; and (d) This term should be renamed to a more neutral or generic term. Subjects were asked how strongly they agreed or disagreed with each statement on a 5-point Likert scale (strongly agree to strongly disagree). Brief introduction for the labeling terms were provided before the items as follows: the term 'ARMS'/'UHR' is used to identify young people who may be at increased risk of developing psychosis; or 'APS' has recently been considered as a new diagnosis for DSM-5 based on the 'UHR'

criteria. Additionally, the participants were also asked their opinion about the need to rename the official diagnosis of 'schizophrenia'.

The Mental Health Consumers' Experience of Stigma scale was used to assess patients' experiences of stigma (Wahl, 1999). This stigma scale, which is composed of two subscales (9 stigma-related items and 12 discrimination-related items), measures patients' experiences with stigma and discrimination using a five-point Likert scale ("never" to "very often"). We administered the nine-item stigma subscale to assess the general level of perceived stigma. A higher total score indicated a higher level of perceived stigma. Data on the current psychiatric diagnoses, age, length of treatment at the PACE clinic and family history of psychiatric illness were collected from medical records.

Professionals were asked when they were likely to use the term 'psychosis' with young people during different time points in the pre-psychotic and transitioned phases. They were also asked which term they used most often when speaking to youths at risk of psychosis. Data on sociodemographic characteristics and occupational classification, were also collected from the professionals.

### 2.3. Statistical analysis

The answers 'agree' and 'strongly agree' regarding opinions about the labels were classified as agreement with the item. The frequency of agreement was compared between the patients and professionals using the chi-square test. The analysis was conducted separately in the patient and professional groups to compare agreement according to the sociodemographic and clinical characteristics using chi-square test for categorical variables and independent *t*-test for continuous variables. The associations of scores on the Stigma scale with opinions about the labels and the sociodemographic and clinical characteristics were analysed with independent *t*-test or analysis of variance for categorical variables or Pearson's correlation analysis for continuous variables. All statistical tests were two-tailed, with a significance level (*p*-value) of 0.05. SPSS ver. 21.0 for Windows software was used for the statistical analysis.

## 3. Results

### 3.1. Participants

A total of 105 subjects (50 patients and 55 professionals) participated in the study. Mean (standard deviation [SD]) ages of the patients and professionals were 19.1(3.1) and 36.6(9.8) years, respectively. Females comprised 60.0% of the patients and 63.6% of the professionals. Mean age of the patients at first contact with a mental health service was 16.1(4.0) years, and length of treatment at the PACE clinic was 9.0(6.2) months. Eleven (22.0%) patients had transitioned to psychosis from UHR while receiving mental health care at the PACE clinic. Twelve (24.0%) patients had a family history of psychosis, 21 (42.0%) had a family history of another psychiatric illness, such as depression or substance abuse, and 17(34.0%) had no family history of a psychiatric illness. Mean (SD) employment duration of the professionals at Orygen Youth Health was 9.0(6.2) years. The occupational classification of the professionals was as follows: 18(32.7%) nurses, 16(29.1%) psychologists, 10(18.2%) psychiatrists, 3(5.5%) social workers, 4(7.3%) occupational therapists and 4(7.3%) others.

### 3.2. Opinions about the labeling terms

Table 1 shows the responses of the patients and professionals to the questionnaire on opinions about the labeling terms. The patients were significantly less likely to agree that there is stigma associated with the terms 'UHR' and 'APS' compared with the mental health professionals. Patients tended to be less likely to agree than professionals that people are afraid and ashamed as a result of receiving the label 'APS', a difference approaching statistical significance ( $p = 0.073$ ). In

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