



Development and validation of the illness perceptions questionnaire for youth anxiety and depression (IPQ-Anxiety and IPQ-Depression)

Holly Alice Bear, Zoe Moon, Akash Wasil, Isaac Ahuvia, Julian Edbrooke-Childs & Miranda Wolpert

To cite this article: Holly Alice Bear, Zoe Moon, Akash Wasil, Isaac Ahuvia, Julian Edbrooke-Childs & Miranda Wolpert (2024) Development and validation of the illness perceptions questionnaire for youth anxiety and depression (IPQ-Anxiety and IPQ-Depression), *Counselling Psychology Quarterly*, 37:3, 441-469, DOI: [10.1080/09515070.2023.2232320](https://doi.org/10.1080/09515070.2023.2232320)

To link to this article: <https://doi.org/10.1080/09515070.2023.2232320>



© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



[View supplementary material](#)



Published online: 11 Jul 2023.



[Submit your article to this journal](#)



Article views: 1558



[View related articles](#)



[View Crossmark data](#)



Citing articles: 2 [View citing articles](#)



OPEN ACCESS



Development and validation of the illness perceptions questionnaire for youth anxiety and depression (IPQ-Anxiety and IPQ-Depression)

Holly Alice Bear^{a,b,c}, Zoe Moon^d, Akash Wasil^e, Isaac Ahuvia^f, Julian Edbrooke-Childs^{a,b} and Miranda Wolpert^{a,g}

^aResearch Department for Clinical, Educational and Health Psychology, University College London, Bloomsbury, London, UK; ^bEvidence-Based Practice Unit, Anna Freud National Centre for Children and Families, The Kantor Centre of Excellence, London, UK; ^cDepartment of Psychiatry, University of Oxford, Oxford, UK; ^dHealth Psychology Section, Institute of Psychiatry, Psychology & Neuroscience, King's College London, Guy's Hospital Campus, London Bridge London, UK; ^eDepartment of Psychology, University of Pennsylvania, Philadelphia, USA; ^fDepartment of Psychology, Stony Brook University, Stony Brook, USA; ^gWellcome Trust, Bloomsbury, London, UK

ABSTRACT

Background: The Revised Illness Perceptions Questionnaire (IPQ-R) is a well-established measure for measuring illness representations with sound psychometric properties. However, one limitation is that it provides a generic measure of illness representations and lacks specificity to individual health conditions, making it difficult to capture the nuances of illness beliefs for different populations.

Objective: The aim of this study was to develop reliable and valid versions of the IPQ-R for young people with anxiety and depression to better understand how they perceive and cognitively represent the course, severity, impact, and treatability of their anxiety and depression.

Methods: This mixed-methods study consisted of a qualitative study, involving semi-structured interviews ($n = 26$) followed by think-aloud interviews ($n = 13$), and a quantitative study ($n = 349$), resulting in the development of the IPQ-Anxiety (IPQ-A) and IPQ-Depression (IPQ-D). Item development is reported, along with the psychometric properties of the measures. Concurrent validity was assessed by correlating the IPQ-A and IPQ-D with the Brief Illness Perceptions Questionnaire (B-IPQ) across equivalent dimensions.

Results: Results suggest that the IPQ-A, IPQ-D, B-IPQ-A and B-IPQ-D are valid and reliable tools for measuring mental illness representations. The measures show acceptable model fit, high factor loadings, and good to excellent internal consistency, test – retest reliability across subscales and concurrent validity with mental health measures.

Conclusions: The development of these measures represents an important step in the field of youth mental health by providing the opportunity for reliable assessment of young people's conceptualisations of their anxiety and depression. Better understanding of young people's illness beliefs has the potential to open a range of intervention possibilities by prioritising illness perceptions over the supposed objective condition severity and trajectory.

ARTICLE HISTORY

Received 10 October 2022
Accepted 29 June 2023

KEYWORDS

Anxiety; Depression; Young people; Illness representations; Measure validation

CONTACT Holly Alice Bear  holly.bear@psych.ox.ac.uk

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09515070.2023.2232320>

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Background

Anxiety and depression are among the most common mental health disorders in adolescents and young people (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015), with a high probability of recurrence into adulthood (Fergusson, Boden, & Horwood, 2007) and associated functional impairment (Swan & Kendall, 2016). Effective interventions for anxiety and depression exist, in particular cognitive behavioural therapy (CBT), however, most young people in need of services do not access them (James, Reardon, Soler, James, & Creswell, 2020; Reardon, Harvey, & Creswell, 2020). Of those who do access specialist treatment for anxiety and depression, only approximately 40% show reliable improvement in symptoms (Bear, Edbrooke-Childs, Norton, Krause, & Wolpert, 2020; Edbrooke-Childs, Wolpert, Zamperoni, Napoleone, & Bear, 2018) and dropout rates are around 50% (de Haan, Boon, de Jong, Hoeve, & Vermeiren, 2013). One possible explanation for the observed variation in treatment outcomes are individual differences in *illness representations*, that is, how young people cognitively and emotionally perceive, think about and respond to the course, severity, impact, and treatability of their anxiety and depression (Bear, Krause, Edbrooke-Childs, & Wolpert, 2021). Illness representations guide *attitudes towards mental health services*, impact how individuals *engage in treatment* and also drive the uptake of *self-management and coping strategies* used by those with mental health problems (Baines & Wittkowski, 2013; Law, Tolgyesi, & Howard, 2014; McAndrew et al., 2018; Munson, Floersch, & Townsend, 2009, 2010). However, the study of illness representations among young people with mental health problems has been held back by a lack of valid and reliable measures for assessing them. In order to enhance treatment engagement and self-management, it is critical to understand how young people perceive and cognitively represent their mental health conditions using valid, mental health-specific measures.

Illness representations are described in a theoretical framework known as the Common Sense Model of Self-Regulation (CSM) (Leventhal, Meyer, Nerenz, & Rachman, 1980). The CSM posits that when one encounters a health threat (e.g. the symptoms of a specific illness or a new diagnosis), they develop parallel, yet interrelated, cognitive, and emotional representations. The cognitive representations consist of five core dimensions: (1) identity, or how the illness and its symptoms are identified and labelled; (2) cause, or the perceptions of what caused or sustains the illness; (3) timeline, or the sense of how long it will last; (4) consequences, or the expected impact on life; and (5) control/cure, or the perceived chances of recovering from or being able to control the illness, either with the help of treatment or through personal coping (Leventhal, Meyer, Nerenz, & Rachman, 1980). In parallel, the emotional response may involve feelings of fear, worry, or anger. These representations guide the formation and selection of coping strategies (e.g. avoidance, help-seeking, treatment adherence). According to the CSM, individuals choose coping strategies by evaluating the merits of available strategies and selecting the one with the best fit, based on their cognitive representations of the illness or health threat (e.g. perceived causation and consequences) (Hagger & Orbell, 2021). The choice of coping strategy is subsequently related to clinical outcomes in both physical and mental illnesses (Hagger, Koch, Chatzisarantis, & Orbell, 2017; McAndrew et al., 2018).

The CSM has been widely applied to adults and young people with physical illnesses and has enhanced understanding of illness self-management in a range of clinical populations (Hagger & Orbell, 2003). Research suggests that illness perceptions can

motivate self-management and coping behaviours, such as lifestyle changes, treatment seeking and adherence among those with physical health conditions (Dempster, Howell, & McCorry, 2015; Hagger & Orbell, 2021; Richardson, Schüz, Sanderson, Scott, & Schüz, 2017). Associations have been shown between illness perceptions and treatment adherence in adolescents with cystic fibrosis (Bucks et al., 2009), hypertension (Zugelj et al., 2010) and diabetes (Kyngäs, 2007); and between illness perceptions and quality of life in paediatric type 1 diabetes (Terrasson et al., 2018), cancer (Fonseca et al., 2010) and chronic fatigue syndrome (CFS) (Gray & Rutter, 2007).

Despite progress, there has been relatively little focus on illness representations for mental health problems, particularly among young people. Recent preliminary qualitative research has offered important initial insights into young people's illness beliefs, demonstrating that the CSM can be used to understand the illness perceptions of young people with anxiety and depression (Bear, Krause, Edbrooke-Childs, & Wolpert, 2021). The themes identified in this research were broadly consistent with the illness perceptions domains outlined in the CSM. This suggests that models of illness representation share a common conceptual structure between paediatric physical and mental health conditions and that there are structural parallels in how young people perceive illness identity, cause, consequences, control/curability, and timeline. Although this study supported a common structure of illness beliefs, the content of these beliefs was idiosyncratic and unique to youth anxiety and depression. The research identified novel domains of illness perception relating to the non-linear, complex journey of recovery and a strong emphasis on prioritising learning to cope and self-management skills. There was a widely held belief that anxiety and depression followed a relapse remitting, yet lifelong trajectory and youth expected to live with these conditions for some time. However, the complex and non-linear nature of the recovery process and the building of resilience strategies over time are largely absent from studies using the CSM in physical health contexts. Many young people also described the notion of a "silver lining" or "benefit finding" e.g. the ability to derive psychological benefit, including a deeper sense of purpose and closer family relationships from threatening situations such as mental illness (Bear, Krause, Edbrooke-Childs, & Wolpert, 2021). However, benefit finding is currently not measured in quantitative studies of illness perceptions and has not been commonly explored in illness perceptions research. Existing research highlights the distinct, anxiety- and depression-specific content of these beliefs, illustrating the shortcomings of generic measures for illness representations in this population, and the need for valid and reliable *anxiety- and depression-specific* tools to measure illness representations in this group.

Illness representations can be measured using the generic Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996), which measures core illness representations across five domains: identity, cause, timeline, consequences, and curability/controllability. The measure has since been revised (IPQ-R), with improvements to the internal consistency of several existing subscales and the addition of a further two subscales: (1) emotional representations, or the emotional responses generated by the illness and (2) coherence, or how the illness is understood or comprehended (Moss-Morris et al., 2002). A shorter nine-item version has also been developed (Brief-IPQ), which differs from the IPQ-R by using single-item scales (Broadbent et al., 2015; Broadbent, Petrie, Main, & Weinman, 2006). Although well-established, a limitation of these measures is that they are *generic measures of illness perceptions* and are *inappropriate for the study of specific disorders*, particularly when it comes to mental illness (French & Weinman, 2008; Pedley, Bee, Wearden, Berry, & Eisenbarth, 2019). The

existence of unique and novel aspects of illness perceptions in mental health conditions means that there is an added layer of complexity in our understanding of “illness” which requires validated, condition-specific measurement tools to capture this information. These novel aspects of illness perceptions necessitate the adaptation of measurement tools, such as the IPQ-R, to reliably measure these representations (Bear, Krause, Edbrooke-Childs, & Wolpert, 2021; Pedley, Bee, Wearden, Berry, & Eisenbarth, 2019; Teh et al., 2021). Identifying the illness representations that are specific to young people with anxiety and depression, using an illness-specific modified version of the IPQ-R, may go some way towards improving understanding of the association between illness representations and outcomes, including treatment engagement, self-management, and coping. Using validated tools, it may be possible to develop interventions that harness more adaptive illness belief models with the aim of improving health-related outcomes. It may also be possible to inform clinical practice by incorporating the young person's illness models, including their own perceptions of identity, cause, timeline to recovery, consequences, and personal and treatment control into clinical formulation and shared decision-making during treatment.

To address the shortcomings of the generic measure, researchers have initiated a series of steps for modifying and validating the IPQ-R for specific clinical populations. These steps consist of a qualitative phase to elicit population-specific illness perceptions, a questionnaire modification phase which is informed by the qualitative data, a think-aloud phase to inform further modifications, and, finally, a quantitative measure validation phase. Qualitative methods are crucial for informing the initial modification of the tool and to check the face-validity and acceptability of the final measure. This validation process has been carried out successfully with populations including breast cancer survivors treated with tamoxifen (IPQ-BCS) (Moon, Moss-Morris, Hunter, & Hughes, 2017), patients with atrial fibrillation (AF IPQ-R) (Taylor, O'Neill, Hughes, & Moss-Morris, 2018), adults with obsessive compulsive disorder (OCD) (Pedley, Berry, Bee, Gellatly, & Wearden, 2019), and pain in young people (PPQ-YP) (Ghio et al., 2018).

The current study

The overarching aim of this study was to develop adapted versions of the IPQ-R for young people with anxiety and depression. The primary research objectives were twofold: (1) Using qualitative interviews, develop versions of the IPQ-R for anxiety (IPQ-A) and for depression (IPQ-D); and (2) using a cross-sectional sample of young people with anxiety or depression, assess the psychometric properties of the IPQ-A and IPQ-D, including the factor structure, internal consistency, test – retest reliability, construct validity, and concurrent validity.

Methods

Design

A cross-sectional design was used, consisting of both a qualitative phase to inform the adaptation of the IPQ-R, involving semi-structured interviews and think-aloud interviews, and a quantitative phase to assess the psychometric properties of the IPQ-A and IPQ-D. The study was pre-registered on the Open Science Framework (OSF) at <https://osf.io/fvyqn>.

Questionnaire development phase

Participants and recruitment

Young people with a history of anxiety or depression were recruited online from community settings via opportunity sampling. Recruitment happened online, including social media (e.g. Twitter and Facebook), newsletters sent to youth and practitioner networks, and advertisements placed on university and charity websites. Participants had to be UK residents, aged between 14 and 24 years old, and self-report experiencing anxiety or depression either currently or in the past. Participants were asked to self-report current or past anxiety or depression based on a definition provided to them in the participant information sheet. The definitions provided to participants are available in supplementary materials. Taking this approach meant we avoided discounting the views and experiences of young people who did not have a formal diagnosis or who were not experiencing clinically significant levels of anxiety or depression at the time of the interview. Full details of participant recruitment, procedures and data analysis for the semi-structured interviews are reported elsewhere (please see Bear, Krause, Edbrooke-Childs, & Wolpert, 2021).

Qualitative methods were used to explore young people's beliefs about their anxiety and depression, assessed across five illness perception dimensions outlined in the CSM of Self-Regulation (Leventhal, Meyer, Nerenz, & Rachman, 1980). Semi-structured interviews were conducted with 26 young people between July and October 2018. Participants were aged between 16 and 24 years, mean age = 20.3 years, 73% female (see Table 1). Following initial modifications and item development, a further 13 think-aloud interviews were conducted with a sub-group of participants from the initial qualitative sample to assess the face validity of the IPQ-A and IPQ-D to determine if the items were easily understood and interpreted in the expected way (mean age = 20.2 years, 77% female). Think-aloud methods require participants to verbalise their thoughts as they complete the questionnaire to explore the manner in which they respond to items (Van Someren, Barnard, & Sandberg, 1994). Previous think-aloud studies have highlighted those adaptations that simply replace the word "illness" with the illness name is insufficient (Aujla, Vedhara, Walker, & Sprigg, 2020; McCorry, Scullion, McMurray, Houghton, & Dempster, 2013). Think-aloud interviews are also important for highlighting items that may be misunderstood by participants prior to implementation (Van Oort, Schröder, & French, 2011). In this study, participants were asked to complete both the IPQ-A and IPQ-D whilst expressing their thought processes throughout. Participants were also asked if any questions were not easily understood and provide their overall impression of the measures. With prior consent, all interviews were audio-recorded. All participants were reimbursed for their time with a £10 Amazon voucher.

Item modifications

Themes from the qualitative interviews broadly mapped onto the dimensions of the CSM, suggesting that there are parallels in the ways that young people with mental and physical health problems perceive illness identity (i.e. symptoms), cause, consequences, control/cure, and timeline. However, within these dimensions, we identified beliefs and experiences that are specific to anxiety and depression. Anxiety and depression were seen to have a non-linear relapse and remitting, but lifelong course, and youth strongly emphasized the importance to learn coping and self-management skills. While youth

Table 1. Participant characteristics, questionnaire development phase.

Participant characteristics	Semi-structured interviews (<i>n</i> = 26)	Think aloud interviews (<i>n</i> = 13)
Age (years) , mean $\pm$ SD	20.3 $\pm$ 2.53	20.2 $\pm$ 2.7
Gender		
Female, <i>n</i> (%)	19 (73.1)	10 (76.9)
Male, <i>n</i> (%)	7 (26.9)	3 (23.1)
Nationality		
British, <i>n</i> (%)	22 (84.6)	10 (76.9)
Other, <i>n</i> (%)	4 (15.4)	3 (23.1)
Ethnicity		
White British, <i>n</i> (%)	17 (65.4)	10 (76.9)
Other, <i>n</i> (%)	9 (34.6)	3 (23.1)
Religious or spiritual , “Yes” <i>n</i> (%)	5 (19.2)	5 (38.5)
Currently in paid employment , <i>n</i> (%)	11 (42.3)	3 (23.1)
Currently in full-time education , <i>n</i> (%)	17 (65.4)	10 (76.9)
Highest level of education completed		
Secondary Education (GCSE/O-Level, A-Level)	8 (30.8)	3 (23.1)
Further Education (Higher National Certificate, Diploma)	6 (23.1)	2 (15.4)
Higher Education (Bachelor’s, Master’s, Doctorate)	12 (46.2)	7 (53.9)
Currently experiencing anxiety and/or depression , <i>n</i> (%)	22 (84.6)	12 (92.3)
Experienced anxiety and/or depression in the past , <i>n</i> (%)	26 (100)	13 (100)
Long-term condition (mental or physical) , <i>n</i> (%)	13 (50)	6 (46.2)
Family history of anxiety or depression , <i>n</i> (%)	17 (65.4)	9 (69.2)
Friend history of anxiety or depression , <i>n</i> (%)	22 (84.6)	11 (84.6)
Currently receiving help or treatment for anxiety and/or depression , <i>n</i> (%)	18 (69.2)	11 (84.6)
Received help or treatment for anxiety and/or depression in the past , <i>n</i> (%)	23 (88.5)	10 (76.9)

described pervasive negative impacts of these conditions on their lives, they also frequently described benefits or positive aspects (e.g. relating to personal growth).

Using the qualitative data, initial modifications were made to the IPQ-R based on the language used by the young people and the illness representations and beliefs they conveyed. The original and amended items are presented in Table S1 and detailed explanation of the modifications made are available in supplementary materials. In summary, a key theme was that young people often distinguished between the positive and negative aspects of anxiety and depression. In addition to describing negative consequences, they also identified positive consequences, such as being more open-minded, resilient, empathetic, and self-aware (Bear, Krause, Edbrooke-Childs, & Wolpert, 2021). To capture this in the IPQ-A and the IPQ-D, a new five-item “positive consequences” subscale was added, which mirrored the original “consequences” subscale in structure. This was achieved by incorporating the most frequently mentioned positive consequences from the qualitative interviews.

As suggested by Moss-Morris and colleagues, the “identity” scale and “cause” scale of the IPQ-R were revised to ensure that the measure assessed symptoms and causes that young people with anxiety and depression see as relevant to their condition (Moss-Morris et al., 2002). Young people used different language to describe their symptoms than that used in the original IPQ-R, therefore, steps were taken to standardise the language used for the symptom list in the “identity” subscale by referring cross-referencing with the wording used in existing psychometric measures, including the Revised Children’s Anxiety and Depression Scale (RCADS) (Ebesutani et al., 2012) and the Strengths and Difficulties Questionnaire (SDQ)

(Goodman, Ford, Simmons, Gatward, & Meltzer, 2003). Eighteen new symptoms, spanning both anxiety and depression, were added to the original list of 14 symptoms in the core version of the IPQ-R (Table S2). Additional changes were made to the original IPQ-R “identity” subscale. For example, “pain” was changed to “physical pain”, “sleep difficulties” was changed to “trouble falling or staying asleep or sleeping too much” and “weight loss” was changed to “weight loss/gain”. The “cause” subscale was modified by adding anxiety and depression specific causes (e.g. “Chemical or hormonal changes”, “Puberty” and “My thinking style”) and removing causes which were not applicable (e.g. “Smoking” and “a germ or virus”), resulting in a twenty-six-item scale. The cause items were derived from the qualitative interviews and were supplemented with key risk factors taken from the literature that were supported by evidence (e.g. poverty and bullying). Cause items included adverse childhood experiences and illness or death of a close friend or family member.

Think-aloud interviews served as an important step in the development of the IPQ-A and IPQ-D. Several suggestions and insights were provided by young people which improved the clarity, usability, and acceptability of the measures. For example, in the “personal control” subscale, many young people did not understand the term “course” and based on suggestions from participants, this word was changed to “journey”. Other participants agreed that the term “course” had medical connotations and suggested that the outcome of their problems was pre-set, whereas a “journey” has ups and downs and is a term used often in psychological therapy. In the “coherence” domain, there was a consistent view that the term “puzzling” may pose a problem for some young people. It was suggested that while this term may make sense for native English speakers it may be difficult to decipher for non-native English speakers or for individuals who interpret language literally (e.g. for those with autism spectrum disorder). The word “puzzling” was therefore amended to “confusing”. Additional details of the further item modifications that were made are available in supplementary materials.

Measure validation phase

Participants and recruitment

Young people with a history of anxiety or depression were recruited via opportunity sampling. Recruitment happened online, including social media (e.g. Twitter and Facebook), newsletters sent to youth and practitioner networks, advertisements placed on university and charity websites ($n = 255$) and recruitment site Prolific.ac ($n = 102$). Participants had to be UK residents, be aged between 14 and 24 years old, and self-report experiencing anxiety or depression either currently or in the past. Participants were asked to self-report current or past anxiety or depression based on a definition provided to them in the participant information sheet. Questionnaire data were collected between November 2018 and June 2019. The questionnaires were completed on the online platform Gorilla.sc and took approximately 20 minutes to complete. Participants recruited via Prolific.ac were reimbursed £2 for their time. Participants recruited via social media were entered in a prize draw to win one of two £50 Amazon vouchers. With prior consent, participants were contacted after approximately two weeks to complete the IPQ-A and IPQ-D for a second time in order to provide a test-retest sample.

A total of 357 participants completed the questionnaire battery. Eight participants were 25 years old or older and were excluded from further analyses, leaving a final sample of 349. Of

those, 312 had a history of anxiety and completed the anxiety-specific IPQ-A, and 291 had a history of depression and completed depression-specific IPQ-D. There were 259 participants who had a history of both anxiety and depression and who completed both the IPQ-A and IPQ-D. Participant demographic characteristics are presented in [Table 2](#).

Table 2. Participant demographic characteristics, validation phase.

	Participants with a history of anxiety (<i>n</i> = 312)	Test-retest anxiety sample (<i>n</i> = 64)	Participants with a history of depression (<i>n</i> = 291)	Test-retest depression sample (<i>n</i> = 58)
Age (years) , mean ± SD	2.6 ± 2.1	2.2 ± 2.6	2.5 ± 2.5	2.0 ± 2.7
Gender				
Female, <i>n</i> (%)	259 (83)	55 (85.9)	238 (81.8)	51 (87.9)
Male, <i>n</i> (%)	49 (15.7)	7 (1.9)	49 (16.8)	5 (8.6)
Non-binary or transgender	4 (1.3)	2 (3.1)	4 (1.4)	2 (3.4)
Nationality				
British, <i>n</i> (%)	231 (74)	42 (65.6)	221 (75.9)	41 (7.7)
Other, <i>n</i> (%)	81 (26)	22 (34.4)	70 (24.1)	17 (29.3)
Ethnicity				
White	211 (67.6)	42 (65.6)	198 (68)	40 (69.0)
Black/African/ Caribbean/Black British	10 (3.2)	1 (1.6)	10 (3.4)	1 (1.7)
Mixed/Multiple ethnic groups	15 (4.8)	2 (3.1)	15 (5.2)	2 (3.4)
Asian/Asian British	65 (2.8)	19 (28.1)	57 (19.6)	14 (24.1)
Other ethnic group	11 (3.5)	1 (1.6)	11 (3.8)	1 (1.7)
Religious or spiritual, “Yes” <i>n</i> (%)	102 (32.7)	19 (29.7)	93 (32.0)	17 (29.3)
Currently in full-time education, “Yes” <i>n</i> (%)	217 (69.6)	48 (75.0)	194 (66.7)	43 (74.1)
Current education level				
No qualifications	11 (3.5)	2 (3.1)	11 (3.8)	2 (3.4)
Secondary Education	66 (21.2)	16 (25.0)	63 (21.7)	15 (25.9)
Further Education	16 (5.1)	2 (3.1)	15 (5.2)	2 (3.4)
Higher Education	163 (52.2)	34 (53.1)	144 (49.5)	29 (50.0)
Other qualifications	7 (2.2)	2 (3.1)	7 (2.4)	2 (3.4)
Currently in paid employment, <i>n</i> (%)	130 (41.7)	27 (42.2)	123 (42.3)	25 (43.1)

Measures

Demographic questions included age, gender, ethnicity, nationality, current employment, religiousness and spirituality, and educational attainment. Clinical questions included history of mental health problems, family and friends’ history of mental health problems, other long-term conditions, and past and current treatment for mental health problems.

The Illness Perceptions Questionnaire – Depression (IPQ-D) and Illness Perceptions Questionnaire – Anxiety (IPQ-A)

The IPQ-A and IPQ-D were used to assess participants’ cognitive and emotional representations of anxiety and depression. The “identity” dimension of the IPQ-A and IPQ-D consists of 32 symptoms; respondents are asked to rate whether they have experienced a symptom

since their anxiety or depression started (yes/no), and if they believe the symptom to be directly related to their anxiety or depression (yes/no). Symptoms attributed to the anxiety and depression are summed to give an “identity” total score. The main body of the IPQ-A and IPQ-D measures a further six illness representation domains, which map on eight subscales, across 48 items. The domains are “Timeline” (chronic/acute, cyclical), “Control” (personal, treatment), “Negative Consequences”, “Positive Consequences”, “Emotional Representations”, and “Coherence”. Items are rated on a 5-point Likert-Scale and are scored from 1 to 5, except for reverse-scored items (see [Tables 4](#) and [S2](#)). Higher scores on these scales reflect stronger beliefs in a chronic or longer duration of the condition and more variability in the fluctuation of the symptoms, a greater perceived negative impact on life, stronger beliefs in the ability to control the condition by their own internal locus of control, stronger beliefs in the ability to control the condition by treatment, a greater positive impact on life, a better understanding of the condition and a stronger emotional response. The “causes” domain consists of 26 possible causes (see [Table S7](#)). Respondents were asked to indicate to what extent they agree or disagree with the possible causes of their anxiety or depression. Items are rated on a 5-point Likert-Scale and are scored from 1 to 5.

The Brief Illness Perceptions Questionnaire (B-IPQ)

Concurrent validity was assessed using the B-IPQ, a 9-item brief version of the IPQ-R designed to rapidly assess the cognitive and emotional representations of illness using single item subscales (Broadbent, Petrie, Main, & Weinman, 2006). The B-IPQ uses a single-item scale approach to assess perception on a continuous linear 11-point scale of 0 (e.g. no affect at all, a very short time, absolutely no control) to 10 (e.g. severely affects my life, forever, extreme amount of control). The nine items map on to an equivalent subscale of the IPQ-R. The B-IPQ has good test – retest reliability and concurrent validity with the IPQ-R (Broadbent et al., 2015; Broadbent, Petrie, Main, & Weinman, 2006). In line with recommendations, the B-IPQ was amended to create two versions that measured anxiety-and depression-specific representations. In addition, item 8 “How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset, or depressed?)” was modified to reflect the modifications in the IPQ-A and IPQ-D “How much does your depression affect you emotionally? (e.g. does it make you upset, angry, afraid, ashamed or guilty?)”. The modified versions will herein be referred to as B-IPQ-A and B-IPQ-D. All modifications were made with prior permissions from the author who originally developed the B-IPQ.

The Generalised Anxiety Disorder-7 (GAD-7)

The GAD-7 is a 7-item screening and assessment tool used to measure generalised anxiety disorders (GAD), validated for ages 12 and older. Scores of 5, 10, and 15 are taken as the cut-off points for mild, moderate, and severe anxiety, respectively (Spitzer, Kroenke, Williams, & Löwe, 2006). Using the threshold score of 10, the GAD-7 has a sensitivity of 89% and a specificity of 82% for generalised anxiety disorder (Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007). The measure has good internal consistency when applied in primary care ($\alpha = .92$) (Spitzer, Kroenke, Williams, & Löwe, 2006).

The Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 is a 9-item measure of depression severity, validated for ages 13 and older (Kroenke, Spitzer, & Williams, 2001). Scores of 5, 10, 15, and 20 are taken as the cut-off

points for mild, moderate, moderately severe, and severe depression, respectively. Scores greater than 10 indicate caseness and are considered clinically significant. Using the threshold score of 11, the PHQ-9 has a sensitivity of 89.5% and a specificity of 77.5% when assessed against the Child Diagnostic Interview Schedule (DISC-IV) (Richardson et al., 2010). The measure demonstrates high internal consistency at baseline and end of treatment ($\alpha = .83$ and $.92$) (Cameron, Crawford, Lawton, & Reid, 2008).

Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

The WEMWBS is a 14-item measure of mental well-being, validated for use with individuals aged 13 to 74 (Tennant et al., 2007). The WEMWBS has five response categories, summed to provide a single score ranging from 14–70, with higher scores reflect higher well-being. The WEMWBS is established as reliable and valid for use with young people in the United Kingdom, demonstrating strong internal consistency and a high Cronbach's alpha of .87 (95% CI (0.85–0.88), $n = 1,517$) (Clarke et al., 2011).

The Outcome Expectancy Scale (OES)

The OES is a 3-item self-report measure of patients' expectation of treatment outcome (Ogrodniczuk & Sochting, 2010). Items are rated on a 5-point Likert Scale, ranging from 1 (not at all) to 5 (completely), summed to provide total scores which range from 3 to 15. Higher scores reflect more positive outcome expectation. Principal component analysis of the scale supports a single factor that accounts for 86% of the variance in item ratings and internal consistency is high ($\alpha = 0.92$) (Tsai, Ogrodniczuk, Sochting, & Mirmiran, 2014).

Sample size calculation

There are different recommendations regarding the appropriate sample size to use for conducting factor analysis, usually presented as a minimum ratio of sample size to number of variables (Mundfrom, Shaw, & Ke, 2005). Recommendations vary; for example, Cattell proposed a range of 1:3 to 1:6 (Bartholomew & Cattell, 1980) whereas Gorsuch argued for a minimum ratio of 1:5 (Gorsuch, 1983). The IPQ-A and IPQ-D have 48 items, with sample sizes of $n = 312$ and $n = 291$, respectively, representing a ratio of approximately 1 to 6, and 1 to 3 following the random sample split, which fall within the range recommended in the literature (Bartholomew & Cattell, 1980; Gorsuch, 1983).

Statistical analysis

There were no missing data in the questionnaire battery, as respondents were required to complete all items. Analyses were conducted in several stages. The Lavaan package in RStudio version 1.1.456 was used to conduct the factor analysis. In the first stage, we conducted exploratory factor analysis (EFA) to determine the underlying set of factors using a randomised split of the data in the sample. Parallel analysis was then conducted to inform how many factors to retain (Hayton, Allen, & Scarpello, 2004). Items that constituted the most coherent subscales and with the least cross-loadings were then selected. Next, Confirmatory Factor Analysis (CFA) was carried out on the remaining participants to test how well the items, or indicator variables, represented the expected constructs, or latent variables, of the suggested

model and to determine if the factor structure required modification. Latent factors were constrained to have a mean of 0 and a variance of 1 in order to standardise them. The underlying factor structure and model fit was examined using multiple indices, including the comparative fit index (CFI), with a recommended approximate cut-off of > 0.95 ; the root-mean-square error of approximation (RMSEA), with a recommended approximate cut-off of < 0.06 indicating a good fit and < 0.08 indicating a reasonable fit; Tucker-Lewis index (TLI), with a recommended approximate cut-off of > 0.95 ; and the standardized root-mean-square residual (CSMR) with a recommended approximate cut-off of < 0.08 (Hu & Bentler, 1999). In general, if most of the indices indicate a good fit, then there is likely a good fit to the data.

Next, we assessed the internal consistency of each subscale using Cronbach's alpha. The test-retest reliability was also assessed using a sub-sample of participants who completed the questionnaire twice, two weeks apart. Intraclass correlation coefficients (ICCs) were used to assess test-retest reliability of each IPQ-A and IPQ-D subscales between time-point one and time-point two. Values less than 0.5, between 0.5 and 0.75, between 0.75 and 0.9, and greater than 0.90 are indicative of poor, moderate, good, and excellent reliability, respectively (Koo & Li, 2016).

Previous research and meta-analytic studies have shown a consistent and stable pattern of inter-correlations between the dimensions of cognitive representations of the CSM. The construct validity was evaluated by checking if the dimensions of each scale correlate in the expected way, consistent with the CSM and with previous research (Hagger & Orbell, 2003). To further investigate the validity of the dimensions, associations with theoretically related constructs such as distress, coping, well-being, treatment outcome expectations, demographic and clinical variables were explored. Finally, concurrent validity was assessed by comparing the IPQ-A and IPQ-D to the B-IPQ and B-IPQ-D on all the equivalent dimensions. This step served the additional purpose of cross-validating the B-IPQ-A and B-IPQ-D, which had undergone minor modifications for use with young people with anxiety and depressive problems. Test-retest reliability was also assessed using ICCs.

The causal attribution subscale was examined using EFA as there was no existing theoretically derived factor structure for this population. Parallel analysis was conducted to inform how many factors to retain and items that constituted the most coherent subscales and with the least cross-loadings were selected (Hayton, Allen, & Scarpello, 2004).

Ethical approval

Ethical approval was granted by University College London Research Ethics Committee (9777/003) on 18 July 2018. All participants in both the qualitative and quantitative studies provided informed written consent.

Results

Among participants who self-reported a prior history of anxiety ($n = 312$; referred to as the "anxiety group"), 57% of participants scored above the clinical cut-off for moderate anxiety on the GAD-7. Among participants who self-reported a prior history of depression ($n = 291$;

referred to as the “depression group”), 68% of participants scored above the clinical cut-off for moderate depression on the PHQ-9. Notably, the groups were not mutually exclusive; individuals with a history of depression *and* anxiety were members of both groups. Participants’ mental health and treatment characteristics are presented in [Table 3](#).

Table 3. Participant mental health and treatment characteristics, validation phase.

	Anxiety group (<i>n</i> = 312)	Depression group (<i>n</i> = 291)
Currently experiencing anxiety, <i>n</i> (%)	243 (77.9)	210 (72.2)
Currently experiencing depression, <i>n</i> (%)	158 (5.6)	170 (58.4)
Family history of anxiety or depression, <i>n</i> (%)	237 (76.0)	218 (74.9)
Friend history of anxiety or depression, <i>n</i> (%)	270 (86.5)	248 (85.2)
Currently receiving help or treatment for anxiety/depression, <i>n</i> (%)	110 (35.3)	107 (36.8)
Received help or treatment for anxiety/depression in the past, <i>n</i> (%)	201 (64.4)	192 (66)
Other long-term condition (mental or physical), <i>n</i> (%)	85 (27.2)	81 (27.8)
GAD-7, mean $\pm$ SD	1.82 $\pm$ 5.6	1.8 $\pm$ 5.7
PHQ-9, mean $\pm$ SD	12.65 $\pm$ 7.1	13.2 $\pm$ 7.0
WEMWBS, mean $\pm$ SD	39.4 $\pm$ 9.8	38.7 $\pm$ 9.8
OES, mean $\pm$ SD	9.3 $\pm$ 2.6	9.3 $\pm$ 2.7

Note: GAD-7, Generalised Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; WEMWBS, Warwick-Edinburgh Mental Wellbeing Scale; OES, Outcome Expectancy Scale; SD, standard deviation.

Validation of main body

The main body of the IPQ-D and IPQ-A measures the following domains: chronic and cyclical timeline, personal and treatment control, negative and positive consequences, emotional representations, and coherence. The methods and results of the validation process were similar for both the IPQ-D and the IPQ-A.

Exploratory factor analysis

For the IPQ-D, parallel analysis was conducted on the first half of the sample (*n* = 147) and suggested a nine-factor model. A varimax rotation of the factors yielded a solution which was almost identical to the hypothesised IPQ-R eight factor model. A new factor, henceforth termed “no control”, comprised of two negatively phrased items from both treatment control and personal control (ip25d, ip26d, ip27d and ip33d). This factor accounted for 4% of the variance and factor loadings ranged from 0.40 to 0.74.

For the IPQ-A, parallel analysis was conducted on the first half of the sample (*n* = 156) and suggested a ten-factor model. A varimax rotation of the factors yielded a solution which was very similar to the original hypothesised eight factor model of the IPQ-R. On closer inspection, seven factors were consistent with the hypothesised IPQ-R model factor structure. Consistent with the theorised model, items in factors nine and ten cross loaded on to the theorised factors and so were assigned to those factors instead. A detailed description of the factor structure and factor loadings is available in supplementary materials.

Confirmatory factor analysis

For the IPQ-D, confirmatory factor analysis was then carried out on the second half of the sample ($n = 144$) to test the nine-factor model. This model (with all items retained) consisted of 48 items across 9 factors and showed reasonable model fit (RMSEA = 0.056, 95% CI 0.052–0.060, CFI = 0.92, TLI = 0.91, CSMR = 0.079). The factor loadings of items ip17d, ip18d and ip31d were below the cut-off of 0.4 and were removed. This resulted in a model which showed slightly better fit (RMSEA = 0.053, 95% CI 0.049–0.057, CFI = 0.94, TLI = 0.93, CSMR = 0.071). [Table 4](#) contains the factor loadings for each of the items in the IPQ-D. Factor loadings were all above the required threshold of 0.40 (Ford, MacCallum, & Tait, 1986), ranging from 0.47 to 0.95.

For the IPQ-A, confirmatory factor analysis was then conducted on the second half of the sample ($n = 156$) to test the seven-factor model (treatment control and personal control combined) and the eight-factor model (treatment control and personal control separate). Upon inspection of the model fit indices, the eight-factor model had better model fit and made more theoretical sense, in that treatment control and personal control measure different constructs. This model (with all items retained) consisted of 48 items across 8 factors and showed reasonable model fit (RMSEA = 0.06, 95% CI 0.057–0.063, CFI = 0.89, TLI = 0.88, CSMR = 0.086). The factor loadings of items ip30a, ip31a and ip32a were below the cut-off of 0.4 and were removed. Item deletion did not change the model fit (RMSEA = 0.064, 95% CI 0.061–0.068, CFI = 0.90, TLI = 0.89, CSMR = 0.087). [Table 5](#) contains the factor loadings for each of the items. Factor loadings were all above the required threshold of 0.40 (Ford, MacCallum, & Tait, 1986), ranging from 0.44 to 0.95.

Internal and test-retest reliability

For the IPQ-D, all scales within the final model showed acceptable internal consistency: chronic timeline (6 items, $\alpha = 0.90$), negative consequences (7 items, $\alpha = 0.85$), positive consequences (5 items, $\alpha = 0.77$), personal control (4 items, $\alpha = 0.81$), treatment control (4 items, $\alpha = 0.68$), no control (4 items, $\alpha = 0.80$), coherence (5 items, $\alpha = 0.88$), timeline cyclical (4 items, $\alpha = 0.69$), emotional response (6 items, $\alpha = 0.81$). Test – retest reliability was tested in a separate sample of 58 young people. Participants completed the questionnaire twice; on average, 28 days apart. The intra-class correlation coefficient was calculated for each subscale: chronic timeline (ICC = 0.84, 95% CI = 0.73–0.91, $p < .001$), negative consequences (ICC = 0.83, 95% CI 0.72–0.90, $p < .001$), positive consequences (ICC = 0.90, 95% CI 0.83–0.94, $p < .001$), personal control (ICC = 0.75, 95% CI 0.58–0.85, $p < .001$), treatment control (ICC = 0.65, 95% CI 0.41–0.79, $p < .001$), no control (ICC = 0.66, 95% CI 0.43–0.80, $p < .001$), coherence (ICC = 0.66, 95% CI 0.43–0.80, $p < .001$), timeline cyclical (ICC = 0.83, 95% CI 0.71–0.90, $p < .001$), emotional response (ICC = 0.83, 95% CI 0.71–0.90, $p < .001$). The intra-class correlation coefficients for each scale ranged from 0.65 to 0.90, indicating good to excellent test – retest reliability.

For the IPQ-A, all scales in the final model showed acceptable internal consistency: chronic timeline (6 items, $\alpha = 0.87$), negative consequences (7 items, $\alpha = 0.83$), positive consequences (7 items, $\alpha = 0.78$), personal control (6 items, $\alpha = 0.79$), treatment control (4 items, $\alpha = 0.69$), coherence (5 items, $\alpha = 0.87$), timeline cyclical (4 items, $\alpha = 0.70$), emotional response (6 items, $\alpha = 0.80$). Test – retest reliability was tested in a sub-sample of 64 young people (mean = 28 days apart). The intra-class correlation coefficient was calculated for each subscale: chronic timeline (ICC = 0.82, 95% CI 0.70–0.89, $p < .001$), negative

Table 4. CFA factor loadings for the IPQ-D.

Subscale		B Standardised	SE
Chronic timeline			
IP1D ^R	My <i>depression</i> will last a short time	0.83	0.03
IP2D	My <i>depression</i> is likely to be permanent rather than temporary	0.86	0.02
IP3D	My <i>depression</i> will last for a long time	0.91	0.02
IP4D ^R	This <i>depression</i> will pass quickly	0.85	0.02
IP5D	I expect to have <i>depression</i> for the rest of my life	0.86	0.02
IP6D ^R	My <i>depression</i> will improve in time	0.65	0.04
Negative consequences			
IP7D	My <i>depression</i> is a serious condition	0.75	0.03
IP8D	My <i>depression</i> has major consequences on my life	0.87	0.02
IP9D ^R	My <i>depression</i> does not have much effect on my life	0.82	0.03
IP10D	My <i>depression</i> strongly affects the way others see me	0.66	0.04
IP11D	My <i>depression</i> negatively impacts my relationships with others	0.76	0.04
IP12D	My <i>depression</i> makes it difficult for me to attend school/college/university/work	0.69	0.04
IP13D	My <i>depression</i> prevents me from socialising with friends and family	0.67	0.04
Positive consequences			
IP14D	My <i>depression</i> has made me more open-minded	0.49	0.05
IP15D	My <i>depression</i> has made me more resilient	0.67	0.04
IP16D	My <i>depression</i> has made me more self-aware	0.50	0.06
IP17D	My <i>depression</i> has made me more empathetic towards others	0.36	0.07
IP18D	My <i>depression</i> has made me who I am today	0.40	0.05
IP19D	My <i>depression</i> has had some positive impact on my life	0.94	0.02
IP20D ^R	My <i>depression</i> has not had any positive impact on my life	0.95	0.02
Personal control			
IP21D	There are things which I can do to control my <i>depression</i> symptoms	0.81	0.03
IP22D	What I do can determine whether my <i>depression</i> gets better or worse	0.75	0.03
IP23D	I have the power to influence my <i>depression</i>	0.85	0.03
IP24D	The journey of my <i>depression</i> depends on me	0.70	0.04
No control			
IP25D	Nothing I do will affect my <i>depression</i>	0.77	0.03
IP26D	My actions will have no effect on the outcome of my <i>depression</i>	0.72	0.03
IP27D	There is very little that can be done to improve my <i>depression</i>	0.92	0.03
IP33D	There is nothing which can help my <i>depression</i>	0.74	0.04
Treatment control			
IP28D	My treatment will be effective in curing my <i>depression</i>	0.83	0.05
IP29D	The negative effects of my <i>depression</i> can be prevented or avoided by treatment	0.69	0.05
IP30D	Therapy with a mental health professional can control my <i>depression</i>	0.61	0.05
IP31D	Medication prescribed by my doctor can control my <i>depression</i>	0.13	0.08
IP32D	There are things my family and friends can do to control my <i>depression</i>	0.48	0.06
Coherence			
IP34D ^R	The symptoms of my <i>depression</i> are confusing to me	0.80	0.03
IP35D ^R	My <i>depression</i> is a mystery to me	0.83	0.02
IP36D ^R	I don't understand my <i>depression</i>	0.92	0.01
IP37D ^R	My <i>depression</i> doesn't make any sense to me	0.90	0.02
IP38D	I have a clear picture or understanding of my <i>depression</i>	0.66	0.04
Cyclical timeline			
IP39D	The symptoms of my <i>depression</i> change a great deal from day to day	0.47	0.07
IP40D	My <i>depression</i> symptoms come and go in cycles	0.64	0.05
IP41D	My <i>depression</i> is very unpredictable	0.91	0.06
IP42D	I go through cycles in which my <i>depression</i> gets better and worse	0.66	0.06
Emotional response			
IP43D ^R	My <i>depression</i> does not worry me	0.81	0.03
IP44D	When I think about my <i>depression</i> I get upset	0.74	0.03
IP45D	My <i>depression</i> makes me feel angry	0.67	0.04
IP46D	My <i>depression</i> makes me feel afraid	0.65	0.04
IP47D	My <i>depression</i> makes me feel ashamed	0.71	0.04
IP48D	My <i>depression</i> makes me feel guilty	0.65	0.04

Table 5. CFA factor loadings for the IPQ-A.

Subscale		B Standardised	SE
Chronic timeline			
IP1A ^R	My <i>anxiety</i> will last a short time	0.83	0.02
IP2A	My <i>anxiety</i> is likely to be permanent rather than temporary	0.83	0.02
IP3A	My <i>anxiety</i> will last for a long time	0.90	0.02
IP4A ^R	This <i>anxiety</i> will pass quickly	0.77	0.03
IP5A	I expect to have <i>anxiety</i> for the rest of my life	0.80	0.03
IP6A ^R	My <i>anxiety</i> will improve in time	0.58	0.05
Negative consequences			
IP7A	My <i>anxiety</i> is a serious condition	0.70	0.03
IP8A	My <i>anxiety</i> has major consequences on my life	0.85	0.02
IP9A ^R	My <i>anxiety</i> does not have much effect on my life	0.77	0.03
IP10A	My <i>anxiety</i> strongly affects the way others see me	0.50	0.04
IP11A	My <i>anxiety</i> negatively impacts my relationships with others	0.55	0.04
IP12A	My <i>anxiety</i> makes it difficult for me to attend school/college/university/work	0.56	0.04
IP13A	My <i>anxiety</i> prevents me from socialising with friends and family	0.54	0.04
Positive consequences			
IP14A	My <i>anxiety</i> has made me more open-minded	0.54	0.04
IP15A	My <i>anxiety</i> has made me more resilient	0.66	0.04
IP16A	My <i>anxiety</i> has made me more self-aware	0.50	0.05
IP17A	My <i>anxiety</i> has made me more empathetic towards others	0.44	0.05
IP18A	My <i>anxiety</i> has made me who I am today	0.47	0.05
IP19A	My <i>anxiety</i> has had some positive impact on my life	0.90	0.02
IP20A ^R	My <i>anxiety</i> has not had any positive impact on my life	0.93	0.02
Personal control			
IP21A	There are things which I can do to control my <i>anxiety</i> symptoms	0.74	0.04
IP22A	What I do can determine whether my <i>anxiety</i> gets better or worse	0.63	0.04
IP23A	I have the power to influence my <i>anxiety</i>	0.75	0.03
IP24A	The journey of my <i>anxiety</i> depends on me	0.65	0.04
IP25A ^R	Nothing I do will affect my <i>anxiety</i>	0.78	0.03
IP26A ^R	My actions will have no effect on the outcome of my <i>anxiety</i>	0.75	0.03
Treatment control			
IP27A ^R	There is very little that can be done to improve my <i>anxiety</i>	0.95	0.03
IP28A	My treatment will be effective in curing my <i>anxiety</i>	0.54	0.05
IP29A	The negative effects of my <i>anxiety</i> can be prevented or avoided by treatment	0.56	0.05
IP30A	Therapy with a mental health professional can control my <i>anxiety</i>	0.40	0.05
IP31A	Medication prescribed by my doctor can control my <i>anxiety</i>	0.14	0.06
IP32A	There are things my family and friends can do to control my <i>anxiety</i>	0.18	0.06
IP33A ^R	There is nothing which can help my <i>anxiety</i>	0.71	0.03
Coherence			
IP34A ^R	The symptoms of my <i>anxiety</i> are confusing to me	0.73	0.03
IP35A ^R	My <i>anxiety</i> is a mystery to me	0.84	0.02
IP36A ^R	I don't understand my <i>anxiety</i>	0.92	0.02
IP37A ^R	My <i>anxiety</i> doesn't make any sense to me	0.90	0.02
IP38A	I have a clear picture or understanding of my <i>anxiety</i>	0.65	0.03
Cyclical timeline			
IP39A	The symptoms of my <i>anxiety</i> change a great deal from day to day	0.66	0.07
IP40A	My <i>anxiety</i> symptoms come and go in cycles	0.59	0.05
IP41A	My <i>anxiety</i> is very unpredictable	0.78	0.05
IP42A	I go through cycles in which my <i>anxiety</i> gets better and worse	0.65	0.06
Emotional response			
IP43A ^R	My <i>anxiety</i> does not worry me	0.80	0.03
IP44A	When I think about my <i>anxiety</i> I get upset	0.70	0.04
IP45A	My <i>anxiety</i> makes me feel angry	0.64	0.04
IP46A	My <i>anxiety</i> makes me feel afraid	0.70	0.04
IP47A	My <i>anxiety</i> makes me feel ashamed	0.70	0.03
IP48A	My <i>anxiety</i> makes me feel guilty	0.65	0.04

Note: ^R denotes reverse scored items.

consequences (ICC = 0.79, 95% CI 0.66–0.87, $p < .001$), positive consequences (ICC = 0.87, 95% CI 0.79–0.92, $p < .001$), personal control (ICC = 0.79, 95% CI 0.65–0.87, $p < .001$), treatment control (ICC = 0.77, 95% CI 0.62–0.86, $p < .001$), coherence (ICC = 0.77, 95% CI 0.63–0.86, $p < .001$), cyclical timeline (ICC = 0.66, 95% CI 0.42–0.78, $p < .001$), emotional response (ICC = 0.83, 95% CI 0.71–0.90, $p < .001$). The intra-class correlation coefficients for each scale ranged from 0.66 to 0.89, indicating good to excellent test – retest reliability across subscales.

Construct validity

Construct validity was assessed using the combined dataset. The inter-correlations between IPQ-D and IPQ-A subscales are presented in Tables 6 and 7, respectively. For both the IPQ-D and the IPQ-A, the direction of the correlations is consistent with theory and with previous research (Hagger & Orbell, 2003). As hypothesised, identity was correlated with chronic timeline, negative consequences, cyclical timeline, and emotional response. As expected, chronic timeline was positively correlated with negative consequences, cyclical timeline and emotional response and negatively correlated with personal control, treatment control and coherence.

To further explore the construct validity of the IPQ-D and IPQ-A subscales, correlations were inspected with measures of self-reported anxiety and depression severity (as measured by the GAD-7 and PHQ-9), psychological wellbeing (as measured by the WEMWBS), and treatment outcome expectations (as measured by the OES). These correlations were consistent with hypothesised relationships and supported the construct validity of the IPQ-R dimensions. Correlations for the IPQ-D and IPQ-A are presented in Tables 8 and 9, respectively.

Concurrent validity

To assess the concurrent validity of the IPQ-A and IPQ-D, subscales were compared to the corresponding items on the B-IPQ-A and B-IPQ-D. For the IPQ-D and IPQ-A, the correlations between the scales are presented in Tables 10 and 11, respectively. Results show that the equivalent scales of the B-IPQ-D and the IPQ-D are appropriately correlated, indicating concurrent validity for both depression measures. The intra-class correlation coefficients for each B-IPQ-D scale ranged from .63 to .86 indicating good test – retest reliability.

Table 6. Inter-correlations between IPQ-D subscales.

	1	2	3	4	5	6	7	8	9	10
1.Identity	1									
2.Chronic timeline	.36**	1								
3.Negative consequences	.39**	.53**	1							
4.Positive consequences	.05	-.19**	-.06	1						
5.Personal control	-.12*	-.34**	-.18**	.26**	1					
6.No control	.13*	.34**	.15**	-.26**	-.54**	1				
7.Treatment control	-.04	-.33**	-.15**	.07	.38**	-.30**	1			
8.Coherence	-.12*	-.34**	-.25**	.23**	.26**	-.19**	.12*	1		
9.Cyclical timeline	.12*	.24**	.19**	.02	.01	.07	-.06	-.28**	1	
10.Emotional response	.27**	.45**	.56**	-.18**	-.23**	.24**	-.12*	-.37**	.32**	1
Subscale mean $\pm$ SD	11.8 $\pm$ 6.3	3.4 $\pm$.90	3.8 $\pm$.80	3.1 $\pm$.90	3.4 $\pm$.87	2.3 $\pm$.70	3.2 $\pm$.71	3.1 $\pm$.95	3.7 $\pm$.79	3.5 $\pm$.83

** $p < 0.01$, * $p < 0.05$.

Table 7. Inter-correlations between IPQ-A subscales.

	1	2	3	4	5	6	7	8	9
1.Identity	1								
2.Chronic timeline	.32**	1							
3.Negative consequences	.437**	.54**	1						
4.Positive consequences	.11	-.04	.07	1					
5.Personal control	-.03	-.32**	-.12*	.24**	1				
6.Treatment control	-.06	-.43**	-.22*	.18**	.61**	1			
7.Coherence	-.06	-.15**	-.15*	.15**	.26**	.21**	1		
8.Cyclical timeline	.22**	.23**	.25**	.02	-.07	-.19**	-.31**	1	
9.Emotional response	.42**	.46**	.55**	-.08	-.26**	-.27**	-.26**	.29**	1
Subscale mean $\pm$ SD	13.6 $\pm$ 7.0	3.4 $\pm$.82	3.7 $\pm$.76	3.3 $\pm$.75	3.7 $\pm$.62	3.5 $\pm$.98	3.1 $\pm$.90	3.6 $\pm$.78	3.6 $\pm$.80

** $p < 0.01$, * $p < 0.05$.

For anxiety, the correlations between the scales are presented in Table 11 and show that the equivalent scales of the B-IPQ-A and the IPQ-A are appropriately correlated, indicating concurrent validity for both anxiety measures. The intra-class correlation coefficients for each B-IPQ-A scale ranged from .65 to .83 indicating good test – retest reliability.

Identity subscale

Participants in the depression group attributed an average of 12 ± 6.3 symptoms to their depression, out of a possible 32. The most common symptoms attributed to depression were negative thinking, little interest or pleasure in doing things, feeling down or hopeless, loneliness, isolation, lack of energy/feeling tired, trouble falling or staying asleep, or sleeping too much, suicidal thoughts, not taking care of myself, trouble doing normal daily tasks, poor appetite or overeating, difficulty leaving my house, self-harm, weight loss/gain and irrational thoughts; each was attributed to depression by more than 50% of participants. The least common symptoms attributed to depression were palpitations, difficulty breathing, wheeziness and sore throat; each was attributed to depression by less than 7% of participants.

Table 8. Correlations between IPQ-D, anxiety, depression, wellbeing, and expectancy.

	PHQ-9	GAD-7	WEMWBS	OES
GAD-7	.79**			
WEMWBS	-.65**	-.48**		
OES	-.27**	-.24**	.31**	
Identity	.32**	.19**	-.24**	-.12*
Chronic timeline	.47**	.31**	-.47**	-.28**
Negative consequences	.43**	.36**	-.42**	-.10
Positive consequences	-.26**	-.22**	.34**	.107
Personal control	-.25**	-.25**	.20**	.19**
No control	.30**	.28**	-.35**	-.27**
Treatment control	-.11	-.13*	.17**	.41**
Coherence	-.32**	-.22**	.26**	.10
Cyclical timeline	.21**	.20**	-.10	-.02
Emotional response	.45**	.44**	-.37**	-.12*

Note: ** $p < 0.01$, * $p < 0.05$. GAD-7, Generalised Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; WEMWBS, Warwick-Edinburgh Mental Wellbeing Scale; OES, Outcome Expectancy Scale.

Table 9. Correlations between IPQ-A, anxiety, depression, wellbeing, and expectancy.

	PHQ-9	GAD-7	WEMWBS	OES
GAD-7	.72**			
WEMWBS	-.67**	-.51**		
OES	-.26**	-.21**	.32**	
Identity	.24**	.33**	-.16**	-.03
Chronic timeline	.33**	.51**	-.39**	-.29**
Negative consequences	.31**	.45**	-.31**	-.09
Positive consequences	-.23**	-.11*	.27**	.051
Personal control	-.28**	-.20**	.32**	.25**
Treatment control	-.30**	-.29**	.41**	.45**
Coherence	-.25**	-.18**	.22**	.06
Cyclical timeline	.27**	.28**	-.18***	.06
Emotional response	.31**	.47**	-.28**	-.09

Note: ** $p < 0.01$, * $p < 0.05$. GAD-7, Generalised Anxiety Disorder-7; PHQ-9, Patient Health Questionnaire-9; WEMWBS, Warwick-Edinburgh Mental Wellbeing Scale; OES, Outcome Expectancy Scale.

Participants in the anxiety group attributed an average of 14 ± 7.0 symptoms to their anxiety, out of a possible 32. The most common symptoms attributed to anxiety were worrying a lot, irrational thoughts, panic attacks, negative thinking, restlessness, palpitations, low self-esteem, isolation, trouble falling or staying asleep, or sleeping too much, trembling/shaking and difficulty leaving my house; each was attributed to anxiety by more than 50% of participants. The least common symptoms attributed to anxiety were sore throat, sore eyes, stiff joints, and self-harm; each was attributed to anxiety by less than 18% of participants. The symptom-level frequencies for both anxiety and depression are available in Table S2.

Cause subscale

In line with recommendations in the literature to use the causal attributions subscale as an exploratory tool in the identification of groups of causal attributions specific to particular patient groups, an exploratory factor analysis was undertaken using the combined datasets (Moss-Morris et al., 2002). The most frequently endorsed causes for depression were worries (83.8%), stress (83.5%), a gradual build-up of things (83.5%), thinking style (77.7%) and loneliness/isolation (72.5%). The least frequently endorsed causes for depression were autism spectrum disorder (9.3%), disability (8.2%) and poverty (15.8%). Item frequencies for the causal attribution subscale are available in Table S3. For depression, parallel analysis on the entire sample ($n = 291$) using the 26 cause items suggested a seven-factor solution, explaining 41% of the total variance. The factor structure and factor loadings are presented in supplementary materials. The internal consistency of the causal subscales in the IPQ-D are presented in Table S4. The scales showed only low to good reliability, with Cronbach's alpha values ranging from 0.46 to 0.73.

The most frequently endorsed causes for anxiety were stress (91.9%), worries (90.8%), thinking style (85.6%), a gradual build-up of things (81.9%) and personality/character (71.5%). The least frequently endorsed causes for anxiety were autism spectrum disorder (9.6%), disability (8%) and poverty (18%). For anxiety, parallel analysis on the entire sample ($n = 312$) using the 26 cause items suggested a seven-factor solution, explaining 46% of the total variance. The internal consistency of the causal subscales in the IPQ-A are presented Table S5. The scales showed only low reliability, with Cronbach's alpha values ranging from 0.40 to 0.67.

Table 10. Correlations between the B-IPQ-D and the IPQ-D.

B-IPQ-D							
IPQ-D	Identity	Timeline	Consequences	Personal control	Treatment control	Concern	Emotional response
Identity	.34**	.34**	.39**	-.28**	-.01	.33**	.25**
Chronic timeline	.58**	.71**	.57**	-.54**	-.34**	.51**	.45**
Negative consequences	.53**	.47**	.59**	-.42**	-.08	.57**	.48**
Positive consequences	-.14*	-.002	-.15**	.24**	.001	-.17**	-.12*
Personal control	-.20**	-.29**	-.22**	.46**	.24**	-.22**	-.21**
No control	.25**	.27**	.25**	-.36**	-.29**	.26**	.24**
Treatment control	-.13*	-.27**	-.09	.27**	.52**	-.05	-.13*
Coherence	-.33**	-.28**	-.34**	.32*	.04	-.33**	-.34**
Cyclical timeline	.33**	.35**	.31**	-.20**	-.04	.35**	.41**
Emotional response	.52**	.46**	.56**	-.43**	-.10	.62**	.61**
Intra-class correlation	ICC=.79, CI	ICC=.84, CI	ICC=.86, CI	ICC=.66, CI	ICC=.72, CI	ICC=.72, CI	ICC=.79, CI
coefficients for B-IPQ-A	=.63-.87, <i>p</i>	=.73-.91, <i>p</i> <.001	=.77-.92, <i>p</i>	=.56-.74, <i>p</i>	=.53-.84, <i>p</i> <.001	=.53-.86, <i>p</i>	=.65-.88, <i>p</i>
	<.001	<.001	<.001	<.001	<.001	<.001	<.001

***p* < 0.01. **p* < 0.05. Note: cells highlighted in bold represent inter-correlation between equivalent illness perception constructs. B-IPQ uses two items assess emotional representations (concern and emotions).

Table 11. Correlations between the B-IPQ-A and the IPQ-A.

B-IPQ-A								
IPQ-A	Identity	Timeline	Consequences	Personal control	Treatment control	Concern	Emotional response	Coherence
Identity	.33**	.33**	.43**	-.011	0.10	.34**	.37**	.13*
Chronic timeline	.54**	.73**	.56**	-.42**	-.21**	.43**	.41**	-.002
Negative consequences	.56**	.40**	.64**	-.26**	0.03	.52**	.45**	0.06
Positive consequences	0.05	0.09	0.05	.18**	0.05	-.08	0.01	.27**
Personal control	-.011	-.27**	-.12*	.42**	.33**	-.15**	-.16**	.22**
Treatment control	-.15**	-.36**	-.18**	.35**	.56**	-.14*	-.21**	.25**
Coherence	-.008	-.12*	-.14*	.26**	0.06	-.18**	-.15**	.52**
Cyclical timeline	.24**	.23**	.23**	-.13*	-.08	.23**	.34**	-.15**
Emotional response	.48**	.39**	.57**	-.38**	-.08	.61**	.58**	-.006
Intra-class correlation coefficients for B-IPQ-A	ICC=.77, $p < .001$	ICC=.83, $p < .001$	ICC=.74, $p < .001$	ICC=.73, $p < .001$	ICC=.65, $p < .001$	ICC=.66, $p < .001$	ICC=.82, $p < .001$	ICC=.68, $p < .001$
		= .72-.90, $p < .001$	= .56-.84, $p < .001$	= .55-.83, $p < .001$	= .43-.79, $p < .001$	= .44-.79, $p < .001$	= .71-.89, $p < .001$	CI.47-.81, $p < .001$

Note: ** $p < 0.01$, * $p < 0.05$.

cells highlighted in bold represent inter-correlation between equivalent illness perception constructs. B-IPQ uses two items assess emotional representations (concern and emotions).

Discussion

Summary of findings

This study used a mixed methods approach to develop adapted versions of the IPQ-R for young people with anxiety and depression, the IPQ-A and IPQ-D. Preliminary qualitative work highlighted that young people's illness beliefs are highly idiosyncratic and unique to the individual, emphasising the need for modified, anxiety- and depression-specific versions of the original IPQ-R in order to capture illness representations that are specific to anxiety and depression. The adapted measures included an identity scale which was modified to assess symptoms attributed to anxiety and depression, a new "positive consequences" subscale, and the "consequences" and "cause" scales were modified to reflect the beliefs described by young people in the qualitative interviews. The results of the quantitative phase confirmed that the IPQ-A, IPQ-D, and the equivalent brief versions (the B-IPQ-A and B-IPQ-D), were valid and reliable tools for measuring mental illness representations in young people and largely conformed to the original factor structure of the IPQ-R. Both measures showed acceptable model fit, with high factor loadings, and good to excellent internal consistency, test – retest reliability across subscales and concurrent validity with mental health and wellbeing measures. The final version of the IPQ-A consisted of forty-five items across eight subscales, and the final version of the IPQ-D consisted of forty-five items across nine subscales.

For both the IPQ-A and the IPQ-D, correlations between subscales were consistent with previous research with other populations and showed good construct validity (Hagger & Orbell, 2003; Moon, Moss-Morris, Hunter, & Hughes, 2017; Taylor, O'Neill, Hughes, & Moss-Morris, 2018). For both anxiety and depression, the number of symptoms experienced was correlated with a more chronic timeline, negative consequences, cyclical timeline, and emotional response, suggesting that there is a relationship between symptom experience and perceptions of risk of recurrence and of negative life impact. As expected, chronic timeline was positively correlated with negative consequences, cyclical timeline and emotional response and negatively correlated with personal control, treatment control and coherence. To further assess the construct validity of the IPQ-A and IPQ-D subscales, correlations were inspected with anxiety and depression severity, as measured by the GAD-7 and PHQ-9, psychological wellbeing as measured by the WEMWBS, and treatment outcome expectations, as measured by the OES. These correlations were consistent with hypothesised relationships and supported the construct validity of the IPQ-R dimensions. Correlations were largely congruent with previous research (Moon, Moss-Morris, Hunter, & Hughes, 2017; Moss-Morris & Chalder, 2003; Taylor, O'Neill, Hughes, & Moss-Morris, 2018; Wittkowski, Richards, Williams, & Main, 2008). The study confirmed the interrelationships between illness representations, which were broadly consistent with the domains outlined in the original CSM. This suggests that models of illness representation share a common conceptual structure between paediatric physical and mental health conditions and that there are structural parallels in how young people perceive illness identity, cause, consequences, control/curability, and timeline.

In relation to the causal attribution subscale, results suggested that meaningful categorisations of causes exist, such as "stress and overwork", "loneliness and relational

issues”, “external social pressures”, “health conditions”, and “predisposition and experience”. It should be noted that categorisation of causes differed very slightly for anxiety and depression. For example, 72.5% of participants attributed loneliness and isolation as being a cause of their depression compared to only 59.9% for anxiety. Loneliness and isolation were clustered with other mental health problems and relationship problems for depression but clustered with only relationship problems for anxiety. This finding is consistent with the literature, where young people described the symptoms of their depression as leading to social withdrawal and isolation (Achterbergh et al., 2020). Our findings suggest that while clusters of causes may exist, factor loadings and internal consistencies were below the acceptable threshold for several subscales, meaning the causal subscales of the IPQ-A and IPQ-D should be treated with caution and further investigations into their psychometric properties are warranted. Clear categories of causal attributions have been identified for physical illnesses including psychological attributions, risk factors, immune system factors and chance factors (Moon, Moss-Morris, Hunter, & Hughes, 2017; Moss-Morris et al., 2002). However, these categories are likely less defined for anxiety and depression and individuals may attribute a variety of causes to their mental health problems, spanning multiple domains.

Limitations

While this study has important implications for research and practice, it is subject to a number of methodological limitations. Foremost, measuring the illness representations of two highly comorbid conditions in tandem may have presented respondents with difficulties in distinguishing between them when answering the questionnaire items. The majority of the sample reported a history of both anxiety and depression making it unclear the extent to which individuals were able to distinguish between the two if they were experiencing both. Future research should aim to delineate this relationship by comparing the representations of anxiety and depression using sub-samples of young people who have comorbid anxiety and depression, only anxiety and only depression to determine if illness perceptions are distinct or overlap.

In addition, the sample was recruited using a self-selected, opportunity sample of young people. It is likely that participants, who were mostly female, only represent a sub-sample of anxious and depressed youth, and the views expressed may not be representative of the views of all young people. The sample also consisted of young people who had experienced anxiety and depression in the past, and we did not require participants to have a current episode of depression or anxiety. In the anxiety group, 57% of participants scored above the clinical cut-off of 10 on the GAD-7. In the depression group, 68% of participants scored above the clinical cut-off of 10 on the PHQ-9. It is suggested that future research should investigate if differences in illness perceptions exist based on current mental health status. Depending on the findings of this work, further confirmatory validation work may be carried out which considers the role of current mental health problems on the reliability and patterns of associations of the tools. Additionally, the sample consisted of youth in the UK recruited prior to the pandemic of coronavirus disease 2019 (COVID-19). It is likely that additional factors, precipitated and perpetuated by the pandemic, may now influence young people’s cognitive and emotional representations of anxiety and depression. Future work should investigate the role of pandemic-

related perceptions as well as examine illness perceptions among participants in other samples, including youth in non-western contexts, to better understand how illness perceptions may vary across cultures and societal changes. Such work could help us understand the extent to which western taxonomies of mental illness are perceived as important, concerning, and culturally relevant among youth around the world (Wasil, Gillespie, Park, & DeRubeis, 2021; Wasil, Venturo-Conerly, Gillespie, Osborn, & Weisz, 2021).

Finally, as with all cross-sectional research, there is a need for longitudinal studies to determine if and how illness perceptions change over time and how illness perceptions are related to health-related outcomes such as coping, outcome expectancy and mental health. It is also of interest to consider the moderators of change in this process such as treatment type and experience of treatment. Using research designs that capture the dynamic processes in the CSM, such as cross-lagged panel and intervention designs, it may be possible to model temporal change in illness representations. This may include investigating the extent to which illness perceptions are associated with important treatment-related outcomes, including help-seeking, treatment engagement, coping, self-management, symptom change and outcome expectations among youth with anxiety and depression across time and before, during and after treatment.

Implications for research and practice

This study has generated four reliable and valid tools which have several potential uses across research and practice settings. The brief versions (B-IPQ-A and B-IPQ-D) have the added benefit of providing simple and rapid assessment of illness perceptions which may be particularly useful in clinical settings. The development of these measures represents an important step in the field of child and adolescent mental health by providing the opportunity for the reliable assessment of young people's conceptualisations and cognitive representations of their anxiety and depression. The tools developed as part of this study provide researchers and clinicians with a means to track changes in both cognitive and emotional representations, which can be targets for psychological interventions designed to improve clinical outcomes. This may include understanding a person's beliefs about what caused their mental health problems and whether they believe their symptoms are controllable with treatment to ensure that this aligns with the clinician's understanding and what is plausible and achievable with their therapeutic input. In addition, these measures will aid in the study of self-management strategies used by individuals outside of treatment i.e. by improving our understanding of what people deem to be controllable without treatment and helping to develop more adaptive beliefs about controllability.

It may be that clinicians are able to benefit from incorporating a young person's illness model, including their perceptions of identity, cause, timeline to recovery, consequences, and personal and treatment control, into clinical case formulation. By incorporating illness belief models into clinical case formulation, it may be possible to improve patient-clinician-family relationships through increasing the congruence of illness perceptions. In turn, increased congruence between the belief models of young people, families, clinicians, and the reality or true nature of likely treatment outcomes may improve treatment outcomes or clinical improvement in practice. Discrepancies in illness perceptions between patients and their families have been related to poorer outcomes in individuals with psychosis and their family members (Kuipers et al., 2007). For example, unmet expectations

about treatment can lead to poorer engagement and outcomes in therapy (Watsford & Rickwood, 2013). The phenomenon that occurs when expectations influence outcomes is referred to as an expectancy effect (Tambling, 2012). Several studies have examined the expectancy effect on a number of important treatment-related outcomes, such as change in symptoms (Constantino, Arnkoff, Glass, Ametrano, & Smith, 2011), premature termination and therapeutic alliance (Constantino, Arnow, Blasey, & Agras, 2005). Although research suggests that patients' outcome expectations are associated with several post-treatment outcomes, there has been limited research on the specific mechanisms through which they operate (Constantino, 2012). Applying the CSM within child and adolescent mental health research and clinical practice has the potential to open up a range of intervention possibilities as it prioritises the individual's understanding and emotional response to their illness above other factors such as the clinicians' understanding and the supposed objective illness severity and trajectory.

Conclusion

This is the first study to undertake a multi-phase, mixed methods approach to developing and validating anxiety- and depression-specific tools for measuring illness perceptions in young people. Overall, results suggest that the IPQ-A, IPQ-D, B-IPQ-A and B-IPQ-D are valid and reliable tools for measuring illness perceptions in young people. This study suggests that young people's beliefs about anxiety and depression are multifactorial and highly idiosyncratic yet can be organised according to the underlying dimensions of Leventhal's CSM, which allow them to be reliably measured and classified as latent constructs.

Abbreviations

Revised Illness Perceptions Questionnaire (IPQ-R); Illness Perception Questionnaire – Anxiety (IPQ-A); Illness Perception Questionnaire – Depression (IPQ-D); Brief Illness Perceptions Questionnaire (B-IPQ); Brief Illness Perception Questionnaire – Anxiety (B-IPQ-A); Brief Illness Perception Questionnaire – Depression (B-IPQ-D)

Acknowledgments

We would like to thank the young people who gave their time to participate in this research and who shared their experiences with us. We are also grateful to all those who helped with recruitment, including Beth Ingram, Nick Morgan, Karima Abdou, Molly Gilbert, Katie Brown, Noa Metta and Aimee Pathak. Finally, we would like to thank Professor Steve Pilling and Professor John Weinman for their helpful feedback on an earlier version of this paper.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This research was funded through an IMPACT scholarship awarded to Holly Bear by University College London and the Anna Freud National Centre for Children and Families (AFNCCF) for the completion of a three-year PhD project (2016–2019). This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

ORCID

Holly Alice Bear  <http://orcid.org/0000-0002-6737-6120>

Julian Edbrooke-Childs  <http://orcid.org/0000-0003-0401-4058>

Miranda Wolpert  <http://orcid.org/0000-0002-7463-4976>

Data availability statement

Participant consent to data sharing in a public repository or upon request was not obtained for this research, so supporting data are not available.

References

- Achterbergh, L., Pitman, A., Birken, M., Pearce, E., Sno, H., & Johnson, S. (2020). The experience of loneliness among young people with depression: A qualitative meta-synthesis of the literature. *BMC Psychiatry*, 20(1), 1–23. doi:10.1186/s12888-020-02818-3
- Aujla, N., Vedhara, K., Walker, M., & Sprigg, N. (2020). Evaluating a stroke-specific version of the illness perception questionnaire–revised, using the think-aloud method. *Journal of Health Psychology*, 25(12), 1989–2005. doi:10.1177/1359105318781942
- Baines, T., & Wittkowski, A. (2013). A systematic review of the literature exploring illness perceptions in mental health utilising the self-regulation model. *Journal of Clinical Psychology in Medical Settings*, 20(3), 263–274. doi:10.1007/s10880-012-9337-9
- Bartholomew, D. J., & Cattell, R. B. (1980). The scientific use of factor analysis in behavioural and life sciences. In *International Statistical Review/Revue Internationale de Statistique* (Vol. 48, Issue 2). Springer Science & Business Media. 10.2307/1403162
- Bear, H. A., Edbrooke-Childs, J., Norton, S., Krause, K. R., & Wolpert, M. (2020). Systematic review and meta-analysis: Outcomes of routine specialist mental health care for young people with depression and/or anxiety. *Journal of the American Academy of Child and Adolescent Psychiatry*, 59(7), 810–841. doi:10.1016/j.jaac.2019.12.002
- Bear, H. A., Krause, K. R., Edbrooke-Childs, J., & Wolpert, M. (2021). Understanding the illness representations of young people with anxiety and depression: A qualitative study. *In press Psychology & Psychotherapy: Theory, Research & Practice*, 94(4), 1036–1058. doi:10.1111/papt.12345
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60(6), 631–637. doi:10.1016/j.jpsychores.2005.10.020
- Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the brief illness perception questionnaire. *Psychology & Health*, 30(11), 1361–1385. doi:10.1080/08870446.2015.1070851
- Bucks, R. S., Hawkins, K., Skinner, T. C., Horn, S., Seddon, P., & Horne, R. (2009). Adherence to treatment in adolescents with cystic fibrosis: The role of illness perceptions and treatment beliefs. *Journal of Pediatric Psychology*, 34(8), 893–902. doi:10.1093/jpepsy/jsn135
- Cameron, I. M., Crawford, J. R., Lawton, K., & Reid, I. C. (2008). Psychometric comparison of PHQ-9 and HADS for measuring depression severity in primary care. *British Journal of General Practice*, 58(546), 32–36. doi:10.3399/bjgp08X263794

- Clarke, A., Friede, T., Putz, R., Ashdown, J., Martin, S. . . Stewart-Brown, S. (2011). Warwick-Edinburgh Mental Well-being Scale (WEMWBS): Validated for teenage school students in England and Scotland. A mixed methods assessment. *BMC Public Health*, 11(1), 1–9. doi:10.1186/1471-2458-11-487
- Constantino, M. J. (2012). Believing is seeing: An evolving research program on patients' psychotherapy expectations. *Psychotherapy Research*, 22(2), 127–138. doi:10.1080/10503307.2012.663512
- Constantino, M. J., Arnkoff, D. B., Glass, C. R., Ametrano, R. M., & Smith, J. A. Z. (2011). Expectations. *Journal of Clinical Psychology*, 67(2), 184–192. doi:10.1002/jclp.20754
- Constantino, M. J., Arnow, B. A., Blasey, C., & Agras, W. S. (2005). The association between patient characteristics and the therapeutic alliance in cognitive-behavioral and interpersonal therapy for bulimia nervosa. *Journal of Consulting and Clinical Psychology*, 73(2), 203–211. doi:10.1037/0022-006X.73.2.203
- de Haan, A. M., Boon, A. E., de Jong, J. T. V. M., Hoeve, M., & Vermeiren, R. R. J. M. (2013). A meta-analytic review on treatment dropout in child and adolescent outpatient mental health care. *Clinical Psychology Review*, 33(5), 698–711. doi:10.1016/j.cpr.2013.04.005
- Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, 79(6), 506–513. doi:10.1016/j.jpsychores.2015.10.006
- Ebesutani, C., Reise, S. P., Chorpita, B. F., Ale, C., Regan, J. . . Weisz, J. R. (2012). The revised child anxiety and depression scale-short version: Scale reduction via exploratory bifactor modeling of the broad anxiety factor. *Psychological Assessment*, 24(4), 833–845. doi:10.1037/a0027283
- Edbrooke-Childs, J., Wolpert, M., Zamperoni, V., Napoleone, E., & Bear, H. (2018). Evaluation of reliable improvement rates in depression and anxiety at the end of treatment in adolescents. *BJPsych Open*, 4(4), 250–255. doi:10.1192/bjo.2018.31
- Fergusson, D. M., Boden, J. M., & Horwood, L. J. (2007). Recurrence of major depression in adolescence and early adulthood, and later mental health, educational and economic outcomes. *British Journal of Psychiatry*, 191(OCT), 335–342. doi:10.1192/bjp.bp.107.036079
- Fonseca, M., Missotten, P., Etienne, A.-M., Dupuis, G., Lemétayer, F., & Spitz, E. (2010). The influence of children's and parents' illness perceptions on paediatrics cancer patients' quality of life. *Psychology and Health*, 25(7 Supp1), 126.
- Ford, J. K., MacCallum, R. C., & Tait, M. (1986). the application of exploratory factor analysis in applied psychology: A critical review and analysis. *Personnel Psychology*, 39(2), 291–314. doi:10.1111/j.1744-6570.1986.tb00583.x
- French, D. P., & Weinman, J. (2008). Current issues and new directions in psychology and health: "Assessing illness perceptions: Beyond the IPQ. *Psychology and Health*, 23(1), 5–9. doi:10.1080/08870440701616714
- Ghio, D., Thomson, W., Calam, R., Ulph, F., Baildam, E. M., Hyrich, K., & Cordingley, L. (2018). The prioritization of symptom beliefs over illness beliefs: The development and validation of the pain perception questionnaire for young people. *British Journal of Health Psychology*, 23(1), 68–87. doi:10.1111/bjhp.12275
- Goodman, R., Ford, T., Simmons, H., Gatward, R., & Meltzer, H. (2003). Using the Strengths and Difficulties Questionnaire (SDQ) to screen for child psychiatric disorders in a community sample. *International Review of Psychiatry*, 15(1–2), 166–172. doi:10.1080/0954026021000046128
- Gorsuch, R. L. (1983) *Factor analysis* (2nd ed. ed). Hillside, NJ: Lawrence Erlbaum Associates. *Hillsdale, NJ*.
- Gray, S. E., & Rutter, D. R. (2007). Illness representations in young people with chronic fatigue syndrome. *Psychology and Health*, 22(2), 159–174. doi:10.1080/14768320600774595
- Hagger, M. S., Koch, S., Chatzisarantis, N. L. D., & Orbell, S. (2017). The common sense model of self-regulation: Meta-analysis and test of a process model. *Psychological Bulletin*, 143(11), 1117–1154. doi:10.1037/bul0000118
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), 141–184. doi:10.1080/088704403100081321
- Hagger, M. S., & Orbell, S. (2021). The common sense model of illness self-regulation: A conceptual review and proposed extended model. *Health Psychology Review*. doi:10.1080/17437199.2021.1878050

- Hayton, J. C., Allen, D. G., & Scarpello, V. (2004). Factor retention decisions in exploratory factor analysis: a tutorial on parallel analysis. *Organizational Research Methods*, 7(2), 191–205. doi:[10.1177/1094428104263675](https://doi.org/10.1177/1094428104263675)
- Hu, L., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, 6(1), 1–55. doi:[10.1080/10705519909540118](https://doi.org/10.1080/10705519909540118)
- James, A. C., Reardon, T., Soler, A., James, G., & Creswell, C. (2020). Cognitive behavioural therapy for anxiety disorders in children and adolescents. *Cochrane Database of Systematic Reviews*, 2020(11), 11. <https://doi.org/10.1002/14651858.CD013162.pub2>
- Koo, T. K., & Li, M. Y. (2016). A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *Journal of Chiropractic Medicine*, 15(2), 155–163. doi:[10.1016/j.jcm.2016.02.012](https://doi.org/10.1016/j.jcm.2016.02.012)
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16(9), 606–613. doi:[10.1046/j.1525-1497.2001.016009606.x](https://doi.org/10.1046/j.1525-1497.2001.016009606.x)
- Kroenke, K., Spitzer, R. L., Williams, J. B. W., Monahan, P. O., & Löwe, B. (2007). Anxiety disorders in primary care: Prevalence, impairment, comorbidity, and detection. *Annals of Internal Medicine*, 146(5), 317–325. doi:[10.7326/0003-4819-146-5-200703060-00004](https://doi.org/10.7326/0003-4819-146-5-200703060-00004)
- Kuipers, E., Watson, P., Onwumere, J., Bebbington, P., Dunn, G., . . . Garety, P. (2007). Discrepant illness perceptions, affect and expressed emotion in people with psychosis and their carers. *Social Psychiatry and Psychiatric Epidemiology*, 42(4), 277–283. doi:[10.1007/s00127-007-0165-4](https://doi.org/10.1007/s00127-007-0165-4)
- Kyngäs, H. A. (2007). Predictors of good adherence of adolescents with diabetes (insulin-dependent diabetes mellitus). *Chronic Illness*, 3(1), 20–28. doi:[10.1177/1742395307079191](https://doi.org/10.1177/1742395307079191)
- Law, G. U., Tolgyesi, C. S., & Howard, R. A. (2014). Illness beliefs and self-management in children and young people with chronic illness: A systematic review. *Health Psychology Review*, 8(3), 362–380. doi:[10.1080/17437199.2012.747123](https://doi.org/10.1080/17437199.2012.747123)
- Leventhal, H., Meyer, D., Nerenz, D., & Rachman, S. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology*, 2, 7–30.
- McAndrew, L. M., Martin, J. L., Friedlander, M. L., Shaffer, K., Breland, J. Y., Slotkin, S., & Leventhal, H. (2018). The common sense of counseling psychology: Introducing the common-sense model of self-regulation. *Counselling Psychology Quarterly*, 31(4), 497–512. doi:[10.1080/09515070.2017.1336076](https://doi.org/10.1080/09515070.2017.1336076)
- McCorry, N. K., Scullion, L., McMurray, C. M., Houghton, R., & Dempster, M. (2013). Content validity of the illness perceptions questionnaire - revised among people with type 2 diabetes: A think-aloud study. *Psychology and Health*, 28(6), 675–685. doi:[10.1080/08870446.2012.746690](https://doi.org/10.1080/08870446.2012.746690)
- Moon, Z., Moss-Morris, R., Hunter, M. S., & Hughes, L. D. (2017). Measuring illness representations in breast cancer survivors (BCS) prescribed tamoxifen: Modification and validation of the Revised Illness Perceptions Questionnaire (IPQ-BCS). *Psychology and Health*, 32(4), 439–458. doi:[10.1080/08870446.2016.1275629](https://doi.org/10.1080/08870446.2016.1275629)
- Moss-Morris, R., & Chalder, T. (2003). Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, 55(4), 305–308. doi:[10.1016/S0022-3999\(03\)00013-8](https://doi.org/10.1016/S0022-3999(03)00013-8)
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health*, 17(1), 1–16. doi:[10.1080/08870440290001494](https://doi.org/10.1080/08870440290001494)
- Mundfrom, D. J., Shaw, D. G., & Ke, T. L. (2005). Minimum sample size recommendations for conducting factor analyses. *International Journal of Testing*, 5(2), 159–168. doi:[10.1207/s15327574ijtt0502_4](https://doi.org/10.1207/s15327574ijtt0502_4)
- Munson, M. R., Floersch, J. E., & Townsend, L. (2009). Attitudes toward mental health services and illness perceptions among adolescents with mood disorders. *Child & Adolescent Social Work Journal*, 26(5), 447–466. doi:[10.1007/s10560-009-0174-0](https://doi.org/10.1007/s10560-009-0174-0)
- Munson, M. R., Floersch, J. E., & Townsend, L. (2010). Are health beliefs related to adherence among adolescents with mood disorders? *Administration and Policy in Mental Health and Mental Health Services Research*, 37(5), 408–416. doi:[10.1007/s10488-009-0255-6](https://doi.org/10.1007/s10488-009-0255-6)

- Ogrodniczuk, J. S., & Sochting, I. (2010). *Outcome expectancy scale*. Vancouver, BC, Canada: The University of British Columbia.
- Pedley, R., Bee, P., Wearden, A., Berry, K., & Eisenbarth, H. (2019). Illness perceptions in people with obsessive-compulsive disorder; a qualitative study. *PLoS ONE*, 14(3), e0213495. doi:10.1371/journal.pone.0213495
- Pedley, R., Berry, K., Bee, P., Gellatly, J., & Wearden, A. (2019). Testing the psychometric properties of the illness perceptions questionnaire for OCD (IPQ-O). *BMC Psychiatry*, 19(1), 1–19. doi:10.1186/s12888-019-2195-3
- Polanczyk, G. V., Salum, G. A., Sugaya, L. S., Caye, A., & Rohde, L. A. (2015). Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 56(3), 345–365. doi:10.1111/jcpp.12381
- Reardon, T., Harvey, K., & Creswell, C. (2020). Seeking and accessing professional support for child anxiety in a community sample. *European Child and Adolescent Psychiatry*, 29(5), 649–664. doi:10.1007/s00787-019-01388-4
- Richardson, L. P., McCauley, E., Grossman, D. C., McCarty, C. A., Richards, J. . . . Katon, W. (2010). Evaluation of the patient health questionnaire-9 item for detecting major depression among adolescents. *Pediatrics*, 126(6), 1117–1123. doi:10.1542/peds.2010-0852
- Richardson, E. M., Schüz, N., Sanderson, K., Scott, J. L., & Schüz, B. (2017). Illness representations, coping, and illness outcomes in people with cancer: A systematic review and meta-analysis. *Psycho-Oncology*, 26(6), 724–737. doi:10.1002/pon.4213
- Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine*, 166(10), 1092–1097. doi:10.1001/archinte.166.10.1092
- Swan, A. J., & Kendall, P. C. (2016). Fear and missing out: Youth anxiety and functional outcomes. *Clinical Psychology: Science & Practice*, 23(4), 417–435. doi:10.1111/cpsp.12169
- Tambling, R. B. (2012). A literature review of therapeutic expectancy effects. *Contemporary Family Therapy*, 34(3), 402–415. doi:10.1007/s10591-012-9201-y
- Taylor, E. C., O'Neill, M., Hughes, L. D., & Moss-Morris, R. (2018). An illness-specific version of the Revised Illness Perception Questionnaire in patients with atrial fibrillation (AF IPQ-R): Unpacking beliefs about treatment control, personal control and symptom triggers. *Psychology and Health*, 33(4), 499–517. doi:10.1080/08870446.2017.1373113
- Teh, W. L., Samari, E., Cetty, L., Kumarasan, R., Devi, F. . . . Subramaniam, M. (2021). A reduced state of being: The role of culture in illness perceptions of young adults diagnosed with depressive disorders in singapore. *PLoS ONE*, 16(6 June), e0252913. doi:10.1371/journal.pone.0252913
- Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S. . . . Stewart-Brown, S. (2007). The Warwick-Edinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes*, 5(1), 63. doi:10.1186/1477-7525-5-63
- Terrasson, J., Terrade, F., Somat, A., Adamiak, S. N., Guitteny, M. A., & de Kerdanet, M. (2018). Association between quality of life of adolescents with type 1 diabetes and parents' illness perception as evaluated by adolescents. *Psychology, Health and Medicine*, 23(3), 347–359. doi:10.1080/13548506.2017.1348608
- Tsai, M., Ogrodniczuk, J. S., Sochting, I., & Mirmiran, J. (2014). Forecasting success: Patients' expectations for improvement and their relations to baseline, process and outcome variables in group cognitive-behavioural therapy for depression. *Clinical Psychology & Psychotherapy*, 21(2), 97–107. doi:10.1002/cpp.1831
- Van Oort, L., Schröder, C., & French, D. P. (2011). What do people think about when they answer the brief illness perception questionnaire? A 'think-aloud' study. *British Journal of Health Psychology*, 16(2), 231–245. doi:10.1348/135910710X500819
- Van Someren, M. W., Barnard, Y. F., & Sandberg, J. A. C. (1994). *The think aloud method: A practical approach to modelling cognitive* (Vol. 11, pp. 29–41). London: Academic Press.
- Wasil, A. R., Gillespie, S., Park, S. J., & DeRubeis, R. J. (2021). Not all depressive symptoms matter equally: Ratings of the relative importance of nine DSM symptoms in a sample of Indian adolescents. *PsyArxiv*.

- Wasil, A. R., Venturo-Conerly, K. E., Gillespie, S., Osborn, T. L., & Weisz, J. R. (2021). In their own words: Using open-ended assessment to identify culturally relevant concerns among Kenyan adolescents. *Culture, Medicine and Psychiatry*, 46(2), 297–321. doi:[10.1007/s11013-020-09706-1](https://doi.org/10.1007/s11013-020-09706-1)
- Watsford, C., & Rickwood, D. (2013). Disconfirmed expectations of therapy and young people's clinical outcome, help-seeking intentions, and mental health service use. *Advances in Mental Health*, 12(1), 75–86. doi:[10.5172/jamh.2013.12.1.75](https://doi.org/10.5172/jamh.2013.12.1.75)
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11(3), 431–445. doi:[10.1080/08870449608400270](https://doi.org/10.1080/08870449608400270)
- Wittkowski, A., Richards, H. L., Williams, J., & Main, C. J. (2008). Factor analysis of the revised illness perception questionnaire in adults with atopic dermatitis. *Psychology, Health and Medicine*, 13(3), 346–359. doi:[10.1080/13548500701487697](https://doi.org/10.1080/13548500701487697)
- Zugelj, U., Zupancic, M., Komidar, L., Kenda, R., Varda, N. M., & Gregoric, A. (2010). Self-reported adherence behavior in adolescent hypertensive patients: The role of illness representations and personality. *Journal of Pediatric Psychology*, 35(9), 1049–1060. doi:[10.1093/jpepsy/jsq027](https://doi.org/10.1093/jpepsy/jsq027)