Development of a Self-help Digital Intervention for Young People with Tourette Syndrome

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Abstract

Young people (YP) with Tourette Syndrome (TS) and Tic Disorders (TD) experience difficulties with psychological wellbeing and reduced quality of life (QoL). Nonetheless, accessing healthcare support for these YP is difficult due to barriers including a lack of healthcare professionals, low healthcare coverage and reduced help-seeking behaviour of YP. Current psychological interventions for people with tics do not show the cost-savings or effectiveness to substantiate large-scale implementation. Interventions delivered digitally, utilising a self-help approach may overcome these limitations and have been shown to be effective in YP with mental health difficulties. Furthermore, the development of a wellbeing intervention using person, evidence and theory-based approaches could promote adherence and engagement to such an intervention.

The current research aims to develop a digital self-help intervention to support and promote psychological wellbeing in YP with TDs. A person-based approach (PBA) was applied throughout. The research included a systematic review to assess similar interventions that were available for YP with TDs and YP with reduced psychological wellbeing. Qualitative research methods were used to interview YP with TDs, professionals who work with YP with TDs, and focus groups with parents and YP with TDs to explore what would be needed from such an intervention. Thematic analysis was used to code data inductively and a hybrid thematic analytical approach was used to apply deductive analysis to the data. The findings from across the methods were integrated to develop guiding principles and a logic model to support the future development of the intervention.

The systematic review identified 985 studies, leaving 11 to be included in the review. Across the qualitative methods, 16 professionals, 51 YP and 35 parents or caregivers were recruited for interviews or focus groups. A digital health intervention (DHI) that would be suitably applied to YP with tics was not identified in the literature, and it was concluded that such an intervention would be desired by YP and thought useful by professionals. Many features and functions of the intervention were highlighted across participant groups, and the most important features were prioritised. These were combined with theory to develop guiding principles and a logic model.

The research outputs include the development of guiding principles and a logic model, informed using the PBA, behaviour change theory and evidence. These findings will

support future developers in creating an engaging and effective intervention for YP with tics, to promote and support their wellbeing.

Collaborations and Contributions to thesis

The original proposal for this studentship was developed by Dr Elena Nixon (EN) and Professor Georgina Jackson (GJ) as a collaboration with Tourette's Action, a charity for people with TDs in England and Wales and was funded by the Economic and Social Science Research Council (ESRC) Doctoral Training Collaborative PhD Scheme (grant number ES/J500100/1). A partnership with MindTech, an NIHR MedTech Co-operative, focusing on the development, adoption, and adaptation of technologies for mental health care with special interests in depression and anxiety and neurodevelopmental disorders (such as TS and ADHD), was also formed to support the intervention development.

The studies presented were designed by the author who was also responsible for obtaining ethics, participant recruitment, data collection, analysis and interpretation, with support and guidance from her supervisors (EN and GJ). Study One (Chapter 2) was assisted by Dr Bethan Davies (EBD), who performed full paper screening for inter-rater agreement and EN and GJ who screened 20% of full text articles to check for agreement and supported in any incongruities for screening and risk of bias. Study Three (Chapter 6) was supported with data collection and analysis assistance from Ellen Simpson, a third-year BMedSci student, supervised by EN. MindTech supported the development of the research presented in Chapter 7 suggesting possible methodology. This study (Chapter 7) was supported with recruitment, data collection and analysis assistance from Madeleine Roche, an MSc student, co-supervised by the author and EN.

Abbreviations

(-) - Missing Data

ACS-Short - Adolescent Coping Scale

ADHD – Attention Deficit Hyperactivity Disorder

ADIS-C - Anxiety Disorders Interview Schedule For Children

ASD – Autism Spectrum Disorder

ASMR - Autonomous Sensory Meridian Response

C&A-GTS-QOL – Gilles de la Tourette Syndrome–Specific Quality of Life scale

CASQ-R - The Revised Children's Attributional Style Questionnaire

CBA - Controlled Before After/ Pre-Post Studies

CBIT – Comprehensive Behavioural Intervention for Tics

CBMT - cognitive bias modification training

CBT - Cognitive Behavioural Therapy

cCBT - Computerised CBT

CDRS-R - The Children's Depression Rating Scale-Revised

CES-D - Centre For Epidemiologic Studies Depression Scale

CGI - Clinical Global Impression Scale

CNSIE - Children's Nowicki- Strickland Internal-External Control Scale Short

CRSQ - Child Response Styles Questionnaire

DASS - Depression Anxiety Stress Scale

DHI – Digital Health Interventions

DSM-5 – Fifth Diagnostic and Statistical Manual of Mental Disorders

EQ-5D-Y - Euroqol

ERP – Exposure and Response Prevention

ESA - Emotional Self Awareness Scale

ESRC – Economic and Social Science Research Council

FU - Follow-Up

GP - General Practitioner

GSE-Norwegian - Norwegian Version Of The General Self-Efficacy Scale

HRT - Habit Reversal Therapy

HUI-2 - Health Utility Index Mark 2

IAC - Interpersonal Activities Checklist

ICD-11 - International Statistical Classification Of Diseases and Related Health Problems 11th Revision
IPR - Index Of Peer Relationship
JSE - Judgment Of Social–Emotional Condition
K10 - The Kazdin Hopelessness Scale For Children
LWT – Living With Tics
MBSR - Mindfulness Based Stress Reduction
MCT - Minimal Contact Therapy
MFQ - Mood And Feelings Questionnaire
MHL - Mental Health Literacy
N - Number
NGC - Non-guidance Contact
NICE - National Institute for Health and Care Excellence
PBA - Person Based Approach
PC - Personal Computer
PHQ-A - Patient Health Questionnaire–Adolescent
Post - Post-Test
PQ-LES-Q - Paediatric Quality Of Life Enjoyment And Satisfaction Questionnaire
Pre - Pre-Test
PSA - Predominately Self-Administered
QoL - Quality of Life
RCADS - Revised Child Anxiety and Depression Scale
RCT - Randomised Controlled Trials
RSES - The Rosenberg Self Esteem Scale
SA – Self-Administered
SAEQ - Satisfaction And Enjoyment Questionnaire
SCARED - Screening For Child Anxiety Related Emotional Disorders
SCAS - Spence Children’s Anxiety Scale
SPD - Sensory Processing Disorder
STAI - Spielberger Test Anxiety Inventory
Stiat - Single Target Implicit Association Test
TD - Tic Disorder
TODS-PR - Tourette’s Disorder Scale – Parent Rated

TS - Tourette Syndrome

Web - Internet Delivered

WL - Waitlist

YP – Young People

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Overview of Thesis

The aim of this study was to develop a digital self-help intervention for YP with tics using a person, evidence, and theory-based approach to overcome barriers to accessing healthcare and challenges of DHIs. The intervention sought to improve and promote psychological wellbeing in this population.

Chapter One gives an overview of the literature pertaining to TS and TDs, highlighting the difficulties of living with a TD and the impact on psychological wellbeing and QoL. The potential for DHIs in overcoming barriers to support and their effectiveness for mental health are presented, building the rationale for DHIs with YP with tics for wellbeing.

Chapter Two includes a systematic review of the literature to identify other self-help DHIs for wellbeing and YP. The findings were used to capture features of interventions that might be relevant to the current project. An overview of the methods and measures used throughout the research are presented in **Chapter Three**.

Interviews were carried out in **Chapter Four** with YP with tics and **Chapter Five** with professionals who work with YP. These chapters aimed to explore wellbeing in YP with tics, and to assess whether a wellbeing intervention was needed for YP, and if so, what it would include.

Chapter Six highlights the findings from focus groups with YP with tics and their caregivers, which developed ideas around what features would be required to support wellbeing in the intervention and began to consider functions of the intervention. The findings from the previous empirical chapters were integrated at the start of **Chapter Seven**, to be able to consider which features had been supported by which studies. This led to the final focus groups with YP and their caregivers to prioritise the proposed features in terms of importance and need.

The concluding chapter, **Chapter Eight**, included the development of guiding principles and a logic model based on the findings from the study. These outputs enable the inclusion of theory, person, and evidence to be incorporated, to support developers in the future design of the intervention ensuring it achieves its key objectives. The overall limitations, strengths and future directions of the research are also presented.

Aims of PhD

This PhD aims to explore whether a self-help digital intervention to improve psychological wellbeing for YP with TS is needed, and if so whether it would be useful and what it would feature. Initially, a systematic review of the literature was required to assess the currently available digital self-help interventions for psychological wellbeing for YP with and without TDs, to inform the development of this tool. Qualitative exploration of the opinions of professionals who work with YP with tics and YP themselves through interviews was undertaken to assess whether an intervention was needed and desired for YP’s wellbeing. Further qualitative research using focus groups with YP and their caregivers were used to explore whether an intervention would be acceptable, what features would be desired and how an intervention would function. Additional focus groups with YP and caregivers were required to prioritise the most important components for development. At the end of the study, the use of guiding principles and a logic model were needed to identify the core features and functions of the intervention to support and promote the psychological wellbeing in YP with tics for the next stage of development.

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Chapter 1 – Introduction

Classification of Neurodevelopmental Disorders

A neurodevelopmental disorder (NDD) is classified by the diagnostic and statistical manual of mental disorders – fifth version (DSM-5) as conditions with onset during the developmental period, which can cause functional impairment in personal, social, academic and occupational areas of life (American Psychiatric Association, 2013). The DSM-5 notes the following as neurodevelopmental conditions: intellectual disability, communication disorders, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), neurodevelopmental motor disorders and specific learning disorder. Within the international statistical classification of diseases and related health problems 11th revision (ICD-11), NDDs are classified under the category: 'Mental, behavioural or neurodevelopmental disorders.' These are described as syndromes which cause clinically significant disturbance in an individuals' cognition, emotional regulation and behaviour, caused by psychological, biological or developmental dysfunction, and similarly to DSM-5, these may cause distress and impairment in personal, family, social, educational and occupational areas of functioning (World Health Organization, 2019a). The ICD-11 includes similar conditions to the DSM-5 within the neurodevelopmental domain: intellectual development disorders, developmental language, and speech disorders, ASD, ADHD, developmental motor coordination disorders, and developmental learning disorder, but also include the disorders:stereotyped movement, primary tics and tics, secondary neurodevelopmental disorders, other specified NDD and NDD unspecified. Primary tics or TDs sit within both neurodevelopmental disorders and movement disorders, within the parent node: 'Diseases of the nervous system'. This reflects both the neurological and psychological basis of TD, suggesting 'the crossroads of neurology and psychiatry' in the pathogenesis of TD (Woods & Thomsen, 2014, pp. S54).

Tic Disorders and Tourette Syndrome

Diagnostic Criteria

TS is defined by the DSM-5 and ICD-11 as the presence of chronic motor and vocal tics for over a year. The classification systems for the four subtypes of TD are outlined in Table 1 with both classifications systems presenting similar symptomatology for TS and TDs.

ICD-11	DSM-5
Parent node: Mental, behavioural or neurodevelopmental disorders Neurodevelopmental Disorders Tic Disorders Primary tics or tic disorders & Diseases of the nervous system Movement Disorders Tic Disorders Primary tics or tic disorders	Parent node: Neurodevelopmental disorder Tic Disorders
8A05.00 Tourette syndrome	307.23 Tourette's Disorder
8A05.01 Chronic motor tic disorder 8A05.02 Chronic phonic tic disorder	307.22 Persistent (chronic) Motor or Vocal tic Disorder Specify if: With motor tics only With vocal tics only
8A05.03 Chronic motor tic disorder	307.21 Provisional Tic Disorder

Table 1 The diagnostic criteria from the ICD-11 and DSM-5 for TDs, which shows where TDs are placed within the hierarchical structure of each classification and the different conditions associated with TDs.

Prevalence

Although once thought rare, TS is now considered as common. Recent studies have proposed rates of 8 children (referring to those under the age of 18), 3 YP (YP; meaning those under the age of 25; Knight et al., 2012), and 0.6 adults per 1000 people in the population (Yang et al., 2016). The difference between findings for adult and child samples highlight the improvement in tic-related symptoms as children grow older (Bloch, Peterson, et al., 2006; Bloch & Leckman, 2009; Levine et al., 2019; Novotny et al., 2018). Longitudinal studies show significant improvement in tic-related symptoms into adulthood (not related to medication use), finding most people's tics improve with time, a third of people are tic-free and less than 5% have worse tics into adulthood than in their childhood (Bloch, Peterson, et al., 2006; Bloch, Sukhodolsky, et al., 2006; Pappert et al., 2003). Across studies, a predominance of male to female prevalence of around 3:1 or 4:1 has been reported (Robertson, 2015). Other than under-reporting of TS in African-American and sub-Sahara African populations, which could be due to low-income or poverty affecting help-seeking, TS has been reported across most cultures and classes (Robertson, 2008a).

Comorbidities and Coexisting Psychopathologies

‘Pure TS’, a diagnosis of TS without any comorbid condition, is rarer than ‘complicated TS’, noted in clinical, non-clinical, and community settings (Robertson et al., 2017). A comorbid condition is more common in the primary condition and has clinical or genetic similarities to the primary condition (Robertson et al., 2017). Rates of comorbid conditions have reached up to 90% in clinical samples of YP with at least one cooccurring diagnosis (Hirschtritt et al., 2015; Robertson, 1989; Sambrani et al., 2016) supported in international investigations (Freeman et al., 2000). The most common cooccurring conditions include ADHD (54%), and Obsessive Compulsive Disorder (OCD) or subclinical OCD (50%), showing much higher prevalence than in a neurotypical child population (Z. S. Liu et al., 2020). ADHD is characterised by attention and hyperactivity dysregulation and impulsive behaviours and OCD symptoms include recurrent and intrusive thoughts and impulses, leading to repetitive acts to reduce anxiety or distress (Z. S. Liu et al., 2020). On average, tic onset occurs around seven years, but ADHD symptoms appear at around five years old, whilst OCD tends to begin within the year of tic onset or earlier (Freeman et al., 2000). ASD also commonly cooccurs with TS (Robertson, 2015).

Coexisting psychopathologies are also highly common, but to date genetic or aetiological overlaps have not been identified (Robertson et al., 2017). Mood and anxiety disorders are prevalent in 30-36% of samples of people with TS respectively (Hirschtritt et al., 2015). Similarly to OCD, anxiety symptoms were prevalent within the year of tic onset but mood disorders were distributed, with age of onset beginning around 5 years and becoming more frequent around 7-8 years old. In addition, people with TS have reported increased hostility, personality disorder, bipolar disorder, conduct disorder, anger control problems, sleep difficulties, rage attacks, self-injurious behaviour, social-functioning problems, learning difficulties and eating disorders (Eapen et al., 2004; O’Hare, Helmes, Reece, et al., 2016; Rizzo et al., 2014; Robertson, 2006, 2015; Sambrani et al., 2016). Such rates tend to be compared to healthy controls; however, one study compared YP with TS to age-matched controls with epilepsy, finding increased rates of depression and social anxiety in the TS sample (Eddy, Cavanna, et al., 2011) suggesting YP with TS experience psychopathologies above that of other YP living with physical conditions. The heterogeneity in psychopathologies has created proposals that TS may not be a unitary condition, backed up by findings that certain psychopathologies relate to particular tic-types (Robertson, 2008b). Such findings suggest the prevalence of variance in TS psychopathology is likely to be multifactorial, not only as a result of difficulties living with a tic-condition but also a genetic link (Eapen et al., 2015). For example, less severe TDs, such as chronic motor or vocal TD have lower rates of cooccurring conditions and psychopathology (Khalifa & Von Knorring, 2006) and complex tics, such as coprolalia (see below for tic subtypes), were less frequent in pure TS (Eapen & Robertson, 2015).

For those with TS and cooccurring conditions, reports suggest increased vulnerability to other behavioural problems, and further for those with a triple comorbidity of TS, ADHD and OCD, the highest rates of anger control and sleep problems were reported (Freeman et al., 2000). In a sample of adults with ADHD and TS and adults with TS only, despite both groups having similar measures of tic severity and lifetime diagnosis, the group with both TS and ADHD scored significantly higher on depression, anxiety and obsessive compulsive behaviour scales (Haddad et al., 2009).

Pathophysiology and Etiology

The cause of TS is still unknown; pathophysiology studies have identified strong evidence for the role of potential abnormalities in motor pathways and circuits, and concerning neurotransmitters (Augustine & Singer, 2019; Novotny et al., 2018). The pattern of hereditary transmission within families and twins implies there are genetic vulnerabilities to developing TS, and may represent a polygenic condition with an interplay between genes and environmental factors (Novotny et al., 2018; Singer & Augustine, 2019).

Symptomatology of TDs

Tics

Tics are the characteristic symptom of TDs, and are stereotypical vocal or motor movements onsetting around 6 years old, usually beginning with simple tics and developing into more complex tics (Leckman et al., 2006). Simple tics consist of one muscle group, and include repetitive, automatic, rapid movements, such as blinking, sniffing or grunting whereas a complex tic includes multiple muscle-groups and appear semi-purposeful, such as utterances or looking at a wrist watch (Kumar et al., 2016; Stern, 2006). Complex tics can include repetitions of sounds or movements (echolalia and echopraxia), obscene motor movements or vocal utterances (coprolalia and copropraxia), and repeating one’s own utterances or movements (palilalia and palipraxia) (Robertson et al., 2017). Tics are usually preceded by a sensation known as a premonitory urge, leading to a build-up of intensity relieved through the tic (Leckman et al., 1993). Depending on its intensity, one may feel able to suppress the tic, however if the tension becomes too great the individual tics to relieve the urge (Leckman et al., 2014). Tics are known to fluctuate, so that an individual with tics may experience bouts and decreases in severity, which can happen over hours, days, weeks and months (Leckman, 2003).

Internal factors such as mental states and emotions, and external factors such as environments have been known to impact tic severity, both positively and negatively (Conelea & Woods, 2008b; Leckman et al., 2014). A review exploring the impact of context on tic expression grouped a series of studies that explored events happening prior to a tic which may alter tic-expression (Conelea & Woods, 2008b). In descriptive studies, tics increased with fatigue (Bornstein et al., 1990; Eapen et al., 2004; Robertson et al., 2002; Silva et al., 1995) and social activities (K. P. O'Connor et al., 2003; Silva et al., 1995), and tics decreased with relaxation, concentration and passive states (Eapen et al., 2004; K. P. O'Connor et al., 2003; Robertson et al., 2002). Whilst descriptive studies have limitations such as participant bias and validity due to self-reported measures, greater controlled experimental studies also supported the environmental influence on tics. One study altered the environment by introducing family members and observed heightened tic expression in the presence of a critical father (Malatesta, 1990). Another controlled study found a tic-increase when tics were the topic of conversation (Woods et al., 2001) and authors compared tics during easy, hard, seated and standing school-work, finding increased tics during easier tasks and when the YP was seated (Watson et al., 2005). Together, these studies show how environments impact variably on tic functioning. Although they have limitations, such as small sample sizes, artificial settings and variabilities between participants, the number of anecdotal reports and descriptive studies, and the few experimental studies pertain to a relationship between tics and environments. While more research is needed to examine the nature of this relationship, it is likely that mental states are impacted by environments, which becomes the mediating factor affecting tic expression.

Treatments for Tics

Currently, no national guidance exists to advise on the treatment of TDs, although recommendations have been presented from members of the European Society for Study of Tourette Syndrome based on clinical experience and research evidence (Verdellen et al., 2011). These include intervention at a behavioural, social and physical level, with suggestions that all children should receive psychoeducation, and depending on the need of the child, supportive intervention such as school liaison and social skills training. For children who want to reduce their tics, behavioural interventions of habit reversal therapy (HRT) and exposure and response prevention training (ERP) should be offered as first-line treatment. After 10 sessions, an evaluation of the response is proposed and if the child is showing symptom improvement, a continuation of 10 sessions is suggested or if no improvement, the alternative treatment should be tried. For children experiencing severe symptoms, medication could be offered alongside behavioural treatment or with a view to start behavioural treatment later. If combined treatments are effective, the medication can be phased out to reduce harmful and unpleasant side effects of medication (Robertson, 2011; Whittington et al., 2016). Second-line interventions are also suggested for those not responsive to first line interventions, such as relaxation training, function based interventions or contingency management (Verdellen et al., 2011).

As mentioned previously, both HRT and ERP are considered first-line interventions, both developed to be delivered as one-to-one in-person behavioural therapies. HRT is one of the earliest intervention for tics, has been widely implemented, and found to be effective in reducing tics for children and adults (Andrén et al., 2019; Deckersbach et al., 2006; Himle et al., 2012; Piacentini et al., 2010; Rachamim et al., 2020; Ricketts et al., 2016; Verdellen et al., 2004; Wilhelm et al., 2003, 2012) with recorded improvements lasting up to two years (Van de Griendt et al., 2013). It is based on using a competing response to interrupt the tic-cycle (Azrin & Nunn, 1973), and due to its efficacy it's also recommended in Canadian, American and Chinese guidelines (Z. S. Liu et al., 2020; Martino & Pringsheim, 2018; Murphy et al., 2013; Steeves et al., 2012; Verdellen et al., 2011). ERP intends to reduce tics through interrupting the negative reinforcement observed after a tic is completed, with the aim being to train the suppression of tics so that one becomes habituated to the sensation of the urge (Verdellen et al., 2004). This is supplemented by social support, relaxation, and contingency management. Although fewer studies exist investigating its efficacy, ERP is supported in comparison to HRT and reviews of behavioural interventions for tics indicate its potential (Cook & Blacher, 2007; Himle et al., 2006; Verdellen et al., 2004). Although additional, high quality trials including control arms are needed to gain a better assessment of the effectiveness of ERP, some guidelines already recommend its use (Hollis, Pennant, et al., 2016; Steeves et al., 2012; Verdellen et al., 2011).

Modern therapies are also showing promising efficacy rates. Comprehensive behavioural intervention for tics (CBIT) combines HRT with additional tic-awareness training, self-monitoring, relaxation training and contingency management (Azrin & Nunn, 1973; Hollis, Pennant, et al., 2016), and has been shown to be effective in reducing tics in YP compared to control groups, with the effects maintained at six months post-therapy (Piacentini et al., 2010). Furthermore, CBIT-JR, an adaptation of CBIT for under 9-year-olds which included six sessions of parent-only, parent-child and child-only sessions with a therapist found the intervention was both effective and acceptable (Bennett et al., 2020). Another second-line therapy used mindfulness-based stress reduction (MBSR) to support tic-reduction, arguing that meditative practice would support reduced negative reinforcement as practiced in ERP and that meditation can reduce stress and anxiety related to tic-exacerbation. Nevertheless, mindfulness proved less effective than CBIT and HRT, although it showed improvements in tic-related impairment (Reese et al., 2015).

Modern behavioural therapies are starting to employ different formats, for example using videoconferencing to deliver therapy. Comparable results have been found to traditional face-to-face methods when delivering HRT this way (Himle et al., 2010), as with CBIT (Himle et al., 2012), and a review suggests low-quality evidence supports the acceptability and efficacy of videoconferencing CBIT (Hollis, Pennant, et al., 2016). Other formats have included online self-help programmes, for example TicHelper, an online website based on the therapist-guided protocol of CBIT has been developed into a self-help format for YP eight years and up (Woods et al., 2008). Although no trials exist of TicHelper, it was reviewed highly as being a valuable resource that is better than currently available resources due to its interactive and individualised nature (Conelea & Wellen, 2017). Similarly, a HRT and ERP remote training called BIP TIC HRT and BIP TIC ERP respectively, adapted the core HRT and ERP manuals into online self-help formats. Parents were able to access the online platform for more detailed content, and therapists supported each family with phone calls and written messages. This pilot study assessed the feasibility and acceptability of remote delivery of ERP and HCT, and with 100% participant retention to the trial, and an average of seven (HRT) and eight (ERP) chapters completed of 10 for children and parents, plus 75% of ERP participants and 55% of HRT participants classed as treatment responders, the pilot shows promise for a larger-scale RCT (Andrén et al., 2019).

Overall, while these studies have small participant numbers and there is considerable variability between the interventions and type of technology used, the preliminary consensus shows YP find digitally delivered interventions for tic therapy to be acceptable.

Quality of Life and Wellbeing

Often, the terms wellbeing and QoL are used interchangeably although the terms do not represent the same concepts (Dodge et al., 2012). QoL has traditionally been used in medicine as a way to identify what deficits or functional impairment a person is experiencing as a result of a condition they have (CDC & Centers for Disease Control and Prevention, 2016; Healthy People 2020, 2010; X. J. Lin et al., 2013; Pollard & Lee, 2002). Conversely, subjective wellbeing accounts for an individual's personal satisfaction with life, considering the positive feelings about their life, in contrast to the deficits they may be experiencing (Pollard & Lee, 2002). Subjective wellbeing has two main streams of thought, based on two philosophical stances: hedonia and eudaimonia (Keyes, 2006). The former conceptualises wellbeing as the pursuit of pleasure, so that wellbeing is determined by one's ability to reach their meaning in life, requiring a balance between three components, 'cognitions' to assess satisfaction and happiness, and 'negative' and 'positive affect' which reflect the persons level of happiness, also known as subjective wellbeing (Bradburn, 1969; Linley et al., 2009; Samman, 2007). The latter approach refers to psychological wellbeing, which considers wellbeing to be the completion of activities that are in accord with one's virtue. Arguments propose these are best represented by Ryff's (1989) six scales of psychological wellbeing which include purpose in life, personal growth, environmental mastery, autonomy, self-acceptance and positive relations (Linley et al., 2009). Nonetheless, both approaches have shortfalls, with the hedonic approach assuming that high positive affect should constitute high wellbeing, and the scales of psychological wellbeing neglecting the impact of social wellbeing on health (Keyes, 2002, 2005). To capture the broad influence of social, psychological and subjective wellbeing on mental health and both, positive and negative affect, Keyes developed the dual mental health continuum, arguing all to be indicators of mental health (Keyes, 2005; Keyes et al., 2002). The mental health continuum proposes that high levels of mental health is flourishing i.e. to be filled with positive emotion and functioning psychologically and socially, and low mental health is characterized by languishing i.e. an emptiness, stagnation or quiet despair.

These diagnostics are not the same as measures of mental illness e.g. symptoms of depression or anxiety, which have been found to be distinct factors through modelling (Keyes, 2005; Keyes et al., 2002). Therefore, this explanation proposes that the absence of mental illness does not equate to being mentally healthy, or the presence of an mental illness always results in low wellbeing (Keyes, 2005; Westerhof & Keyes, 2010).

In relation to the current research, the dual continuum model offers an approach to wellbeing that considers the wider implications of living with a TD than just TD symptomatology. For example, using QoL scales such as The Gilles de la Tourette Syndrome Quality of Life Scale for children (C&A-GTS-QOL; Cavanna et al., 2013) would account for psychological, physical, obsessive-compulsive and cognitive factors impairing life, but would not account for factors such as life satisfaction, emotional and social wellbeing. However, it is likely these measures are associated, as studies have found correlations between QoL and wellbeing and reviews have suggested that QoL may be a dimension of wellbeing (Dodge et al., 2012; Keyes, 2005; Keyes et al., 2002). Therefore, the main aim of the current research is to produce a tool that will promote psychological wellbeing for YP with tics, and such an aim is likely to lead to improvements in QoL dimensions. The term psychological is being used to reflect the importance of social wellbeing and other elements of wellbeing such as mood and stress, in addition to mental health.

Psychological Wellbeing and QoL when Living with a TD

There is substantial evidence that living with a TD results in reduced QoL. Reviews assessing QoL in YP with a TD have focused on impairment mainly relating to physical, psychological, obsessional, social, occupational and cognitive domains of life (Eapen et al., 2016; Robertson et al., 2017). Reductions in QoL in these domains have been supported across a range of self -, parent- and clinician ratings (Conelea et al., 2011; Eddy, Cavanna, et al., 2011; Gutierrez-Colina et al., 2015; McGuire, Ricketts, et al., 2015). These findings are upheld when comparing YP with tics to healthy controls (Cutler et al., 2009; Eddy, Rizzo, et al., 2011; Rizzo et al., 2014; Storch, Murphy, et al., 2007) and controls with other conditions (Eapen et al., 2016). Nonetheless, whilst such studies demonstrate that having a TD impairs daily functioning, they do not explain whether YP are distressed by such symptoms of their tics. A review of the qualitative literature regarding the experiences of

YP with tics would help to highlight the daily difficulties experienced by YP relating to their tics, as presented below. These dimensions of QoL and wellbeing will be discussed, bringing together both accounts of impairment on functioning.

The literature has often focused on the physical impact of TS on QoL, finding increased tic severity is often related to decreased QoL (Cavanna et al., 2013; Conelea et al., 2011; K. M. Lewis et al., 2012; S. Liu et al., 2017; Storch, Lack, et al., 2007). Further, the presence of premonitory urges has also been found to be a predictor of QoL in YP with tics (Cavanna et al., 2012). This is not surprising given the increased likelihood of pain and physical damage as a result of increased tics and intensity (Conelea et al., 2013). Qualitative exploration also highlights that painful tics interfere with daily activities and cause fatigue (Cutler et al., 2009; Edwards et al., 2017; Lee et al., 2019). In addition, multiple themes highlight the loss of control experienced as a result of ticcing is the most disabling feature of TDs, which increases with increased tics (Cutler et al., 2009) and is related to impulsive or compulsive behaviour which continued to disrupt daily life (Lee et al., 2019). Beyond day-to-day tic impairment, YP with tics expressed concerns about their future career due to having tics (Wadman et al., 2013).

Academic QoL has been found to be one of the most dysfunctional aspects of TS compared to normative samples (Cutler et al., 2009; Storch, Lack, et al., 2007). In a large survey of over 1000 parents and children with TDs, increased tics were correlated with academic interference including days off school, breaks from school and decreased productivity (Conelea et al., 2011). Studies exploring the impact of TS have generally found TS difficult to manage within the school environment, with school leading to increased tics and anxiety, an increased desire for tic suppression (Conelea & Woods, 2008a; Silva et al., 1995) and TS interfering with academic performance (Conelea et al., 2013). Increased interference at school was noted for those with a cooccurring condition, especially ADHD (Abwender, 1996; Bernard et al., 2009; Conelea et al., 2011; Pringsheim et al., 2009; Storch, Merlo, et al., 2007). The qualitative literature confirms the major impact of tics on YPs lives at school which shows an abundance of themes relating to school difficulties. Similarly, the interference of tics directly on school work, for example eye tics or writing tics, as a result of focusing on tic-suppression rather than school-work (Wadman et al., 2016) or focusing as a problem in general formed a difficulty for young people (Grace & Russell, 2005; Rivera-Navarro et al., 2014). YP also noted an indirect relationship of tics on their wellbeing, with YP being concerned about disturbing or annoying their peers at school (Wadman et al., 2016), and reported embarrassment if peers asked them to ‘shut-up’ (Grace & Russell, 2005) or if they felt they were being observed (Rivera-Navarro et al., 2014). On the other hand, YP who were more satisfied in the classroom reported their classmates ignored their tics and felt able to confront peers about tic-comments (Grace & Russell, 2005). Feeling less capable compared to their peers was also noted (Grace & Russell, 2005; Rivera-Navarro et al., 2014). Finally, a lack of understanding from teachers was identified through themes reporting YP being punished because of tics (Wadman et al., 2016), which was felt to be the result of a lack of knowledge about TS and not making allowances for YP with tics (Grace & Russell, 2005; Rivera-Navarro et al., 2014). As a result, it is not surprising that YP commonly mentioned school was a source of anxiety and stress, especially during times of examination or for YP who may experience challenges with perfectionism (Grace & Russell, 2005; Wadman et al., 2016).

A lack of understanding about TDs was also highlighted in relation to healthcare professionals, which was felt to result in little information dissemination about TDs, treatment mistakes or having to attend different services to receive adequate healthcare (Cuenca et al., 2015; Rivera-Navarro et al., 2014). Other issues regarded how YP conceptualise their own condition, with YP showing limited understanding of TDs themselves (Edwards et al., 2017) and a lack of knowledge from educational professionals and physicians was believed to cause a complex and long process to receive diagnosis (Rivera-Navarro et al., 2009).

A significant amount of the narrative review identified themes in the literature relating to self-acceptance, another element of psychological wellbeing. This part of the literature highlighted the difficulty in living with a condition that makes you question your identity due to its invasion on the self (Wadman et al., 2013), so that increased control over symptoms or with therapy helped in redefining oneself (H. Smith et al., 2016). When considering one’s identity with their tics, their condition was viewed as both ‘a part’ of and an independent entity to the self (Cutler et al., 2009; Lee et al., 2019; Wadman et al., 2013). As YP became more accepting of their tics, they recognised how the condition had developed their maturity, courageousness and empathy (Lee et al., 2019). A general consensus across themes was that this acceptance came with time, and YP often had to undergo a journey to achieve this level of acceptance. YP reported methods for increasing self-acceptance, often recognising family, friends and role-models as facilitators (Cutler et al., 2009; Lee et al., 2019; Nussey et al., 2014; H. Smith et al., 2016), although family were sometimes seen as responsible for increased insecurity (Rivera-Navarro et al., 2014).

The importance of socialising with others, which can be incredibly meaningful and important to YP with tics, has been shown across qualitative studies, also providing much information relevant to the difficulties YP face when socialising. Much socialising-related distress revolved around not fitting into society's expectations of 'normal', or being seen as different from others, reported in focus groups, phenomenological interviews, and when including the viewpoints of parents and health professionals (Cutler et al., 2009; Lee et al., 2016; Rivera-Navarro et al., 2014)**.** These themes identified how YP avoid situations where others may observe their tics (Lee et al., 2016; Rivera-Navarro et al., 2014), or how YP hide their tics (Cutler et al., 2009; Rivera-Navarro et al., 2014), especially for YP with more forceful or visible tics (Wadman et al., 2013). Social difficulties were felt to stem from a lack of understanding from others (Lee et al., 2016; Rivera-Navarro et al., 2014), or worries the YP had about responses to tics, which had included negative reactions, teasing, being perceived as naughty or annoying, and being treated differently to others (Grace & Russell, 2005). YP expressed how lonely it can feel to have tics when others show no understanding (Lee et al., 2019). On the other hand, many themes pointed to the importance of socialising, whereby developing supportive and close friendships was felt to be important to YP, which supported feelings of acceptance (Grace & Russell, 2005; Wadman et al., 2013). Themes relating to positive friendships and a lack of friends in relation to satisfaction with school were also developed (Grace & Russell, 2005).

Existing research exploring social QoL with YP with TS has shown reduced QoL functioning in social areas (Eddy, Rizzo, et al., 2011; O'Hare et al., 2015; O'Hare, Helmes, Reece, et al., 2016; Storch, Merlo, et al., 2007). O'Hare et al. (2016) found social dysfunction with parent-rated scales was related to TS and not to the impact of comorbid diagnosis, suggesting that social difficulties are attributable to TS. Reasons for reduced social functioning may be related to YP with tics forming insecure peer attachments and experiencing increased problems within their friendships compared to healthy control groups (O'Hare et al., 2015). These findings were supported by children who rated their own QoL in psychosocial domains to be similar to that of other YP with psychiatric disorders (Storch, Merlo, et al., 2007). Expanding social QoL to relationship domains which encompass psychosocial functioning, YP with more severe tics experienced lower QoL in relationship domains compared to YP with epilepsy (Eddy, Cavanna, et al., 2011).

Furthermore, a recent report including 205 children with TDs compared to healthy controls investigated individual and family functioning, and found YP with TDs experience reduced parent QoL and family functioning (Vermilion et al., 2020). Challenges of being a parent or caregiver of a child with TS highlighted challenging behaviours at home, a lack of understanding and public stigma outside of the home (Ludlow et al., 2018). Stigma was also present in themes from the wellbeing literature in two qualitative papers (Rivera-Navarro et al., 2009, 2014). Stigma was the topic of one theme which showed how symptoms of TS were misrepresented because of the mental disorder diagnosis and in another theme where it was felt that teacher's lack of knowledge led to stigmatisation of YP's actions (Rivera-Navarro et al., 2014).

A further area of functioning implicated in the QoL literature refers to cognitive QoL, encompassing problems with concentration, forgetfulness and completing tasks (Conelea et al., 2011; Eapen et al., 2016; Evans et al., 2016). Comparisons against a control group of YP without TDs found lower scores on cognitive components when measuring subjective QoL for those with tics (S. Liu et al., 2017). Although reduced functioning has been mostly attributable to ADHD, YP with TS experience reduced cognitive functioning even after controlling for ADHD, suggesting there is an interplay between TDs and cognitive function (Gorman et al., 2010). The current literature stresses the implications of cognitive QoL across the lifespan, arguing that adults with TS may be especially impacted by cognitive dysfunction (Evans et al., 2016; Wilkinson et al., 2002).

Despite the many difficulties YP with tics face, multiple themes in the qualitative literature identified how YP with TS learn to manage their tics and symptoms of their TD in order to be able to fit in or appear normal (Cutler et al., 2009). These included suppressing tics, especially in front of peers who they thought may react negatively to them (Edwards et al., 2017; Lee et al., 2016). This notion of controlling tics was repeatedly identified in studies, with YP reporting a desire to control tics through medication or behavioural interventions (Cuenca et al., 2015; H. Smith et al., 2016). Similarly to the previous literature around self-acceptance, the adolescent sample in Lee et al. (2019) reported a loss of identity as one tries to fit in through suppressing their tics. Yet, using these coping strategies allowed YP to feel more accepted into society (Lee et al., 2019), and were reported to be consistent with techniques often included within tic-related therapies such as HRT, ERP and CBT-related approaches (H. Smith et al., 2016). Nevertheless, YP also reported how attempting to control and supress tics required effort and resulted in a lack of complete engagement with the external world (Cutler et al., 2009). Furthermore, YP reported a lack of control of their emotions (H. Smith et al., 2016) and talked about strategies they used to manage internal states. YP showed an awareness that increased pressure, sleep deprivation or emotional states led to an increase in tics, and therefore these situations were avoided (Lee et al., 2016). Feelings of worry and stress were reported to be worse than the tics themselves (Cuenca et al., 2015).

Within the QoL literature, reduced functioning within psychological domains has also been identified as a hugely impairing factor of TS. A systematic review reports psychological functioning as one of the most affected QoL domains in 10 of the 14 studies with child samples with TS (Evans et al., 2016). Apart from social functioning, which was the most affected domain in 11 of the studies, psychological dysfunction was the most highly reported to affect functioning over school, physical, obsessional and cognitive QoL domains (Evans et al., 2016). Studies included those which compared YP's functioning to healthy controls and those with other conditions (Evans et al., 2016). These findings support the proposal from the qualitative literature that emotions may be more impairing to live with than tics (Cuenca et al., 2015). For example, symptoms of anxiety and depression have been found to be a better predictor of QoL than tic severity in adult samples (Lewin et al., 2011). Further, in a sample of 56 children with TS, ADHD and OCD, symptoms were correlated with total QoL scores, but not with tic severity (Bernard et al., 2009) and parent-proxy measures of impairment were related to cooccurring problems e.g. depressed mood, obsessional behaviours, hyperactivity, inattentiveness over tic-related problems (Storch, Lack, et al., 2007). Evidence that cooccurring conditions cause greater psychological impairment than tics is additionally supported by higher scores of reduced psychological functioning in groups of YP and children with comorbidities (Cavanna et al., 2013; Eapen et al., 2016; Freeman et al., 2000; Storch, Lack, et al., 2007) and psychosocial QoL scores were significantly lower than national norms for children with TS plus groups, but not for TS-only groups (Pringsheim et al., 2009). These findings are supported by caregivers who, when rating children with TS with different psychometric measures, found significant decreases in QoL and emotional symptoms for those with a cooccurring condition over those with pure TS, especially for YP with OCD and anxiety (O'Hare, Helmes, Reece, et al., 2016).

As previously noted, cooccurring conditions can cause greater impact on QoL which is so common for obsessive-compulsive behaviours within TS such as repetitions, copying people, intrusive thoughts and health-anxiety, that it is a sub-scale of the GTS-QOL (Cavanna et al., 2008). In a large longitudinal study, OCD was found to be the main cause of poor QoL and TS+OCD, or TS+OCD+ADHD increased the likelihood of having a mood, anxiety, or substance use disorder (Hirschtritt et al., 2015). Further, in another prevalence study the TS+OCD+ADHD group of YP had the most severe behavioural and mood disorder problems, the highest risk of developing bipolar disorder and the poorest QoL (Rizzo et al., 2014). Adults with TS and OCD reported that while most of their tics had subsided, 40% continued to experience difficulties with their comorbidities of which OCD was one of the most prevalent (Byler et al., 2015). Finally, in a sample of people with OCD who had attempted suicide, there was a significantly higher representation of TDs over other psychiatric comorbidities (Kloft et al., 2018).

This review of the literature pertaining to QoL and psychological wellbeing has highlighted the many areas of impairment a YP with tics can face. The QoL literature features the physical dysfunction of tics causing pain, supplemented by the wellbeing literature highlighting interference to activities and concerns about how they are perceived due to tics. A second domain of QoL, academic functioning was also found to be impacted by tics. Literature exploring aspects of wellbeing at school, in addition to registering impairment in schoolwork, developed themes pertaining to concerns about peers and teachers. Further areas identified in the psychological wellbeing literature related to a lack of understanding from others, especially healthcare professionals, which impacted on receiving appropriate healthcare treatment and self-acceptance. Themes established the difficulty of developing identity when living with TS and the journey of self-acceptance, which was reinforced by friends, family and role-models in the community. The importance of socialising for psychological wellbeing was also highlighted, including stigma and the difficulty of fitting-in which was inflated by those with little understanding of TDs. The impact of tics on social functioning was also underlined by literature which showed YP with tics have reduced social and relationship QoL, which has been found to have greater impairment for YP with tics than other conditions. Another area of relevance to wellbeing included YP attempting to control their tics and emotions. In line with this, QoL literature was presented which found psychological QoL was one of the most affected QoL domains for YP with tics.

This review presents substantial evidence to suggest that living with a TD causes reduction in both QoL domains and impairs functioning in relation to psychological wellbeing. This overview shows the breadth of impaired functioning a YP with tics may experience and highlights the interplay between QoL and psychological wellbeing, whereby an intervention considering one area of functioning is likely to also impact on other areas of functioning and wellbeing.

The need for TS Treatments for Wellbeing

Whilst current behavioural interventions for tics have the main aim of reducing tic severity, under the assumption that tics are wholly responsible for impairment, the review of the QoL and wellbeing literature highlights that physical functioning is not regarded as one of the main disabling features for YP with tics. Instead, social, and psychological dysfunction can be considered as having a greater impact on life. This is supported by the aforementioned findings that psychological and social impairment was noted as the most affected QoL domain across a series of studies looking into children with TS; nearly doubling those reporting physical QoL as one of the most impairing domains (Evans et al., 2016). Additionally, studies have reported that emotional dysfunction and cooccurring conditions are more impairing than tics (Bernard et al., 2009; Storch, Lack, et al., 2007) and YP have reported that emotional states were more detrimental to their wellbeing (Cuenca et al., 2015) and continue to have a greater impact on dysfunction into adulthood, alongside dysfunction in other areas of life such as cognition and obsessionality (Byler et al., 2015; Evans et al., 2016).

Detecting and intervening early when YP are experiencing mental health difficulties may prevent longer-term problems, supporting YP in achieving their potential and reducing societal costs caused by living with a mental disorder (Kieling et al., 2011). For YP who experience physical health concerns and have cooccurring depression, anxiety or stress, mental health difficulties have been found to persist into adulthood suggesting attention focused at psychological wellbeing and QoL for YP with physical health conditions is needed (S. Anderson et al., 2006; Power et al., 2012). Furthermore, prevention is even more cost effective than treatment (Kieling et al., 2011), so an intervention aimed at promoting mental wellbeing could support both prevention of mental illness and presence of mental wellness (Keyes, 2005). This is important because absence of mental illness does not equate to mental health, therefore an intervention must do more than relieve the symptoms causing mental illness, but also promote the symptoms of wellbeing (Keyes, 2005, 2006).

Additionally, the relationship between wellbeing and tics suggests that tic reduction may be supported by a wellbeing intervention. A variety of correlational, descriptive, and experimental designs have reported increased tics with anxiety and stress, stressful life events and small life events, psychosocial stress and depression, feelings of frustration or being tense, emotional stimuli and stressful tasks (Bornstein et al., 1990; Eapen et al., 2004; Findley et al., 2003; Hoekstra et al., 2004; Lees et al., 1984; Lewin et al., 2011; H. Lin et al., 2007; K. P. O'Connor et al., 1994, 2003; Silva et al., 1995; Wood et al., 2003). A biological explanation in a recent review found stress has a modulating role in the neural circuits involved in tic expression, presenting how emotion may impact tic expression (Buse et al., 2014). The research requires more exploration to better understand how stress and TS interact but calls for integration of stress-reduction techniques within TS treatments. Together, these findings demonstrate the need for an intervention that prevents and supports YP with tics for difficulties in wellbeing. Such an intervention could prevent reduced psychological functioning by giving YP the skills to support their wellbeing and could improve functioning in psychological aspects of life for those already experiencing difficulties. As a result of improved psychological functioning, the complex relationship between environments, tics and mental states may also lead to improved tic functioning and impairment in aspects of QoL.

TS Interventions for Wellbeing

Interventions for YP with tics that focus on improving psychological wellbeing as the objective of the treatment are available, including psychotherapy, 'Living With Tics' (LWT) and 'Resource Activation' (Deckersbach et al., 2006; McGuire, Arnold, et al., 2015; Storch et al., 2012; Viefhaus et al., 2019). A further intervention, MBSR had a main objective of reducing tics, but as the method uses a psychological therapy that aims to reduce stress, it has been included here (Reese et al., 2015).

Deckersbach et al. (2006) implemented a supportive psychotherapy treatment with the objective of improving self-esteem, life satisfaction and tic-related psychosocial functioning through components which reduce distress and increase coping skills. This was compared to HRT, with two groups of adults receiving 14 individual sessions. Both groups found improved work, social and family psychosocial functioning, life-satisfaction and psychotherapy also improved depression, OCD and ADHD symptoms. Two studies explored the LWT intervention, which consists of 8-10 weekly sessions and aims to improve psychosocial functioning and tic-related impairment with modules such as psychoeducation, cognitive restructuring and abbreviated HRT (Storch et al., 2012). The initial small sampled study, six of eight YP with tics showed 'much improved' or 'very much improved' global QoL functioning from clinician-ratings and self-reported self-concept ratings such as popularity, happiness and life satisfaction, tapping into domains of psychological wellbeing and parent-reported improved tic-related impairment, despite modest tic severity reduction (Storch et al., 2012). With a slightly larger sample, an RCT compared LWT to waitlist with 24 YP with tics randomised to either group, also finding improvements in tic-related impairment and overall QoL and further, YP reported to be highly satisfied with the intervention (McGuire, Arnold, et al., 2015). The third intervention, known as 'Resource Activation' is a therapy that rather than focusing on problems, reinforces an individual's strengths and abilities, and has been applied to TDs with a focus on improving self-esteem, with the secondary aims of improving tic symptoms and comorbid symptoms. 51 YP were randomised to Resource Activation or a problem-focused intervention control group, and though tic-related symptoms and tic-related impairment were reduced, no improvements were found for self-esteem or comorbid symptoms. Furthermore, compared to the aforementioned therapies, it was not as effective at reducing tic symptoms (Viefhaus et al., 2019). Finally, the MBSR intervention assessed eighteen YP and adults 16 years and above, at baseline, post-intervention and follow-up, which included eight 2-hour group classes and a 4-hour retreat. With the primary focus to reduce tics, MBSR was found to be significantly effective at improving tic-severity and tic-related impairments such as work and social functioning were also improved and upheld at a one-month follow up (Reese et al., 2015).

Collectively, these interventions have shown efficacy with both YP and adult samples in improving psychosocial difficulties, tic-impairment and tic-severity. These interventions uphold the notion of a complicated relationship between tics and psychological wellbeing, suggesting that interventions that aim to improve aspects of psychological wellbeing, or even tic-functioning in the case of Reese et al. (2015), may improve functioning in both psychological and physical domains of QoL and wellbeing. More research is needed with adequate control conditions and sample sizes to ensure these results are replicable. Nevertheless, despite these interventions being effective, they need to show advantages over currently implemented interventions. The results of these studies do not suggest they are more effective than current treatments and the resources required are intensive. For example, both Resource Activation and MBSR were not as effective at reducing tic-severity or tic-impairment as CBIT or HRT, and no differences were found between the psychotherapy group and the HRT group (Deckersbach et al., 2006; Reese et al., 2015; Viefhaus et al., 2019). Furthermore, CBIT is effective after eight sessions, totalling nine hours and these interventions were all considerably more time consuming (Piacentini et al., 2010). Overall, the LWT intervention appears to have the most promise, with moderate reductions in tic-symptom severity across two studies that are within the range of trials of behaviour therapy, plus requiring the least amount of therapist time. This led the authors to conclude that such an intervention could serve as an adjunct to current behavioural tic therapy for YP who may need further support with tic-related impairment (McGuire, Arnold, et al., 2015).

Taken together, an intervention such as LWT may also have advantages over behavioural interventions. Whilst CBIT is regarded as effective for some YP, only 53% were classed as treatment responders meaning nearly half were not (Piacentini et al., 2010) with similar reports elsewhere (Rizzo et al., 2018; Whittington et al., 2016). These findings suggest behavioural therapy is not appropriate for everyone. Furthermore, the stepped-care approach recommends the least intensive and expensive intervention should be applied first, with increasing intensity with no response (Rapee et al., 2017). Whilst the online self-help version of CBIT, TicHelper, may be regarded as less expensive due to not needing a therapist, the absence of a therapist means there’s no help for feedback or troubleshooting (Conelea & Wellen, 2017). This is important because behavioural treatment for tics is difficult and requires effort, meaning self-help CBIT may be challenging and intensive (Cutler et al., 2009). It is argued instead, that an intervention such as LWT which aims to support psychological wellbeing could be the first port-of-call for YP with tics (Rapee et al., 2017) before receiving behavioural therapy. This intervention has the advantage that it may be better applied to a self-help setting, supported by systematic reviews that highlight YP receiving self-help support for mental health difficulties show better outcomes than groups receiving no support (Bennett et al., 2019).

The evidence presented in this section demonstrates significant disability to YP living with TDs as a result of comorbidities and coexisting conditions in addition to their tics. The studies presented suggest TDs cause impairment beyond tics themselves, with impacts not only in physical domains but also in cognitive, psychological, social, obsessional and occupational domains and on psychological wellbeing. Some evidence suggested impairment in these domains could continue to impact on lives, even into adulthood. This led to the proposal that interventions considering such impairment in psychological QoL and wellbeing could be more useful to YP, however currently available interventions require more resources and do not show levels of improvements that would substantiate their implementation. Self-help interventions to improve psychological functioning in YP without tics provides evidence to suggest these types of intervention could be applied to YP with tics. Such interventions would hopefully improve areas of functioning as identified by impairments to QoL and wellbeing but could also have a positive impact on tic impairment and severity.

The Rationale for Digital Self-Help Tools for YP with TS

Self-help interventions, by strict definition, are delivered without professional support, and can exist through text, audio, video, group or individual exercises (Bower et al., 2001). Digital self-help interventions that aim to improve wellbeing or QoL in YP vary in their content, often adapting CBT into a digital format (Richardson et al., 2010; Rummel-Kluge et al., 2015), but also include other types of intervention, such as bibliotherapy and psychoeducation (Ahmead & Bower, 2008), serious games (Fleming et al., 2014), peer-to-peer support (Ali et al., 2015), self-monitoring and medication adherence (Grist et al., 2017). Using the NICE (National Institute for Health and Care Excellence) definition for digital health technologies, DHIs include ‘apps’ programmes and software used in the health and care system’ (NICE, 2019b).

As mentioned previously, the stepped-care approach proposes an individual be initially treated with the least intensive and least expensive intervention i.e. self-help, which increases at a rate proportional to the need of the individual (Rapee et al., 2017). Digitally delivered self-help enables large scale delivery at low costs (Andersson & Cuijpers, 2008) and is recommended to healthcare professionals to offer to YP with depression during coordination of care and assessment by national guidelines (NICE, 2011a). There are no guidelines set by NICE for other common mental health disorders such as anxiety for YP, although the ‘Improving Access to Psychological Therapies’ (IAPT) programme who employ the stepped-care approach are increasing therapist training on self-help, suggesting increased evidence in support of self-help therapies is leading to greater implementation of such interventions (Bennett et al., 2019). Therefore, digital delivery of self-help is both cost effective and in-line with stepped-care models to care.

Newman et al. (2011) categorised the degree of therapist support into three levels: i) self-administered (therapist assessment of state only; SA), ii) predominately self-administered (therapist provides the rationale for the intervention and instructions; PSA), iii) minimal contact therapy (therapist actively involved in applying techniques; MCT). SA therapies have also been further grouped into non-guidance contact (NGC), whereby contact does not include any therapist input or assistance in applying therapy techniques, and guidance contact which involves assistance with therapy techniques (Talbot, 2012). Taking into account the level and type of support provided by professionals is important when trying to balance accessibility to the therapy without affecting efficacy or adherence (Talbot, 2012).

The introduction of DHIs could overcome the current challenges experienced by healthcare systems worldwide by improving access to care and promoting healthier populations (World Health Organization, 2019b). For YP with tics, self-help interventions have the potential to provide access to care, in particular for psychological wellbeing and cooccurring conditions which can have a great impact on YP with tic's lives; 'self-help options are also often used to treat important comorbidities that are not the main focus of therapy, freeing valuable therapy session time to focus on the primary issue' (Rickwood & Bradford, 2012, pp. 28).

The Digital Revolution

As of March 2018, YP are the greatest technology user population and 95% of adolescents have access to a mobile phone. Over the past four years, online internet usage and mobile phone ownership has increased rapidly. As of 2018, 45% of YP aged 13-17, are online 'almost constantly', and roughly 90% of teenagers go online multiple times daily (M. Anderson & Jiang, 2018). These figures represent a 22-point increase in mobile phone ownership and have nearly doubled for both categories of online internet usage (Lenhart, 2015). The digital revolution has also resulted in increased numbers of self-help tools (Rickwood & Bradford, 2012). The average quarterly growth in the number of available apps related to health and fitness or medical categories increased at a rate of 7.7% from

January 2019 to September 2019 (Statista, 2019a, 2019b) and as of November 2019, users could access over 128,000 apps in this field.

DHIs hold much promise due to their ability to overcome current barriers to care. Barriers include geographic location, embarrassment or stigma which prevents people from help-seeking and a lack of trained professionals who are able to provide support (Eysenbach, 2001; Kauer et al., 2014; Malli et al., 2016). Digital interventions are considered 'low-threshold' designed to make accessing support as feasible as possible, therefore they offer increased accessibility through online or digital delivery, removing concerns YP may have about talking about their condition as the intervention is accessed independently and require no therapist input (Edland-Gryt & Skatvedt, 2013). Furthermore, and potentially most importantly, DHIs have been found to be effective. The main focus of reviews have attended to the guided self-help literature, which include some degree of online or offline therapist input, and have been found to be effective for YP with clinically diagnosed or elevated symptomatology for depression and anxiety, (Ebert, Zarski, et al., 2015; Grist et al., 2019; S. Rice et al., 2014; Rooksby et al., 2015; Whittington et al., 2016). Fewer reviews have focused on unguided self-help interventions, of which only two are known to the author, Bennett et al. (2019) and Grist et al. (2019). The findings from these systematic reviews however provide support for small but positive effects of unguided SHI for YP with anxiety and depression. Together, these reviews are somewhat limited for generalising to broader mental disorders, but these findings suggest an aptitude for unguided self-help interventions for YP with reduced wellbeing.

Accessing Healthcare for YP with Tics

YP aged 10-24 have the lowest healthcare coverage compared to other age groups (G. C. Patton et al., 2016) and the NHS five-year plan will only continue to offer mental health support to one third of children (House of Commons Committee of Public Accounts, 2019). This is concerning for YP with TS, who already show reduced priority by healthcare services, with wait-times for receiving a referral or getting a diagnosis averaging three years (Hollis, Pennant, et al., 2016), and recent cuts to services have resulted in hundreds of patients with TS being discharged (McNally, 2020). Such reports highlight a lack of provision for these YP, which are not anticipated to improve. Recommendations for going digital to increase access to care for YP with TS was one of the priorities set by Hollis et al.'s (2016) work which informs NICE guidance and policy decisions. Additionally, international guidelines by the WHO recognises the value in DHIs to advance universal healthcare coverage (World Health Organization, 2019b) and the NHS intends to use technology to widen access to care (Department of Health, 2020).

Furthermore, a lack of available specialists with knowledge about TS presents a further barrier to access healthcare for YP with tics (Hollis, Pennant, et al., 2016). A survey showed that only 35% of psychologists had heard of HRT and less than 10% knew how to implement it (Marcks et al., 2004). This dearth in professionals trained to give behavioural therapy leads to long waitlists for YP and families trying to access support (McGuire, Ricketts, et al., 2015; Scahill et al., 2013). Guided self-help interventions and remote delivery of therapy still require professional’s time to deliver the intervention, plus planning time and support to the end-user (Andersson et al., 2005; Hetrick et al., 2016; Van’t Hof et al., 2009). Therefore, equipping professionals with digital tools that can provide support, or signpost YP with tics to more support could be useful.

Finally, YP show a reduction in help-seeking behaviour particularly during adolescence (Bradford & Rickwood, 2014) which in itself becomes a barrier to accessing support. Additionally, males have a reduced tendency to seek help than females (Cheng et al., 2018). Some of the most highly reported help-seeking barriers include stigma, MHL, a need for self-reliance and discomfort discussing problems (Bradford & Rickwood, 2014; Ebert, Berking, et al., 2015; Eysenbach, 2001; Gulliver et al., 2010; Kauer et al., 2014; Malli et al., 2016; Pennant et al., 2015). These barriers may explain why only 8.3% of adolescents who had recent anxiety-onset and 21.4% of adolescents with chronic anxiety accessed professional help during Essau et al.'s (2002) longitudinal study. Consequently, digital self-help for adolescents who prefer to be self-reliant may give them feelings of autonomy (Pennant et al., 2015; Shechtman et al., 2016) and concerns about stigma or embarrassment could be reduced as DHIs can be used privately and anonymously (Garrido et al., 2019; Gulliver et al., 2010; Kauer et al., 2014).

Effectiveness of Digital Self-Help Interventions

For unguided digital self-help interventions to become commonplace, they must be shown to be effective. The efficacy of self-help DHIs to improve wellbeing for YP with neurodevelopmental conditions are not known, as to date no reviews of SA DHIs to improve wellbeing have been conducted, and few empirical studies are known. As far as the author is aware, only one review has been conducted looking at the use of technologies across neurodevelopmental conditions, and found around half the reviewed studies showed clinical improvements in clinical-related symptoms, and included samples mainly made up of children (Valentine et al., 2020). However, few of these interventions related to improvement on wellbeing skills, with most aiming to improve symptoms directly related to the condition; although they were delivered via technology, they were not necessarily self-help. Furthermore, the focus of most interventions was on ASD, with no interventions aimed at TS and fewer aimed at ADHD or other NDDs (Valentine et al., 2020). Nonetheless, such findings show promise for the application of DHIs to other NDDs such as TDs. This is similarly supported by self-management technologies for ADHD and ASD alone, as found by two reviews. One review showed statistically significant improvements in the majority of studies aimed at improving ADHD-related difficulties for YP with ADHD using self-management technologies (Powell et al., 2018) and the other found similar results with populations of YP with autism using a variety of technologies to improve symptoms of ASD (Aresti-Bartolome & Garcia-Zapirain, 2014). In line with the former review, these two reviews suggest there is potential for digitally delivered self-help interventions with YP with other NDDs. Nevertheless, these interventions all pertained to improving symptoms more directly related to their condition, and not necessarily management of mood, which could be a result of living with their condition, or a cooccurring condition. It is important to assess whether interventions aimed at wellbeing are effective in populations of YP.

In terms of DHIs that target mental disorders, there is a wide evidence-base in support of their efficacy for YP, especially for anxiety and depression. Meta-analyses and systematic reviews of the adult literature relating to self-help interventions for elevated anxiety and depression, and OCD provides support for the clinical effectiveness of such interventions, most of which included technology interventions (Andersson, 2009; Cuijpers et al., 2011; R. Johansson & Andersson, 2012; Pearcy et al., 2016; Richards & Richardson, 2012; Spek et al., 2007). Similarly, within the child literature, systematic reviews and meta-analyses of DHIs for YP with elevated anxiety or depression also show support for the clinical effectiveness of such interventions, particularly in relation to the incorporation of CBT elements within the intervention (Ebert, Zarski, et al., 2015; Hollis, Falconer, et al., 2016; Pennant et al., 2015; Podina et al., 2016; S. Rice et al., 2014; Rooksby et al., 2015).

In trying to determine the mediators of behaviour change, some reviews have explored how the type of self-help, namely the level of therapeutic contact, impacts the intervention. In adult samples, increased therapeutic contact was found to increase efficacy using digitally-delivered CBT for depression (Andersson, 2009; R. Johansson & Andersson, 2012) and anxiety (Spek et al., 2007). Furthermore, not limiting the search to technology- or CBT-only interventions, a meta-analysis found improved efficacy with guided self-help interventions over purely self-help interventions for depression (Cuijpers et al., 2011). This was mirrored when the included studies were digitally-delivered (Richards & Richardson, 2012). Similarly, reviews with child populations have also found guided self-help to be more efficacious than non-guided self-help, within and outside of technology interventions (Bennett et al., 2019; Grist et al., 2019). An interesting proposal in a recent review suggested that such guidance does not necessarily need to come from a 'real' person, with advancements in technology enabling the development of 'virtual' or 'automated' coaches (Hollis, Falconer, et al., 2016). This suggestion is in line with the benefits of using self-help, which aims to reduce costs, therapist time and resources. Guided interventions, whilst effective, still rely significantly on these resources (Podina et al., 2016) and therefore this still exists as a limitation of guided self-help. The present research shows that SA self-help is effective for YP with mental health conditions and for YP with NDDs. Whilst SA self-help is not as effective as forms of guided self-help, but considering its benefits over guided self-help for a condition that experiences many barriers to care, the potential of a SA self-help tool for TDs is high.

Adherence and Engagement to Digital Self-help Tools

Non-adherence to medical treatments is an ongoing challenge for medical professionals, and is not limited to behavioural interventions, also including medication adherence, appointment adherence, treatment programme adherence, but has become one of the major limitations of DHIs. Reduced adherence means patients do not benefit from the full effects of the treatment, which impacts on recovery and leads to increased healthcare costs (Van Dulmen et al., 2007). Of importance, behaviour change mechanisms within interventions are unlikely to have any effect if participants are only briefly exposed to them (Beintner et al., 2019). For decades, adherence within the DHI literature has been reported as a pressing problem (Eysenbach, 2005), yet the rates of non-adherence have changed very little (Van Dulmen et al., 2007).

Different terms are used to capture adherence, including compliance, engagement, attendance, retention, attrition, dropout, and there are various methods to measure adherence, which may capture different aspects such as ‘login’ to the intervention, completion of post-trial measures, self-reported adherence. Eysenbach (2005) disentangles these distinctions, referring to ‘drop-out attrition’ as participants not completing all questionnaires in a trial, and ‘non-usage attrition’, as participants who display a loss of interest in the intervention. Therefore, rates of attrition may hold both participants who stopped adhering to the trial, and participants who stopped adhering to the intervention. Furthermore, another component relevant to adherence may reflect the subjective experience, characterising attention, interest and affect, namely; engagement (Perski et al., 2017). Together, intervention adherence and engagement capture both the amount or frequency of use, and the depth of the experience (Karekla et al., 2019). Nevertheless, a recent review of online interventions for common mental disorders found wide variability in the reported usage metrics across papers. Additionally, authors used different terms, meaning that in one intervention a ‘complier’ may be someone who has completed half the modules, whereas this term could refer to completing the entire intervention in another (Hollis, Falconer, et al., 2016). The usefulness of these metrics was also variable, for example time spent in an intervention does not necessarily reflect activity (Beintner et al., 2019). These inconsistencies led to the proposal of reporting standards for interventions, which included recommendations that adherence is addressed in every publication regarding online interventions, including at least the average number of completed modules and the number of participants who never logged into the intervention (Beintner et al., 2019).

Increased guidance may impact the efficacy of interventions by increasing the ‘dose’ of the intervention through increased compliance. A meta-analysis of OCD self-help interventions, found increased effect sizes with increased therapeutic contact (Pearcy et al., 2016). One systematic review that specifically addressed guidance in interventions with adults with a diagnosed mental disorder, found increased improvements of symptoms with guidance over non-guided interventions, and increased completer rates for guided interventions. However, they did not find support for increased dose of guidance or higher levels of qualification of the person giving the guidance, on symptom improvement (Baumeister et al., 2014). Whilst reviews with child populations tended to find increased efficacy with guided interventions over non-guided, (Bennett et al., 2019; Grist et al., 2019) neither review highlighted rates of adherence or captured attrition throughout the interventions. Without these rates, it is difficult to begin to understand where problems with adherence may lie. This is further complicated by other reviews finding improved effects of minimal therapist involvement over significant therapist involvement with a computerised anxiety intervention for YP (Podina et al., 2016) and some studies have suggested adherence to digital self-help interventions in 'real-world' settings for YP with a mood disorder are promising (Fleming et al., 2018).

Nonetheless, empirical studies with populations of YP with NDDs give more data on rates of attrition but this does not necessarily enhance our understanding of how adherence may impact the efficacy of these interventions. For example, comparing a parent-guided online self-help format to a therapist-guided behavioural therapy to reduce tics for YP with TS, found high levels of completion with around half of participants completing all chapters, and no drop out attrition (Andrén et al., 2019). However, in a parent and child guided self-help digital intervention for the treatment of anxiety in a sample of YP with ASD, compliance rates were lower, with only 19% of children completing all sessions (Conaughton et al., 2017). Variability between rates of compliance was also found in a review of internet based self-management interventions for YP with physical chronic health conditions such as asthma (Stinson et al., 2014).

One method believed to increase adherence to interventions is through increasing YP's engagement with the intervention. A lack of engagement could be the result of features which are assumed to be appropriate for the users, although the users have not been involved in the design. Qualitative findings from studies have highlighted aspects of interventions that people like for interventions for mental health, such as online or digital based platforms, social support and therapeutic support, useful content, interactive components, gamification of features, personalisation. Features that were not liked included boring, condescending or irrelevant content, limited information about the intervention, extensive text, technical glitches, intensive features that were complex (Achilles et al., 2020; Garrido et al., 2019; O. Johansson et al., 2015). Participatory methods include the incorporation of end-users into the design and development of the intervention (Achilles et al., 2020), which extends beyond an engagement exercise but requires an iterative and continuous process where end-users are collaborators on the project due to their expertise in their experience (Bevan Jones et al., 2020). However, despite the recognition that participatory methods can improve engagement (Bevan Jones et al., 2020; Garrido et al., 2019; Grist et al., 2019; Hollis, Falconer, et al., 2016) reviews highlight a lack of participatory methods in their development. One recent review examining the design and reporting of mental health DHIs for YP identified only six of the 30 interventions involved users in the content and design of the intervention (Bergin et al., 2020). Further, none of the 34 technology delivered interventions for depression and anxiety included in the review reported using any adolescents in their designs (Grist et al., 2019).

Together, the existing research shows there is still much to be gained from further exploration of adherence. This requires future work to record and report more standardised and useful measures of adherence, in particular capturing both drop-out and usage of an intervention, and reporting on engagement. It also requires more work to focus on engagement, and the subjective elements of interventions that may be liked and disliked by end-users. Through understanding adherence and engagement behaviours of end-users, the mediators of what makes an intervention both effective and adhered to can be better understood and captured within the intervention.

Evidence, Theory, and Person-Based approaches

It is now recognised that when developing an intervention, in order for it to be effective and engaging, a combination of theory, evidence and person-based approaches are needed (Band et al., 2017; Bradbury et al., 2017). Guidelines have been presented to support the development of interventions, both which propose that a review of the literature should be undertaken to identify key behaviours and application of theory to learn how behaviour may be changed via the intervention. Both guidelines also propose collecting primary data if questions cannot be answered by the current literature (Bradbury et al., 2014; Craig et al., 2008). Further, they emphasise that these methods do not necessarily need to be completed in a linear fashion, with iterations of the phases suggested.

A theory provides a framework, including concepts, definitions and proposals that can explain or predict events so they can be better understood (Michie & Prestwich, 2010). Use of theory in intervention-design can help to identify constructs that are related to behaviour, and therefore could be targeted by the intervention to promote behaviour change (Michie & Prestwich, 2010). Furthermore, it is advocated that multiple theories and models should be applied to an intervention to consider the wide influencers of behaviour that the intervention could aim to change (Michie et al., 2011) with increased effect sizes related to more extensive use of theory (Michie & Prestwich, 2010). However, there is limited literature on how to apply theory to interventions (Michie et al., 2011; Michie & Prestwich, 2010). In response to the lack of practical guidance, the Behaviour Change Wheel (BCW) was developed. To be coherent and comprehensive, the BCW captures the range of mechanisms of behaviour change by including a synthesis of 19 frameworks, whilst remaining simple and practical for application (Michie et al., 2014). The BCW is doughnut-shaped, with the model of behaviour placed at the hub of the wheel to emphasise behaviour change as the foundation of the intervention, known as the Capability-Opportunity-Motivation Behaviour (COM-B) model, and behaviour is felt to be based on an interaction between these components. Capability can be physical or psychological, and refers to how knowledge, skill or executive functioning, influences behaviour. Opportunity includes physical opportunity and social opportunity, which finds that environments can be behavioural maintainers, or facilitators in behaviour change. Motivation refers to the effort or belief in behaviour change, which can be reflective (e.g. plan-making) or automatic (e.g. emotions) (Michie et al., 2011; National IAPT team, 2015). This model can be applied to interventions to capture the behaviour change techniques that are needed in an intervention to promote behaviour change.

Finally, participatory approaches are also felt to be important in improving engagement with an intervention. The PBA aims to ground the development of an intervention through a deepened understanding of the contexts and perspectives of the end-users, stakeholders, professionals and healthy members of the community (Yardley, Morrison, et al., 2015). This is different from patient-centred approaches where the patient's views are given precedent and other views may not be accounted for (Yardley, Morrison, et al., 2015). The aim is to help the developer understand how end-users may engage with the intervention, what features would be viewed especially relevant and useful, and which would be deemed irrelevant and useless. It is hoped through stressing the importance of user input from the initial development stages, and stepping away from traditional expert-led intervention development, YP may better engage with DHIs that will better meet their needs (Bevan Jones et al., 2020). Through this, the intervention should be more attractive and feasible to that population, which in turn should increase the usability, acceptability and satisfaction of the intervention during implementation (Yardley, Morrison, et al., 2015). However, in addition to other participatory approaches, the PBA aims are more holistic, desiring to ensure interventions are motivating, enjoyable, engaging, informative, convincing and that they change behaviour or enhance wellbeing (Yardley, Morrison, et al., 2015). Through complementing existing theory or evidence-based approaches, the PBA has been deemed especially relevant for DHIs which are designed in an iterative fashion based upon a deep understanding of how people would use an intervention independently (Yardley, Morrison, et al., 2015).

Theory, evidence and person-based approaches have recently been applied to the development of DHIs for a variety of conditions as a comprehensive approach which centres the end-user in the development process and is designed to maximise acceptability, feasibility and effectiveness. Such DHIs have included self-management of hypertension, supporting antidepressant discontinuation, reducing risk of foot ulcers for diabetic patients and developing a set of guidelines for digital ADHD interventions for YP (Band et al., 2017; Bowers et al., 2020; Bradbury et al., 2019; Greenwell et al., 2018; Powell et al., 2019). It is not surprising given their recent development that few of these interventions have trials to support the efficacy of the approach, although some are underway (Bowers et al., 2020; Dougall et al., 2020; Greenwell et al., 2018; Kendrick et al., 2020). Until such trials are available, it is difficult to ascertain whether this approach leads to effective and engaging DHIs, however the findings so far suggest they are acceptable.

A Digital Wellbeing Intervention for YP with TD

A digital self-help intervention for YP with tics could help to overcome the barriers of accessing healthcare to support and promote psychological wellbeing and QoL in this population. Utilising a person, evidence and theory-based approach in the development of the intervention may help to improve challenges with engagement and adherence.

Aims of PhD

This PhD aims to explore whether a self-help digital intervention to support improved psychological wellbeing for YP with TS is needed, and if so whether it would be useful and what it would feature. Initially, a systematic review of the literature is required to assess the current digital self-help interventions available for YP with and without TDs to improve psychological wellbeing so this evidence can be used to inform the development of the tool. Qualitative exploration of the opinions of professionals who work with YP with tics and YP themselves is needed to give an in-depth understanding of whether a wellbeing intervention is desired. Further qualitative research using focus groups with YP and their caregivers will explore what features would be desired and how such an intervention would function. Additional focus groups with YP and caregivers will help to identify the most important features of the intervention to prioritise components for development. By the end of this study, it is hoped that the guiding principles and a logic model will be proposed to identify the core features and functions of the intervention for the next stage of development, to support and promote the psychological wellbeing in YP with tics.

Chapter 2 - Systematic Review of Self-help Interventions for Wellbeing in YP with Reduced Wellbeing[1]

Introduction

The objective of the present systematic review was to identify whether any unguided self-help wellbeing interventions for YP with TDs exist. Furthermore, to capture features of interventions that may be relevant to YP with TDs, encompassing all digital self-help interventions for YP with self-reported low psychological wellbeing, or with low wellbeing manifested as part of their symptomatology of a clinically diagnosed common mental disorder will be included. Expanding the scope of the previous reviews by Bennett et al. (2019) and Grist et al. (2019), all controlled studies and RCT trials will be included. The level of adherence to self-help interventions in PSA, NGC interventions, the retention and attrition to the interventions was also collected and reported. If effective, features of these interventions which would not rely on professional support or clinical diagnoses, could be integrated into a digital mental health support intervention for YP with TS.

Methods

Papers that assessed the efficacy and acceptability of self-help digital interventions targeted at YP with reduced psychological wellbeing, with or without a diagnosis of a mental disorder. A protocol was created and registered on PROSPERO, the International Register of Systematic Reviews (ID: CRD42019129321; https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=129321). Please see Appendix 1 for the PICO table.

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[1] Paper in review with the Journal of Medical Internet Research: http://preprints.jmir.org/preprint/25716. This paper was adapted from the current findings to be more appropriate for a wider audience relating to all mental disorders.

Types of Studies

The search was limited to publications in English as translation was not possible. The search was intended for quantitative studies, therefore qualitative studies, reviews, commentaries, theses and protocols were excluded. Study designs needed to be at least controlled pre-post designs to be included, but randomisation or control groups were not mandatory. Studies using secondary data, where the primary paper was already included, were removed to prevent bias.

Types of Participants

Age

Studies were excluded if participants were under 9 or over 25 years old or had a mean population age ≥18.51 years. This ensured all interventions were used by YP (Bennett et al., 2019).

Conditions

YP with reduced wellbeing indicated by self-diagnosis, meeting a diagnosis for a mental health condition or reaching a clinical threshold on wellbeing measures as specified by the researchers, were included. To comprehensively cover any intervention with YP with TDs, different search terms were used relating to TS, including various terms for TDs and tics including involuntary movements, coprolalia, copropraxia, premonitory urges, tics, stereotyped behaviours. These can all be found in the conditions of the PICO table, Appendix 1. Other mental, behavioural, and neurodevelopmental disorders highly cooccurring with TDs were included, gathered from searching prevalence papers on TS. Studies with only healthy populations were excluded. Data from sub-groups with reduced wellbeing were included. Physical conditions or mental disorders not common to childhood e.g. psychosis were excluded.

Types of Interventions

Interventions had to meet the criterion of being a digitally delivered self-help intervention for wellbeing, hence only interventions using digital delivery were included. Digital delivery included the use of online and offline delivery, such as through websites or software (e.g. downloaded program, CD-ROM, applications) loaded on a technology device (e.g. tablet, phone, computer).

Combination studies of digital interventions with non-digital interventions were excluded. No exclusion criteria were applied to the type of digital delivery, length, or number of intervention sessions.

In meeting the definition for self-help, interventions should require minimal therapist support (Bower et al., 2001). Using the categories proposed by Newman et al. (2011), interventions should be SA or PSA. Therefore, interventions with greater than PSA support (i.e. therapeutic support from a trained professional) were excluded. Interventions with support from gatekeepers or research staff for technical assistance or overseeing the practical provision of the intervention were included, providing this did not provide therapeutic support. Studies including automated emails or feedback were included, but responses containing therapeutic feedback or guidance were excluded. As a note, many studies with YP included safety checks. As safety checks are not offering therapeutic support, and are necessary for ethical conduct, these studies were not excluded.

The aim of the intervention needed to improve the psychological wellbeing of the young person, identified by an outcome measure in the research that pertained to a measure of wellbeing. Interventions aimed at other concepts, such as pain management, were excluded. Whilst pain interventions may be relevant for YP with tics who often experience injury and pain, the focus of this review was on psychological wellbeing.

Types of Outcome Measures

The primary outcome of interest was psychological wellbeing. Studies not measuring change in wellbeing (i.e. pre- and post-intervention) were excluded as this would not allow effectiveness assessment of the intervention.

In defining ‘psychological wellbeing’, this study applied the same definition of psychological wellbeing as identified previously in the introduction, including the domains of mental, psychological, and social wellbeing. Pollard and Lee (2002) conducted a systematic review of the child wellbeing literature and identified a list of positive and negative wellbeing indicators relating to social and psychological wellbeing which were used to identify outcome measures, such as aggression, anxiety, emotional problems, loneliness, happiness, purpose-in-life, self-esteem, anti-social behaviour, negative life events, peer problems, troubled home relationships, prosocial behaviours, social skills, support; see Pollard and Lee (2002) for the full list of indicators.

Secondary outcomes of efficacy and trial retention were recorded.

Search Methods

The search strategy covered the following constructs: 1) YP, 2) mental health conditions, 3) modes of digital intervention and delivery, and 4) self-help. These constructs were searched using the AND boolean term, meaning papers had to meet each of the above constructs to be returned by the database. Each concept included wide-reaching terms, aiming to capture as much of the literature as possible. Further, terms were adapted depending on the relevant subject headings or MeSH terms, to include plurals, singular words and different spellings of the words.

Electronic Searches

Five bibliographic databases (PsychInfo, Embase, Cochrane, Scopus, MEDLINE) were searched electronically for relevant articles from their conception until 28th August 2020, when the search was conducted. Please see an example search strategy in Appendix 2.

Other Searches

Reference lists of relevant systematic reviews (see Appendix 3) were hand-searched by CB. Further, the database, OpenGray, was searched to identify relevant grey literature.

Data Collection and Analysis

All references were imported into Endnote X9 and duplicates were removed. Initially, CB screened the references based on title, excluding irrelevant references and documenting reasoning in the flowchart seen in Figure 1. This process was repeated based on abstract and full papers. At full paper screening, all remaining articles were reviewed by both CB and EBD, a post-doctoral researcher with a lot of experience with systematic review searches. Authors were contacted when more information was required to indicate inclusion or exclusion and if no response, authors took a precautionary stance and papers were excluded. Disagreements were resolved through discussion between CB and EBD.

Selection of Studies

Full text articles were screened in line with the eligibility criteria. Overall, 20% of full text articles that appeared relevant were independently screened by GJ and EN to check for agreement. This systematic review used the PRISMA statement to ensure transparent and comprehensive reporting (Moher et al., 2009).

Data Extraction & Management

Data extraction of papers meeting the inclusion criteria were extracted into Revman 5.3, a systematic review software developed by Cochrane (downloaded from https://training.cochrane.org/), by author CB. Sample characteristics (age range, total number, gender, inclusion criteria, retention and attrition figures), study design, intervention and comparison intervention details (aim, length, number of sessions, components of intervention, professional contact, and delivery method), outcomes measured and when these were measured and key findings were taken from each study and placed into a summary of findings table.

Assessment of Risk of Bias

Risk of bias for each study was assessed by CB using the Cochrane Collaboration tool (Higgins et al., 2011). Disagreements were discussed with EN and GJ and resolved by consensus. This tool assessed validity through risk of bias across five domains including: selection bias, performance bias, detection bias, attrition bias and reporting bias. Experimenter bias was also assessed as part of the other sources of bias. This tool was developed for RCT studies, but this tool was also used on controlled pre- and post-studies using adaptations to the tool suggested in previous protocols (R. Ryan et al., 2013). CB made judgements on the risk of bias including a supporting quote from the text when possible. Attribution of low risk means the bias was unlikely to have caused an effect on the findings and high risk suggests bias may have had a significant effect on the findings. No publications were excluded based on quality as a meta-analysis was not performed on the data. Studies of high bias were given less weighting when applying the findings to a narrative synthesis.

Results

Study selection

In total, 985 studies were returned from the search, of which 169 were duplicates and removed. Subsequently 816 studies were screened by title: 568 were excluded based on title, 154 were excluded based on abstract and 83 were excluded based on screening of full texts, leaving 11 papers included in the review. The reasons for exclusion was documented and can be seen in the flow diagram (Figure 1).

Study characteristics

Table 5 shows a summary of characteristics for each study. Nine studies were RCTs and two were controlled pre-post studies, all published between 2006 and 2017. Sample sizes of YP with reduced wellbeing ranged from 23 to 240 (mean=128). Studies were categorised depending on the intervention's primary aim, which included improving depression, depression and anxiety, and social-functioning. None of the studies included populations of YP with TDs. The majority of studies (n=6) aimed to improve symptoms of depression for YP experiencing depression, and employed three different interventions, *SPARX* (Fleming et al., 2012; Merry et al., 2012; Poppelaars et al., 2016), *The Journey* (Stasiak et al., 2014) and *MoodGYM* (Lillevoll et al., 2014; O'Kearney et al., 2006). Two interventions, *Mobiletype* and *Stressbusters* were aimed at both anxiety and depression symptoms. *Mobiletype* aimed to improve levels of anxiety, depression and stress with populations of YP who were showing reduced general wellbeing (Reid et al., 2011) and *Stressbusters* aimed to improve symptoms of anxiety and depression in YP experiencing low mood and depression, assessed in two studies (P. Smith et al., 2015; Wright et al., 2017). The final two studies explored YP with social functioning difficulties. These included an intervention on blogging about social difficulties (Boniel-Nissim & Barak, 2013) and a cognitive bias modification training (CBMT) intervention (Sportel et al., 2013). Studies originated from Israel (n=1), New Zealand (n=3), Australia (n=2), the Netherlands (n=2) and Norway (n=1) and UK (n=2).

Descriptions of interventions

In total, this review found papers on seven different interventions (*SPARX*, *The Journey*, *MoodGYM*, *Mobiletype*, *Stressbusters,* blogging and CBMT) delivered by mobile phone, internet and, or computer. Of the two freely available interventions, one could be used worldwide (blogging) and one was restricted to those living in the country it was developed (*SPARX*). A more detailed description of the content of the interventions can be found in Appendix 4. One intervention required an annual fee (not required by participants in this study; *MoodGYM*) and four were only available through research institutes (*Mobiletype*, *Stressbusters,* CBMT and *The Journey*). Professional contact during these self-help interventions were at most classroom supervision whilst YP completed the task and site visits to check safety concerns (see Table 4 for contact per study). Length of interventions varied from 5 to 28 sessions, with session duration ranging between 3 to 60 minutes. All studies had a follow-up with the shortest being four weeks and longest at twelve months. All studies had control interventions which included treatment as usual (n=1), delayed intervention (n=1), waitlist control (n=2) and an attentional control group matching the structure of the intervention but different content (n=7).

Outcome measures

Outcome measures, both primary and associated outcomes, across interventions were highly heterogenous, with a variety of different scales used to assess psychological and social wellbeing (see Table 2) for all outcome measures used by multiple studies). The most used outcome measure reflected two mental health conditions: anxiety and depression. The RCADS was the most commonly used scale across four of the six studies aiming to improve depression (Fleming et al., 2012; Merry et al., 2012; Poppelaars et al., 2016; Stasiak et al., 2014). Three studies utilised the MFQ (Merry et al., 2012; P. Smith et al., 2015; Wright et al., 2017), CDRS-R (Fleming et al., 2012; Merry et al., 2012; O'Kearney et al., 2006) and SCAS (Fleming et al., 2012; Merry et al., 2012; Wright et al., 2017), and two studies used the CES-D (Lillevoll et al., 2014; O'Kearney et al., 2006) across interventions aimed at depression, and anxiety and depression. Outside of measures of anxiety and depression, the PQ-LES-Q, a measure of QoL, was utilised by three interventions for improving depression (Fleming et al., 2012; Merry et al., 2012; Stasiak et al., 2014), the RSES, a measure of self-esteem, was used in three separate studies for interventions that aimed to improve anxiety and depression, and social functioning (Boniel-Nissim & Barak, 2013; Lillevoll et al., 2014; O'Kearney et al., 2006) and the ACS-Short to rate coping, was used in interventions for both depression and anxiety interventions (Reid et al., 2011; Stasiak et al., 2014). In total, there were 32 different types of outcome measures, 24 of which were only utilised by individual studies and are reported in Table 5.

Due to few studies using similar outcome measures, three studies having no depression outcomes and those that did measure depression used a variety of scales, two studies reporting on the same data set, skewed data and moderate to high levels of potential bias across the studies, it was decided that conducting a meta-analysis would not reflect the data appropriately and so a meta-analysis was not undertaken.

	Outcome Measure	**Depression**				**QoL**	**Anxiety**	**Self-esteem**	**Coping**
Intervention Aim	Study ID	RCADS	CDRS-R	MFQ	CES-D	PQ-LES-Q	SCAS	RSES	ACS-Short
Depression	Merry 2012	✓	✓	✓		✓	✓		
	Fleming 2012	✓	✓			✓	✓		
	Poppelaars 2016	✓							
	Stasiak 2014	✓	✓			✓			✓
	O'Kearney 2006				✓			✓	
	Lillevoll 2014				✓			✓	
Anxiety and depression	Reid 2011								✓
	Wright 2017			✓			✓		
	Smith 2015			✓					
Social functioning	Boniel-Nissim 2013							✓	
	Sportel 2013								
	Total	4	3	3	2	3	3	3	2

Table 2 Table of studies using multiple outcome measures, separated by intervention aim and target outcome measure. For outcome measures used by individual studies, see Table 5. RCADS = Revised Child Anxiety and Depression Scale (Chorpita et al., 2000); CDRS-R = The children's depression rating scale-revised (Poznanski & Mokros, 1996); MFQ = Mood and Feelings Questionnaire (Costello & Angold, 1988); CES-D = Centre for Epidemiologic Studies Depression Scale (Radloff, 1991); PQ-LES-Q = Paediatric Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott et al., 2006); SCAS = Spence Children's Anxiety Scale (Spence et al., 2003); RSES = The Rosenberg Self Esteem Scale (Rosenberg, 2015); ACS-Short = Adolescent Coping Scale (Frydenberg & Lewis, 1993).

Characteristics of participants

In total there were 1398 participants, ranging from 11 to 24 years, with an average of 15.4 years (for given average age). On intervention commencement, reduced wellbeing levels were indicated by meeting a threshold on a clinical questionnaire in all but one study whose inclusion criteria included expressing a need for intervention due to symptoms of depression (Merry et al., 2012). Sub-group analyses from two studies with school-based populations showed elevated scores on depression symptoms (Lillevoll et al., 2014; O'Kearney et al., 2006).

Risk of bias within and between studies

Type of bias	Selection		Performance	Detection	Attrition	Reporting	Other	Number of quality criteria achieved within studies (out of 7)
Method to protect from biases	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Complete outcome data	Unselective reporting		
Authors								
O'Kearney 2006	🟥	🟥	🟥	🟨	🟩	🟨	🟥	1
Poppelaars 2016	🟩	🟥	🟥	🟥	🟩	🟨	🟥	2
Fleming 2012	🟩	🟩	🟥	🟥	🟩	🟨	🟥	3
Wright 2017	🟩	🟥	🟥	🟨	🟩	🟨	🟥	3
Smith 2015	🟩	🟨	🟥	🟨	🟩	🟨	🟥	2
Lillevoll 2014	🟩	🟥	🟩	🟨	🟩	🟨	🟥	2
Boniel-Nissim 2013	🟥	🟥	🟩	🟩	🟩	🟨	🟩	3
Merry 2012	🟩	🟩	🟥	🟩	🟩	🟨	🟥	4
Reid 2011	🟩	🟩	🟩	🟥	🟩	🟨	🟥	4
Sportel 2013	🟩	🟩	🟩	🟩	🟨	🟥	🟥	4
Stasiak 2014	🟩	🟩	🟩	🟩	🟨	🟨	🟥	5
Number of quality criteria achieved between studies (out of 11)	9	5	5	4	9	1	1	

Table 3 Risk of bias table (Higgins et al., 2011) with the total number of quality criteria achieved across and within studies, ordered from lowest to highest total number of quality criteria.

Table 3 displays risk of bias based on the Cochrane Collaboration's assessment tool (Higgins et al., 2011) which covers six domains of bias including selection bias, performance bias, detection bias, attrition bias, reporting bias and other bias. For each bias, a high, low or unclear risk was allocated and support for that judgement was provided, and if unknown, it should be stated. None of the studies met all six standard quality criteria, five studies met five of the seven criteria, and six of the studies met less than half of the criteria to reduce bias in studies. Most studies (n=9) applied adequate random sequence allocation that is expected to create comparable groups through randomisation, which could be replicated. Fewer studies (n=5) applied group allocation without any prior knowledge of participants which increases risk of groups being selected for or against using an intervention. There was similar high risk for performance bias, where participants were not blind to the intervention (n=4). Less than half the studies utilised blinded outcome assessors (n=4) leading to potential detection bias. Attrition and reporting bias were both found to be of higher quality across studies with most studies reporting complete outcome data (n=9) and not appearing to selectively report (n=10). Across all biases there were eight cases where there was an unknown risk of bias as papers did not supply adequate information. In other bias the highest risk of bias was found, as almost all the studies displayed risk of experimenter bias, whereby the intervention developer was an author of the study (n=10).

Adherence to studies was investigated by looking at the number of participants retained based on those completing outcome measures at post-intervention and follow up, see Table 4. Retention varied from very high scores of 96.8% to very low scores of 10.4%. The very low score obtained by Lillevoll et al. (2014) with MoodGYM may be an outlier, as all other interventions had at least 60.4% retention. Not including Lillevoll et al. (2014), across studies of a total of 1200 participants, 1015 were retained giving an average retention of 84.5%. At follow-up, for the studies who provided the information, the range of retention varied from 57.9% to 89.8%. The amount and type of professional contact described in the intervention did not appear to relate to participant retention, although both school-based populations where sub-group analysis were pooled showed retention rates at the lower end of the scale (Lillevoll et al., 2014; O'Kearney et al., 2006).

Authors	**Professional contact**	**Number participants at Baseline**	**Participants retained (percentage/%)**	
			Post-intervention	Follow Up
Fleming 2012	Completed SPARX during class time under minimal supervision from school staff. Weekly check-ins from researcher (PhD student) conducted for safety checks and practical programme support.	32	31 (96.8)	25 (78.1)
Poppelaars 2016	SPARX was completed at home.	208	201 (96.6)	159 (76.5)
Merry 2012	Safety checks were completed at all time points, and an extra check one month into intervention.	187	170 (90.9)	168 (89.8)
Smith 2015	YP were given information about Stressbusters by a clinical psychologist, before making a decision on whether to take part. It was completed at school in an assigned room.	112	100 (89.2)	99 (88.4)
Stasiak 2014	School counsellors were instructed to support the YP practically in setting up completing The Journey, and would only provide therapeutic support if asked for more help from YP. The Journey was completed in the counsellor's office.	34	30 (88.2)	25 (73.5)
Sportel 2013	YP were given weekly emails with links to completed CBMT and a reminder if it was not completed.	240	200 (83)	139 (57.9)

Boniel-Nissim 2013	Checks via email were conducted to ensure participants had completed diary entries.	161	124 (78)	-
Reid 2011	If a young person indicated they were at risk of suicide or self-harm, a high-risk alert would be activated and the psychologist would assess and alert the young person's community team.	112	87 (77.6)	86 (76.7)
O'Kearney 2006*	Completed MoodGYM in a room at school during their tutor period and were supervised by teachers. Researchers attended the first session to check successful log-in.	23	17 (73.9)	18 (72)
Wright 2017	Researchers met with participants to provide practical support to accessing Stressbusters.	91	55 (60.4)	-
Lillevoll 2014*	Automated standard email reminders of level of MoodGYM use (tailored email group not included in this review)	198	19 (10.4)	-

Table 4 A table of the numbers and percentages of participants enrolled in the studies at baseline, post-study and follow up to display rates of retention, in descending order, with amount of professional contact. Percentages for participants retained were calculated by taking the total number of participants at baseline and dividing it by the participants at post-study or follow-up. These scores were used calculate the overall mean and median percentages.

** Studies marked with asterisk are using sub-group analysis data only, and not original sample numbers*

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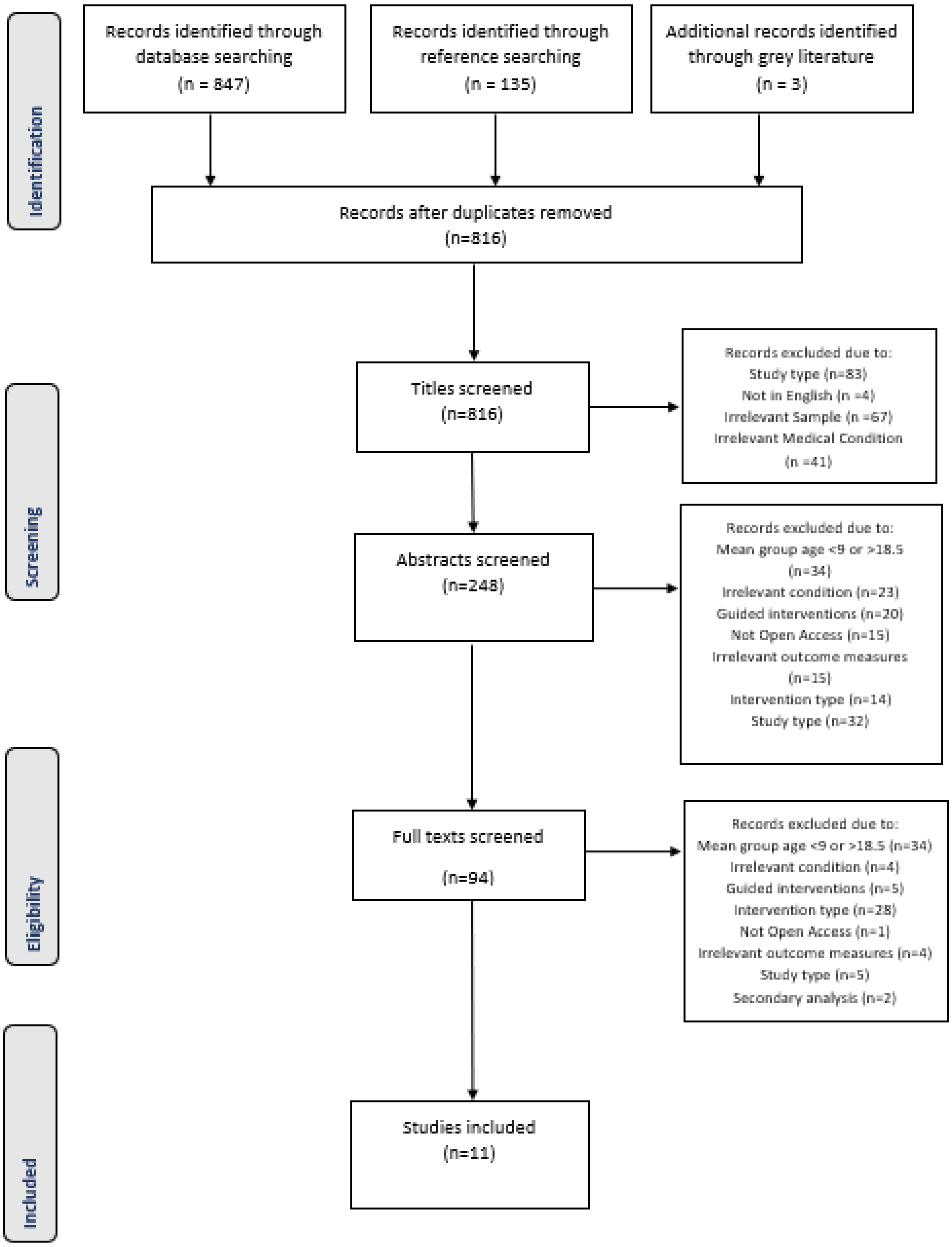


Figure 1 Flowchart of studies in line with PRISMA guidelines (Moher, 2009)

Primary aim of intervention	Authors	**Sample:** **Age range (mean)** **N of participants (males).** ***Inclusion criteria***	Design	Intervention				Comparison			Outcomes		Key Findings relating to aims of SR
				Name	**No. of sessions (length/ minutes)**	**Components**	**Delivery method**	**Components**	**Delivery method**	**No. of sessions (length/ minutes)**	**Measures Used**	**Measured**	
Depression	Merry 2012	12-19 (15.6) N = 187 (64) *YP presenting for treatment for symptoms of depression*	RCT	SPARX	7 (30)	CBT, psycho-education, relaxation skills, problem solving, activity scheduling, challenging and replacing negative thinking and social skills.	PC	TAU	Counselling N= 74 waitlist N= 11 medication N= 2		CDRS-R RADS-2 MFQ PQ-LES-Q SCAS K-10 CGI SAEQ	Baseline, post-intervention, 3 month FU	The SPARX group showed significant improvements on mood and feelings (MFQ), hopelessness (K-10) and anxiety (SCAS) which were maintained at follow-up. Participants in the SPARX group would recommend SPARX to friends and believed it would appeal to others.
	Fleming 2012	13-16 (14.9) N = 32 (18) *>30 on CDRS-R*	RCT	SPARX	7 (30)	CBT, psycho-education, relaxation skills, problem solving, activity scheduling, challenging and replacing negative thinking and social skills.	PC	WL		0	CDRS-R RADS PQ-LES-Q SCAS CNS-IE-Short	Baseline, post-intervention, 5 week FU	SPARX showed significant improvements for depression (CDRS-R; RADS) and may be effective in treating students in special education services who already have minimal symptoms of depression and anxiety for depression, although no differences were found at follow up.
	Poppelaars 2016	11-16 (13.4) N=208 (0) >59 on RCADS	RCT	SPARX	8 (40)	CBT, psycho-education, relaxation skills, problem solving, activity scheduling, challenging and replacing negative thinking and social skills.	PC	Op Volle Kracht (OVK) a depression CBT programme from Tak et al. (2012).	Professional Psychologist	8 (60)	RADS	Baseline, post-intervention, 3 month FU, 6 month FU 12 month FU	Reductions shown in RADS was significant across groups with a medium effect to 1 year FU, but there were no significant differences between groups suggesting no intervention was more effective than the other
								OVK + SPARX	Professional Psychologist + Computer	8 (80-120)	Suicidal Ideation		
								Control Group					

Primary aim of intervention	**Authors**	**Sample:** **Age range (mean)** **N of participants (males).** ***Inclusion criteria***	**Design**	**Intervention**				**Comparison**			**Outcomes**		**Key Findings relating to aims of SR**
				Name	**No. of sessions (length/ minutes)**	**Components**	**Delivery method**	**Components**	**Delivery method**	**No. of sessions (length/ minutes)**	**Measures Used**	**Measured**	
	Stasiak 2014	13-18 (15.2) N=34 (20) *>30 on CDRS-R or >76 on RADS-2*	RCT	The Journey	7 (30)	CBT, linking thoughts and actions to feelings, behavioural activation, pleasant activity scheduling, problem solving and conflict resolution, cognitive restructuring, challenging unhelpful thoughts, thought stopping, relaxation techniques, relapse prevention	PC	Computerized Psycho-education control attention placebo program based on psycho-educational content	Computer	7 (30)	CDRS-R RADS-2 PQ-LES-Q ACS-Short	Baseline, post-intervention, 1-month FU	The intervention group showed a significant improvement in a depression rating scale (CDRS-R) and in problem solving (ACS-Short). Reductions were found in the RADS for depression and PQ-LES-Q for QoL but these did not reach significance. Suggests the program shows efficacy short-term and has good adherence, although secondary measures rarely met significance.
	O'Kearney 2006	15-16 (-) N = 23/78 * (23) >16 on the CES-D	CBA	MoodGYM	5 (60)	CBT, Information, relaxation, problem-solving, dysfunctional thoughts, negative thinking, assesses self-esteem, cognitive restructuring, assertiveness, and coping with relationships.	Web	Private study, ad hoc discussion and physical activities. There was no specific discussion of depression during these activities.	Tutor groups	5 (60)	CES-D CASQ-R RSES	Baseline, 2 weeks post-intervention, 16 week FU	Those at risk of depression showed a reduction of vulnerability at post-treatment compared to the control group on both the CES-D and CASQ-R, which were still reduced at follow up compared to pre-intervention, although the risk reduction was not as large. Results should be interpreted cautiously as the sample size is small.
	Lillevoll 2014	15-20 (16.8)* N = 198/1337 (-)	RCT	MoodGYM	5 (60)	CBT, Information, relaxation, problem-solving, dysfunctional thoughts, negative thinking,	Web	WL	Email	0	CES-D GSE-Norwegian RSES	Baseline, 6-7 week FU	For participants with elevated depression scores on the CES-D, MoodGYM was not found to increase self-esteem (GSE-Norwegian) or reduce risk of depression (CES-D). These results
								MoodGym without reminders	Email + Internet	5 (60)			

Primary aim of intervention	Authors	Sample: Age range (mean) N of participants (males). *Inclusion criteria*	Design	Intervention				Comparison			Outcomes		Key Findings relating to aims of SR
				Name	No. of sessions (length/ minutes)	Components	Delivery method	Components	Delivery method	No. of sessions (length/ minutes)	Measures Used	Measured	
		>16 on the CES-D				assesses self-esteem, cognitive restructuring, assertiveness, and coping with relationships.		MoodGYM with standard reminders	Email + Internet	5 (60)			are likely due to high attrition and adherence problems.
								MoodGYM with tailored reminders	Email + Internet	5 (60)			
Anxiety and Depression	Reid 2011	14-24 (18.1) N = 118 (32) Mild/ severe mental health indicated by GP or >16 on K10	RCT	Mobiletype	14-28 (20)	Recording of current activities, location, companions, mood, recent stressful events, responses to stressful events, alcohol use, cannabis use, quality and quantity of sleep, quantity and type of exercise, and diet	Text	Recording of current activities, location, companions, quality and quantity of sleep, quantity and type of exercise, and diet	Text	14-28 (20)	DASS ESA ACS-Short 12-HS AUDIT	Baseline, post-intervention, 6 week FU	The intervention group showed a main effect of time on the ESA compared to attentional control, with a significant effect being found at 6 weeks follow up. The sample as a whole showed a decrease in mood-related scores for the DASS, which may have been as a result of 91% of the sample receiving a pathways to care prior to the intervention in their pre-test medical review.
	Wright 2017	12-18 (15.4) N = 91 (31) >20 on the MFQ	RCT	Stressbusters	8 (45)	Goal setting, getting activated, emotional recognition, noticing thoughts, thought challenging, problem solving, improving social skills, relapse prevention.	PC	Accessing self-help websites with no CBT content	Online	8	MFQ BDI SCAS HUI-2 EQ-5D-Y Service Use Questionnaire	Baseline, MFQ collected at start of each session, and all at 4 month FU and 12 month FU	Reduction in MFQ scores for intervention group over first 4 sessions, and a rise was seen in the control group, but no significant difference was found between groups at 4 month follow up on the BDI, SCAS or MFQ.

Primary aim of intervention	Authors	Sample: Age range (mean) N of participants (males). *Inclusion criteria*	Design	Intervention				Comparison			Outcomes		Key Findings relating to aims of SR
				Name	No. of sessions (length/ minutes)	Components	Delivery method	Components	Delivery method	No. of sessions (length/ minutes)	Measures Used	Measured	
	Smith 2015	12-16 (-) N=112 (-) >20 on the MFQ-C	RCT	Stressbusters	8 (60)	Goal setting, getting activated, emotional recognition, noticing thoughts, thought challenging, problem solving, improving social skills, relapse prevention.	PC	WL			MFQ SCARED-Child CRSQ MFQ-Parent SCARED-Parent Schol Attendance and Attainment	Baseline, post-intervention, 3 month FU, 6 month FU	Children in the intervention group showed significant decrease in MFQ and SCARED for self-rated and parent-rated scores, compared to the control group. Teachers reported no change but attainment was significantly improved for intervention group.
Social functioning	Boniel-Nissim 2013	14-17 (15.5) N = 161 (37) *Scored lower on standard deviation of index of peer relationship. Interested in starting a blog.*	CBA	Blogging	20 (20)	Blogging about social difficulties in open response blog	Web	Blogging about social difficulties in a blog closed to responses	Blog portal (internet)	20 (20)	RSES IPR IAC JSE	Baseline, post-intervention, 2 month FU	Blogging about social-emotional difficulties led to improvements in the writer's social-emotional condition as rated by independent judges on the JSE, compared to all other groups, and improvements in RSES, IAC and IPR compared to other blogging groups. Blogs relating to social-emotional difficulties that were open to public responses had improved judge-rated outcomes. The findings remained stable at 2 month follow-up.
								Blogging about general subjects in a blog open to responses	Blog portal (internet)	20 (20)			
								Blogging about general subjects in a blog closed to responses	Blog portal (internet)	20 (20)			
								Writing a private diary on a personal computer about social difficulties	Word processor	20 (20)			
								Control Group		0			

Primary aim of intervention	Authors	Sample: Age range (mean) N of participants (males). *Inclusion criteria*	Design	Intervention				Comparison				Outcomes		Key Findings relating to aims of SR
				Name	No. of sessions (length/ minutes)	Components	Delivery method	Components		Delivery method	No. of sessions (length/ minutes)	Measures Used	Measured	
	Sportel 2013	13-15 (14.1) N = 240 (66) >10 RCADS (girls) >9 (boys)	RCT	CBMT	20 (45)	Attentional bias modification tasks, strengthening the association between social-evaluative situations and positive outcomes, enhancing implicit self-esteem	Web	CBT: Psycho-education, task concentration training, cognitive restructuring, exposure, personal pitfalls and relapse.		Licensed psychologist	10 sessions (90)	STAI stIAT ADIS-C RCADS	Baseline, post-intervention, 6 month FU, 12 month FU	The CBMT group showed greatest improvements for stIAT and on the AIBQ. Both CBT and CBMT showed significant improvements at post-test for social and test anxiety, however this was significantly stronger for the CBT group. Follow-up scores suggest that both interventions still have an effect 12 months later, with the CBM group showing lower negative associations than other groups.
								Control Group			0			

*Table 5 Summary of findings table. Abbreviations: N = Number; CBA = Controlled Before After/ pre-post studies; Control Group = No intervention control; PC = Computer; Pre = pre-test; Post = post-test; FU = Follow-up; GP = General Practitioner; Web = internet delivered; WL = waitlist; (-) = missing data; ADIS-C = Anxiety Disorders Interview Schedule for Children (Silverman & Albano, 1996); CASQ-R = The Revised Children's Attributional Style Questionnaire (O'Kearney et al., 2006); CGI = Clinical global impression scale (Guy, 1976); CNSIE = Children's Nowicki- Strickland Internal-External Control Scale short (Nowicki & Duke, 1983), CRSQ = Child Response Styles Questionnaire (Abela et al., 2007);DASS = Depression Anxiety Stress Scale (Lovibond & Lovibond, 1995); EQ-5D-Y = EuroQol (Wille et al., 2010); ESA = Emotional Self Awareness Scale (Reid et al., 2011); GSE-Norwegian = Norwegian version of the General Self-Efficacy Scale (Røysamb et al., 1998); HUI-2 = Health Utility Index Mark 2 (Horsman et al., 2003); IAC = Interpersonal Activities Checklist (Boniel-Nissim & Barak, 2013); IPR = Index of Peer Relationship (Hudson, 1982); JSE = Judgment of social–emotional condition (Boniel-Nissim & Barak, 2013); K10 = The Kazdin hopelessness scale for children (Andrews & Slade, 2001); PHQ-A = Patient Health Questionnaire–Adolescent (J. G. Johnson et al., 2002); SAEQ = Satisfaction and enjoyment questionnaire (Merry et al., 2012); SCARED = Screening for Child Anxiety Related Emotional Disorders (Birmaher et al., 1997); STAI = Spielberger Test Anxiety Inventory (Ploeg, 1988), stIAT = Single Target Implicit Association Test (Sportel et al., 2013); *Sub-group analysis. Numbers are presented so that you can see how many of the total same were included in the sub-group analysis.*

Self-help interventions for depression or depressive symptoms

Of the three depression interventions, two were delivered by an offline computer programme (*SPARX* and *The Journey*), and *MoodGYM* was accessed through the internet. All interventions consisted of key components of CBT which included cognitive restructuring, problem solving, relaxation training, social and communication training and practice. Other components involved in the interventions included psychoeducation (*SPARX*, *MoodGYM*) or explicit homework tasks for skill reflection and application to real-life (*SPARX*).

Self-help interventions aimed at depressive symptoms for YP showing symptoms of depression, were effective when using fantasy-world games; *The Journey* and *SPARX* (Fleming et al., 2012; Merry et al., 2012; Poppelaars et al., 2016; Stasiak et al., 2014). These programs reduced depression at post-intervention, and improvements were maintained at three months (Merry et al., 2012) and one year follow up (Poppelaars et al., 2016). Furthermore, all four studies had at least 88% of participants completing post-intervention outcome measures, and 73% of participants for follow up.

The other self-help intervention studies aimed for depressive symptoms used *MoodGYM*, a traditional linear-style approach of computerized CBT (cCBT) (Lillevoll et al., 2014; O'Kearney et al., 2006). O'Kearney et al. (2006) found risk reduction and vulnerability reduction for depression post-intervention and at follow up, but these findings were not supported by Lillevoll et al. (2014) whose sample had high attrition rates of nearly 70% and reported no significant changes, likely as a result of loss of power. Whilst O'Kearney et al's (2006) study showed trends toward improvement in depressive symptoms, both studies had small final sample sizes and showed high risk of bias.

Self-help interventions for depression and anxiety

Two interventions were found for anxiety and depression, *Mobiletype* (Reid et al., 2011) and *Stressbusters* (P. Smith et al., 2015; Wright et al., 2017). *Mobiletype* is delivered through a mobile phone application that self-monitors to indicate to GPs and patients whether there is a need for greater intervention. The results suggested the use of self-monitoring mood for YP with depression and anxiety symptoms improves emotional self-awareness. These results are promising given very similar attentional control and the study scored highly for low risk of bias. Furthermore, retention rates were good considering this intervention was relatively demanding, requiring participants to make entries five times a day over 2-4 weeks, with results being maintained at six weeks follow up.

Stressbusters is a CBT-based offline computer intervention using a traditional linear-style approach to teach recognising and challenging emotions and thoughts. Both studies showed score reduction in anxiety and depression post-intervention and at four and six month follow-up, however for Wright et al. (2017), this was not significant compared to the control group, who also showed improvement. Further, there was nearly 30% difference between rates of attrition for both studies with Wright et al. (2017) having 60.4% remaining of their sample at follow-up, compared to 89.2% for Smith et al. (2015). Finally, both studies scored poorly with high or unknown risks of bias across five criteria for each study, relating to allocation concealment, blinding of participants, selective reporting and researchers, and a lack of independent researchers conducting the research.

Social functioning

Boniel-Nissim and Barak (2013) found improved outcomes when blogging about social difficulties and greater improvements when the blog was open to responses, for measures of social-emotional distress and social behaviour. These findings were retained at follow-up and showed low risk of bias. Sportel et al. (2013) used CBMT to modify the negative interpretations people with social anxiety may have. This intervention reduced negative associations up to 12 months post-intervention. While the CBT control group showed greater improvements over the CBMT group, the CBMT group showed greater improvements compared to a no intervention control group. Low risk of bias was also associated with this intervention.

Wellbeing outcomes not related to initial aim of intervention

Across studies, interventions aimed to improve particular outcomes, however the effects of the intervention were not always limited to the main aim of the intervention. Of the two studies exploring *SPARX* for depression, one study found improvements on scales for hopelessness and anxiety alongside improvements for depression scales (Merry et al., 2012). *The Journey* succeeded at its intention to improve depression scores, whilst also showing improvements in problem solving skills for coping (Stasiak et al., 2014). As anticipated, one of the *MoodGYM* studies showed patterns toward improvements in depression and vulnerability to depression, but also found improved self-esteem and attitudes toward depression, although none of these reached significance (O'Kearney et al., 2006), and this was not matched by the other *MoodGYM* study (Lillevoll et al., 2014). *Mobiletype* users, while a significant increase in depression and anxiety was not found, a general trend toward improvements was noted and a significant increase in emotional self-awareness compared to control groups was shown (Reid et al., 2011). In Smith et al.'s (2015) study into *Stressbusters*, a significant increase for school attendance was also seen alongside improvements in scores of anxiety and depression. Blogging about social difficulties improved outcomes on social dimensions such as social-emotional distress and engagement in social behaviours but also on self-esteem (Boniel-Nissim & Barak, 2013). For CBMT, the CBMT group showed improvements in implicit associations and for social interpretations, over other groups. Both CBMT and CBT groups showed social phobia and test anxiety reductions (Sportel et al., 2013).

Discussion

Summary of evidence

This review examined the efficacy of self-help interventions aiming to improve psychological wellbeing in YP with reduced wellbeing, indicated by a diagnosed, self-diagnosed or clinical threshold for a mental health condition, including TDs. Eleven studies met the search criteria, nine of which were RCTs and two were CBA studies. Most interventions (Fleming et al., 2012; Lillevoll et al., 2014; Merry et al., 2012; O'Kearney et al., 2006; Poppelaars et al., 2016; Stasiak et al., 2014) were aimed at YP reaching the threshold for depressive symptoms only. Fewer studies were aimed at those with depression or anxiety symptom difficulties (Reid et al., 2011; P. Smith et al., 2015; Wright et al., 2017) or social functioning (Boniel-Nissim & Barak, 2013; Sportel et al., 2013). No interventions were found relating to YP with a TD, or included YP with TDs in their sample. Whilst the findings may lack generalisability to a sample of YP with tics, these results still hold relevance due to the overlap of anxiety, depression and social functioning difficulties in YP with tics, which often occur as comorbidities and coexisting conditions of TS. Overall, the narrative evaluation indicated that unguided self-help interventions improved psychological wellbeing in the areas intended by the intervention. The results also highlighted such interventions lead to improvements in other areas of wellbeing which had not been the primary outcome of the intervention, such as self-esteem or emotional self-awareness. This is promising as it suggests DHIs for YP may have a holistic impact on user's wellbeing. This had been the intention of some wellbeing interventions for tics, although was not achieved (Viefhaus et al., 2019). Further, trial adherence indicated reasonable levels of retention, with three quarters of YP being retained at follow-up for most studies. As previously iterated in the introduction, whilst the relationship between drop-out and non-usage attrition are not the same, it is likely that they follow a similar relationship, in that loss of interest is likely to result in drop-out and vice versa (Eysenbach, 2005). This finding is somewhat contradictory to previously noted limitations of self-guided DHIs due to their lack of adherence and presents a promising outlook for adherence to self-help DHIs. Nevertheless, based on the lack of reported outcomes, it is suggested that future studies follow guidelines proposed by Beintner et al. (2019) to tease apart engagement and effects with the intervention to make better inferences outside of trial settings. Trial settings are believed to consist of 'push factors' that influence attrition rates, with more 'open' trials tending to have greater dropout (Eysenbach, 2005), as is likely illustrated in Lillevoll et al.'s (2014) sample who had reduced adherence, perhaps as a result of running a trial in a setting that resembled fewer trial characteristics. A recent review of unguided DHIs also supported this sentiment, finding trial settings impact user engagement making it difficult to generalise findings to the real-world (Baumel et al., 2019). Overall, these findings suggest YP experiencing reduced wellbeing do complete self-help interventions, which results in improved wellbeing compared with no intervention.

The greatest promise for self-help digital interventions seems to be CBT-based fantasy-style games (e.g. *SPARX, The Journey)* for depression symptoms, which had good trial retention and follow-up rates, whereas traditional linear-style interventions showed greater variation in improvements (*MoodGYM)*. This is in line with the aforementioned improved clinical efficacy of interventions that incorporated CBT elements for YP with elevated anxiety or depression (Ebert, Zarski, et al., 2015; Hollis, Falconer, et al., 2016; Pennant et al., 2015; Podina et al., 2016; S. Rice et al., 2014; Rooksby et al., 2015). Interventions for anxiety and depressive symptomatology showed general improvements for wellbeing, with mood monitoring (*Mobiletype*) leading to increased emotional self-awareness and at follow up, a general decrease in mood-related scores, as similarly found with linear-style interventions (*Stressbusters*), with one of the two studies reaching significance for reductions in depression symptoms. Finally, interventions aiming to improve social functioning were effective post-intervention and remained significantly so at follow-up for the blogging group. Previous reviews have suggested using guidance within self-help interventions improves the magnitude of effect (Bennett et al., 2019; Ye et al., 2014), but these findings suggest standalone interventions can support YP needing to access mental health services without the need for therapist assistance. Self-administered therapies have major advantages to guided self-help due to their scalability, whilst not necessitating further demands from already overburdened services including cost and training professionals (Fleming et al., 2016, 2018).

A meta-analysis on the studies included in this report was not deemed appropriate due to lacking high-quality studies, as nearly half the papers achieved less than half the quality criteria required to protect against biases. Notably, ten of the eleven studies suffered from experimenter bias and only one of the studies were identified as having low risk of bias for selective reporting. Conducting a meta-analysis with biased data can lead to authors producing misleading conclusions (Deeks et al., 2020). For example, inappropriate concealment of participant allocation or selection bias, as found in more than a half of the included studies for this review, can lead to a 30% overestimation of treatment effect (Egger et al., 2002). While there is a need for more high-quality assessments of self-help interventions, the time frames around running empirical studies against the rate of growth for commercial interventions make this difficult (Statista, 2019a). In light of the years it takes to complete and publish RCTs, it is unrealistic for researchers to complete controlled assessments on interventions with the unprecedented rate of growth for apps and digital technology development (Blandford et al., 2018; Grist et al., 2017). Consequently the use of RCTs to assess digital research has been questioned, with proposals that iterative development approaches are used and RCTs only applied to assess the overall functionality of an intervention, or it’s theoretical basis, rather than for minor intervention modifications (Blandford et al., 2018; Murray et al., 2016). For these reasons, this review recommends conducting higher quality CBA studies that do not overlook bias criteria. This meets the NICE best practice standard for self-management DHIs, requiring high quality studies with a comparison group (NICE, 2019b). One crucial method to improve quality, calls for researchers outside of the developing group of an intervention to carry out controlled trials to minimise experimenter bias. Furthermore, the inclusion of non-RCT studies within future systematic reviews will enable evaluation of the most recent interventions to give a comprehensive overview of whether self-help interventions can effectively support YP with mental disorders.

Despite a broad literature search, no self-help interventions aimed at YP with behavioural and NDDs were found. This is surprising given the huge potential benefits of using a digital self-help intervention as the first step in the stepped-care approach, not only for TS but also for other NDDs. A systematic review by Dey et al. (2012) found reduced QoL especially on psychosocial dimensions across studies of YP with a mental disorder, including NDDs. It is likely that YP with other NDDs also experience similar psychological wellbeing difficulties to YP with TS, therefore an intervention for other groups of NDDs would likely be applicable although the findings would suggest such an intervention does not exist. This gap in the literature provides support for the development of a wellbeing intervention for a population of YP with TS.

Limitations

There are several limitations of this review. The cognitive, economic and physical domains of wellbeing were not included in the outcome measures included in this review (Pollard & Lee, 2002). Whilst the authors recognise these domains relate to and are important aspects of child wellbeing, psychological and social functioning were felt to be the most impairing for YP living with a TD, which was our ultimate focus, therefore identifying interventions aimed at improving these aspects of wellbeing was the priority. As this review only considered common childhood disorders, conditions such as psychosis were not included, although it is recognised children with uncommon conditions would also experience reduced wellbeing. Therefore, these results cannot be generalised to rarer disorders that were not included in this review. Finally, data was missing from certain studies which impacted on study inclusion, conclusions that could be drawn for trial retention, and the ability to conduct a meta-analysis. While authors were contacted about missing information, no response meant they were not included. Alongside narrowing the search to English studies online, this may have reduced the pool of the data set.

Conclusion

The findings of this review gives support for the utility of a digital self-help intervention for YP with tics who are experiencing reduced wellbeing. A wellbeing intervention for YP with TS would likely be utilised without therapist assistance enabling it to be scaled up without increased costs or resources, giving it a major advantage over the current wellbeing interventions for TS. Further, whilst the greatest promise was for fantasy-style interventions for YP experiencing symptoms of depression, traditional linear-style interventions were still found to be beneficial to users, especially with integrated CBT components. The collective advantages of unguided, self-help interventions included low costs, ease of access and reduced need for trained professionals, but simple interventions were deemed to be an especially feasible option in helping to overcome barriers to accessing mental healthcare for youth populations. Furthermore, interventions had reasonable levels of retention, suggesting they were also acceptable to youth populations, giving promise the to the acceptability of such an intervention to support wellbeing in TS. Greater efforts are warranted to improve the quality of studies and greater consensus is required on the use of outcome measures in relation to retention and adherence, as well as different aspects of wellbeing, in order to help determine the impact these interventions have on broader wellbeing and in real-world settings. Specifically, further research in this area should focus on improving the quality of studies within the research of purely unguided self-help digital interventions for YP who show elevated symptomatology of mental health problems or who have mental, behavioural and NDDs. With improved quality of studies, a meta-analysis could be performed which would provide more precise indicators of the efficacy of self-help interventions. Research should also explore the use of alternatives to RCTs in the assessment of digital interventions to help close the gap between the progression of technology and dissemination of empirical studies.

Chapter 3 - Methods

Developing Interventions

As outlined in the introduction, theory, evidence and person-based approaches lead to more effective and engaging interventions (Band et al., 2017; Bradbury et al., 2017). In this section, how each of the previously described methods can be applied to the research will be outlined.

The BCW has been selected to guide the intervention development as a comprehensive systematic framework developed from multiple existing theories to overcome their limitations (Michie et al., 2011). Other guidance is being followed which outlines approaches on how to develop interventions, including the Medical Research Council (MRC) guidance (Craig et al., 2008) on developing and evaluating complex interventions, and Bradbury et al.'s (2014) methodological guidance to DHI, especially in relation to feasibility, acceptability and efficacy. Finally, in order to incorporate a person-based approach, Yardley, Morrison, et al.'s. (2015) person-based approach (PBA) which centres the end-user and relevant peoples in the development of the intervention will be used to inform the development of the intervention.

Methodological Guidelines for Interventions

Resources for developing interventions include the MRC guidelines on how to develop and evaluate complex interventions (Craig et al., 2008) and Bradbury et al.'s (2014) guide to the methodological process involved in intervention planning and development. The ‘modelling phase’ of the MRC guidelines are of particular relevance to this research, and Bradbury et al's (2014) guidance was developed with accessibility in mind, making it very practical to implement.

Together, both guidelines can be applied as they follow similar processes. For example, during the MRC guideline’s modelling, existing evidence of literature is identified, or a systematic review is proposed. This enables theoretical understanding of the process of change needed to make the intervention useful. In Bradbury et al.'s (2014) eight key steps of intervention planning (identified in Table 6) steps 1-4 allow the behaviours, and behaviour determinants, to be identified through a review of the existing literature or through primary research, which enables theory to be incorporated which may support behaviour change. The next steps of the MRC guidelines include carrying out design refinements of the intervention to identify any weaknesses of the intervention before implementation of the full-scale evaluation (Craig et al., 2008). This is similarly mapped by Steps 6-8 of Bradbury et al's (2014) guidelines, which includes reviewing the elements for integration and prioritisation, steps that are often missed in guidelines, to develop an intervention plan that is acceptable and feasible. These methods do not need to be completed in a linear fashion, and can be undertaken iteratively (Bradbury et al., 2014; Craig et al., 2008).

	Key Steps of Intervention Planning
1	Identification of behaviours that need to be changed
2	Consideration of modality for intervention delivery
3	Deductive and inductive key behaviour determinants need to be identified. Review of existing literature (qualitative and quantitative) and inductive exploration of behaviour change techniques should be undertaken
4	Incorporation of theory to identify necessary behaviour change functions that can be implemented. Influencers that may have an effect but are lacking also need identifying and implementing
5	Inductive qualitative research to assess the acceptability of the intervention components
6	Views of stakeholders should be incorporated to ensure acceptability and feasibility of the intervention, to be adopted in practice
7	Integration of deductive and inductive approaches to make an intervention plan, consisting of intervention components or practical elements of the intervention
8	Prioritisation of components to decide what is feasible for the intervention team. This should be carried out iteratively throughout the development of the intervention.

Table 6 Key steps of intervention planning based on methodological guidelines from Bradbury et al. (2014). Therefore, in application to this research the two methods can be used in combination to supplement one another and provide valuable proposals for ensuring comprehensive intervention development.

Behaviour Change Wheel

To implement the COM-B model, it is first recommended that one understands the behaviour through identifying a problem in behavioural terms, selecting and specifying the target behaviour and identifying what needs to change (Michie et al., 2014). The second step includes identification of intervention functions. Surrounding the inner hub is a layer of intervention functions including Education, Persuasion, Incentivisation, Coercion, Training, Restriction, Environmental Restructuring, Modelling and Enablement. These can be used alongside the behaviour problems outlined earlier to consider what the function of the intervention will be. Finally, content and implementation options are identified. At this point a taxonomy of behaviour change techniques, defined as ‘a component of an intervention designed to alter or redirect causal processes that regulate behaviour’ (Michie et al., 2013, pp. 82), can be useful. Michie et al. (2013) updated previous taxonomies with a list of 93 behaviour change techniques, built on previous taxonomies and developed with experts from a variety of disciplines.

Whilst the BCW also focuses on policy as the outer layer of the model, this is felt to be outside the remit of the current research aims and so will not be focused on. The BCW will be implemented after the primary research has been collated (Chapter 8), allowing selection of behaviour change techniques that are in line with stakeholders and end-users views. Furthermore, the identification of intervention functions from the second step of the BCW will allow for any components that are missing to be identified.

Person-based Approach

The PBA suggests use of particular methods at each stage of intervention development. For the purposes of this work, the intervention planning and design stages are most relevant. The first stage includes carrying out a synthesis of qualitative research of similar interventions or user experiences, to identify facilitators, barriers or contextual issues relevant to the key target behaviours looking to be changed (Yardley, Morrison, et al., 2015). If there is limited published research, this can be obtained through conducting qualitative research to elicit user views, consultation with experts and stakeholders. Other activities recommended include examination of relevant theory and evidence from trials and real-life context, and the observation of the intended contexts the intervention would be used in (Morrison et al., 2018; Yardley, Morrison, et al., 2015). Moving into intervention design stages, the themes that arise from the intervention planning stages can be used to identify key issues, needs and challenges to help develop guiding principles. Additionally, intervention mapping of behavioural determinants and behaviour change alongside logic models can also be undertaken to describe the possible mechanisms of action for the intervention (Yardley, Morrison, et al., 2015). These stages and activities are documented in Table 7, based on Yardley, Morrison, et al. (2015).

Additional recommendations are made for the PBA approach, which can be integrated as part of the above methods. These include the use of mixed or multiple methods research to investigate attitudes and needs of the target group, in order to identify necessary and feasible intervention components (Yardley, Ainsworth, et al., 2015). Furthermore, suggestions are made to provide succinct and accessible summaries which can be used to enhance communications across disciplines and audiences to support collaboration and involvement of stakeholder groups (Morrison et al., 2018). Additionally, the process is expected to be iterative, in order to obtain that deep understanding which makes the intervention maximally meaningful and engaging (Morrison et al., 2018).

On completion of the planning and design stages, guiding principles can be developed to use in the intervention design phase. These principles should specify the objectives and what the intervention needs to do to address the needs of the end users. Through this, the guiding principles explain how the intervention will address the target populations needs (Morrison et al., 2018). Additionally, a logic model can be developed in these latter stages which summarises how the intervention will work by identifying the key mechanisms of change (Baxter et al., 2014).

Stage of intervention development and evaluation	**Specific person-based approach activities useful at each stage**	**Other activities relevant to person-based approach normally undertaken as part of intervention development**
Intervention Planning	Synthesis previous qualitative studies of user experiences of similar interventions	Consult experts and stakeholders (e.g. members of user groups, practitioners, purchasers of health care services)
	Carry out qualitative research to elicit user views of the planned behaviour changes and intervention (including relevant previous experience, barriers and facilitators)	Examine relevant theory and evidence from previous trials
		Observe real life context of intended intervention
Intervention Design	Use themes arising from the intervention planning stage to identify key issues, needs and challenges the intervention must address	Carry out intervention mapping of behavioural determinants and behaviour change techniques
	Create guiding principles comprising: Key intervention design objectives	Create logic model describing hypothesised mechanisms of action of intervention

	Key distinctive features of the intervention needed to achieve objectives	

Table 7 Stages and activities of the development phase from the PBA, based on Yardley, Morrison, et al. (2015).

Study Design

COREQ and SRQR

Throughout all stages of the qualitative research, the consolidated criteria for reporting qualitative research guidelines (COREQ) have been followed (Tong et al., 2007). Conforming to these guidelines ensures the reporting of interviews and focus groups are comprehensive, and it is believed that such checklists help to improve the quality of research through increased transparency (Tong et al., 2007). The checklist, available from Tong et al. (2007), is made of 32 criteria with a description covering three domains including ‘Research Team and Reflexivity’, ‘Study Design’ and ‘Analysis and Findings’. The COREQ guidelines were supplemented with the Standards for Reporting Qualitative Research (SRQR) (Reed et al., 2014), which crosses the breadth of qualitative methods. The list consists of a framework for reporting research, with 21 items relating to problem formation, research question, research design, methods of data collection and analysis, results, interpretation, discussion and integration, and other information, available from Reed et al. (2014).

There are arguments against the use of checklists in qualitative research, believing that qualitative methodology cannot and should not be judged against measures such as generalisability, reliability and validity, which sit in a positivist paradigm (i.e. that there is a measurable truth that is independent of the researcher) (Mays & Pope, 2000). Downfalls of checklists can include the production of ‘neat’ systematic descriptions rather than in-depth analysis and explanation, multiple coding that only seeks to verify rather than alerting researchers to alternative interpretations, and the use of triangulation for internal validity rather than comprehensiveness (Barbour, 2001). It is hoped that through recognising the potential downfalls of using such checklists, minimises their limitations and use them to increase transparency, rigour and credibility for both developing qualitative methods and procedures, and reporting them.

Online Forms

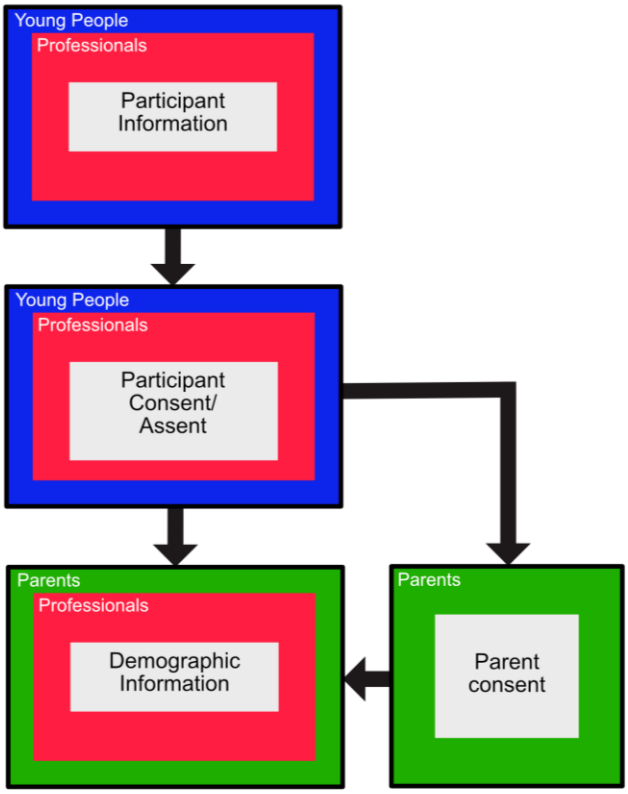


Figure 2 Flow diagram of the process for obtaining participant consent, assent and demographic information for online methods with YP and professionals. Each rectangle presents a different online survey, and the colour in the rectangle shows who was required to complete the survey. YP and professionals were given participant information and consent. Professionals and parents were asked to complete consent and demographic information and young people gave assent.

For all online research studies (Chapters 4, 5 & 7) a similar process was followed whereby participant information, consent and assent were collected through Online Surveys (Jisc, 2020). Recruitment posts or emails linked participants to an initial online participant consent form. All online forms immediately introduced the study through a participant information page. The process to obtain consent, assent and participant information is outlined in Figure 2. If the mandatory consent boxes were not ticked, participants were directed to an exit page explaining participation in the study was voluntary, with the option to return to the consent page if desired. If the correct boxes were completed, participants were linked to the demographic information survey. For professionals, this was the next page of the survey. For YP, parents were asked to complete this part of the survey after giving consent for themselves and their child to be involved. This stage also required ticking mandatory boxes to obtain consent as above. Please see individual methods sections for demographic information asked from participants. This information was then used by the researcher to contact the participant or parent to organise the time of interview or focus group.

Familiarisation Videos

Personalised familiarisation videos were sent to all YP involved in Chapter 4, 6 and 7 to explain the process of the research and help them to feel more comfortable (an example script can be found in Appendix 5). They involved the researcher talking directly to the camera in a friendly matter to outline how the research would be conducted. Videos lasted no longer than three minutes and for each, a basic script was adhered to. These scripts were elaborated with personal details gathered by the researcher when obtaining verbal consent from parents. For interviews, this included using the child name and mentioning personal information, for example explaining to the individual they could bring their pet to the interview. For focus groups, these were personalised to the group, using dates and a general background relatable to all participants e.g. location of focus group. This process aimed to improve the rapport between YP and the researcher and explained the process of the research in an engaging and familiar way. These videos were also used to emphasise that the researchers wanted to hear YP's opinions, and that their honesty was important to help overcome biases such as 'conformity' or 'normative influence' (Bevan Jones et al., 2020; Fern, 2011).

Data storage and protocols

All recordings from interviews and focus groups had personal data removed during transcription, and on completion, the recording was deleted from dictaphones and computers. The same transcription protocol was followed across each method which included making notes of time of speech, speaker, interruptions, removal of nouns and other noises. Depending on the choice of analysis, a word processing or spreadsheet software was used for transcriptions, as highlighted in the chapters. The transcription protocol remained the same throughout.

All data files were stored in accordance with the University of Nottingham's Research Data Management Policy, using encrypted folders with personal participant details, stored in a separate folder and regularly backed up to the hard drives of EN and GJ. Participants were given pseudonyms which were used to refer to participant identities henceforward.

CB and researchers assisting on the project were required to have a DBS check to work with children. Lone-working policies were followed which included sharing a schedule of interview or focus groups times with EN and GJ and contact details when research was conducted outside of working hours. Safeguarding policies were followed, so any disclosure would be reported to GJ and EN and if appropriate, parents. During interviews and focus groups, if an individual became upset, they were given the opportunity to withdraw or take time-out. Participants were signposted in the participant information to tic- and mood-related services. Parents were asked to be present throughout interviews, and if YP became upset the researcher checked in with parents, ensuring the parent was aware of their child's distress and to signpost both the parent and child to relevant resources.

Semi-structured Interviews

Interviews are the most familiar method of qualitative research, which includes talking to participants in a professional manner about their experiences and perspectives, to capture their understanding in relation to a topic determined by the researcher (Braun & Clarke, 2013). Semi-structured interviews are commonly used in qualitative research to provide both a framework for the interviewer and flexibility to probe on certain issues with more open and follow-up questions. As they are especially useful for studying personal experiences and sensitive themes in research, they were felt to be a useful method to explore the experiences of wellbeing in YP with tics which may address sensitive topics for some YP (Tong et al., 2007).

Qualitative Research with YP

Ecocultural theory influenced the way questions were asked as it gives a way to explore abstract and difficult questions from a child-friendly perspective. Ecocultural theory was used as a basis for developing interview questions as an ecocultural interview is semi-structured and conversational, using every-day language to get to the crux of an issue (Grace & Bowes, 2011).

The term 'wellbeing' has been hard to define (Chapter 1), so asking children about their thoughts on a term rarely used or differently understood between people could lead to issues with YP interpreting the same question in different ways. YoungLives highlighted these difficulties when trying to capture child-focused understanding of child poverty, finding different conceptualisations of wellbeing such as 'life is going well', 'has a good life', 'looks good', or 'is happy'. Furthermore, the concept of wellbeing also differs throughout cultures, including between cultures who speak the same language (Crivello et al., 2009). Consequently, the terminology used to refer to wellbeing in interviews and focus groups focused on everyday activities and language opposed to abstract and vague language, e.g. 'what happens in a bad or good day?', 'what happened to make you feel up or down?' (Grace & Bowes, 2011).

Further, to prevent suggestible language the researchers avoided phrasing that may lead responses, using open language where possible. Additionally, as rapport reduces suggestibility (Sumsion, 2003), this enhanced the need to make YP feel comfortable in the research and with the researchers. Wellbeing in the British language often uses metaphor for wellbeing, e.g. 'up', 'down', 'under the weather', so these terms were included alongside less metaphorical language such as feeling 'good' and 'bad'. Finally, beliefs and attitudes can be different to actual behaviours (Hill et al., 1996) which was noted when using action-based questions such as 'what did you do when you felt down?' Therefore, effort was made to question both how YP intended to behave alongside what they do to support their wellbeing.

Focus Groups and Saturation

Originating from political and market research backgrounds, focus groups to collect qualitative data have become increasingly popular (Farnsworth & Boon, 2010). Focus groups include multiple participants who are facilitated to engage in a topic of discussion relevant to the researcher's aims (Braun & Clarke, 2013). Focus groups can be used to gain wide ranging views on a topic, or to explore an under-researched topic in an efficient way, where being with like-minded individuals can spur the conversation and provide access to perspectives (Braun & Clarke, 2013). Within this research, focus groups were used (Chapter 6 and 7) to generate and build upon ideas that had previously been developed from earlier research (Chapter 4, 5). Focus groups have been recommended for intervention planning by qualitative guidelines (Tong et al., 2007) and in the PBA (Yardley, Morrison, et al., 2015). An assistant and a moderator are often recommended, which was included within this research with project students who assisted CB in running the groups (MR and ES). Their roles mainly included note taking, handling interruptions, operating recording equipment and ensuring all focus group questions were addressed

(Liamputtong, 2011). Focus groups aimed to contain between three to nine people, in-keeping with suggested guidelines (Braun & Clarke, 2013; Tong et al., 2007).
Obtaining data saturation from focus groups is more challenging than in interviews (Hancock et al., 2016). Data saturation is defined as data adequacy, whereby the collection of more data will not return new data (Morse, 1995). Another view of saturation suggests replication of the study with a similar sample, would lead to similar themes (Fusch & Ness, 2015). Nevertheless, there is a debate on data saturation in qualitative research questioning that if one looks for data adequacy in their data, they may be paying greater attention to new themes rather than to the generation of deeper analysis of the current data (Morse, 2020). Application of both streams of thought for data saturation would be worthwhile considering for focus group methods to ensure both that broad and in-depth data is generated.

Triangulation

The use of multiple methods to collect data studying the same phenomenon is known as method triangulation, such as the use of interviews and focus groups; data source triangulation is the combination of sources in a study, which can include interviews with a service user group and a service provider group, for example (R. Johnson et al., 2007). Both forms of triangulation are believed to result in a broader understanding of the phenomena of interest (N. Carter et al., 2014; Mays & Pope, 2000). In addition, triangulation methods can be simultaneous or sequential, with the former using the findings to complement one another during integration, or the latter using the results of one approach to plan the next (R. Johnson et al., 2007). Triangulation is sometimes used in research as a method to address internal validity, with one method helping to overcome the biases of another, however this is controversial in qualitative research as it would assume that there is a 'fixed point', that can be measured from different perspectives to find the 'correct' answer (Barbour, 2001), in contradiction of social constructivist or interpretive epistemologies (see Hybrid Thematic Analysis below). Other uses of triangulation enables a more comprehensive understanding of the research area being studied (Mays & Pope, 2000)

Virtual Qualitative Data Collection with YP

Although traditionally regarded as a ‘poor method’ of interviewing, virtual qualitative methods including telephone calls or online video methods have increasingly been seen as having specific advantages and disadvantages (Braun & Clarke, 2013). Virtual data collection opens access to more participants, especially those who are hard to reach, and can lead to considerable cost and time savings for both the researcher and participant (Sturges & Hanrahan, 2004). Disadvantages revolve around potential difficulties to build and maintain rapport, especially when discussing difficult or sensitive topics (James & Busher, 2011; Rubin & Rubin, 2012). Further, the reduced non-verbal communication in virtual methods is believed to reduce the quality of the method of data collection as the researcher has fewer means to understand the participant by (James & Busher, 2011) and concerns exist around participant attrition due to ease of leaving the research (Rubin & Rubin, 2012). Whilst such concerns are valid, and virtual interviews may not be appropriate for all methods, depending on the topic of research it is argued that virtual data collection can be applied effectively (James & Busher, 2011). This is supported by research comparing telephone and face-to-face methods (Sturges & Hanrahan, 2004), and analysis of virtual face-to-face methods such as video call (Janghorban et al., 2014), which propose alternative methods were as effective as traditional methods.

As a result of seeking YP with TS, which is thought to affect less than 1% of the population, virtual methods for collecting data were thought to be especially useful (Seymour, 2001) and could potentially increase the demographic variability of participants. Furthermore, due to Covid-19, the final research chapter could not have been completed without online methods to conduct the focus groups (Chapter 7). Due to the nature of tics waxing and waning and increases in symptoms because of anxiety and stress, enabling the participant to complete the research from their selected location may have made them feel more comfortable. Being comfortable is especially important in focus groups research, and was achievable with virtual focus groups (Liamputtong, 2011).

The proposed disadvantage of virtual methods leading to increased withdrawal was viewed as a positive for research with vulnerable groups of YP, enabling the researcher to carry out their ethical duty by allowing participants opportunities to withdraw (Einarsdóttir, 2007). Given greater control over their involvement, YP may also be more likely to continue in the research. In line with this, developing a rapport with the young person was of the upmost importance. O'Connor and Madge (2016) propose the use of emails can facilitate rapport, which was extended in the current research with the use of videos (See Familiarisation Videos). These processes intended to make it easier for YP to discuss difficult topics.

In terms of the depth of research when using virtual methods, video methods still enable the researcher to capture non-verbal cues of the participants face (Janghorban et al., 2014). Whilst other parts of body language may be missed, it is important to note that YP are digital natives and familiar with communicating online in day to day life (Abrams & Glaiser, 2016). The use of such methods are likely to be very natural to YP who are adept at communicating online and should not hamper the depth of information gained. As the current research is looking to explore developing a digital intervention that is engaging and useful for YP with tics, it is important to capture the views of participants who would be likely to use such an online platform.

Overall, virtual qualitative data collection in this research project was felt to be very appropriate for the sample and research questions being asked. In many ways, virtual methods were also seen to be advantageous to traditional methods for YP with tics. Furthermore, Babbage et al. (2018) explored the feasibility of conducting online interviews to gather information about self-management tools for wellbeing. This small-scale study provided a pilot showing YP were comfortable talking about such topics online and this elicited acceptable data for thematic analysis, providing support for the current methods for data collection.

Clinical Assessments

Measurements were taken from the sample to assess the clinical characteristics of the group to see whether the group represented a diverse range of YP with tics. It was felt to be important that samples included YP with varying tic severity, cooccurring conditions, difficulties with mood and anxiety. The measurements would give a better understanding of who were included in the samples would allow consideration of what was suggested and by who to assess whether the findings could be applied to the different features of the interventions.

All the below measurements were used in each piece of research where YP were participants (Chapter 4, 6, 7). The scales were adapted for use with an online survey platform (Jisc, 2020), but with the intention to keep the survey as similar to the original as possible by changing the verbal instructions to written instructions. To make sure participants didn't miss questions, all questions were compulsory. Researcher contact details were available on each page of the survey if the respondent wanted to get in touch, a finish later button allowed participants to return to the survey later and a progress bar was also available to view how much of the survey was completed. Questions could be personalised to the child by exporting the answer from a previous question. For parents, this enabled clear direction of who the question related to.

To give insight into what the young person's wellbeing status was around the time of the interview, participants and parents were asked to complete the online survey within two weeks of completing the interview. The date and time of completing the questionnaire was automatically stored by the Online Surveys (Jisc, 2020). Participants were offered an inconvenience allowance after the measurements had been completed.

As with all self-reported survey measures, there are limitations. Such limitations can include response bias where the question or context affects the way the participant responds, which can distort the true answer as the respondent may over- and under-report. This is especially relevant to YP as burdensome and boring tasks, also known as respondent fatigue (Ben-Nun, 2011), are increasingly likely to increase response bias. Furthermore, the order of the measures can lead to increased response bias towards the end of the survey, or the order of response options may mean the participant is more likely to select the most recently presented answer, opposed to the one that accurately reflects their opinion (Villar, 2011). To overcome this, the researchers varied measures of child wellbeing between parent-reported and self-reported measures to reduce burden on the YP. Counterbalancing can also help to reduce the impact of respondent fatigue, and the ability to split the survey. Being able to return to the survey at a later point may have also reduced fatigue (Ben-Nun, 2011). It is possible that the use of counterbalancing would have reduced fatigue on the latter responses, which was checked by looking at 'straight-line' responses of the questionnaire (Ben-Nun, 2011).

Revised Child Anxiety and Depression Scale (RCADS)

The RCADS was completed by both the YP and parent as a self-report (RCADS-SR, Appendix 6; Chorpita et al., 2000) and parent reported (RCADS-P, Appendix 7, Chorpita et al., 2005) measurement of symptoms of depression and anxiety in the child participants. The scale includes the following subscales: generalized anxiety disorder (GAD), separation anxiety disorder (SAD), obsessive-compulsive disorder (OCD), social anxiety disorder (SOC), panic disorder (PD), and major depressive disorder (MDD) measured across 47 items, giving a total anxiety and total depression score. The raw scores are graded depending on the child's age and gender. Age is identified through school grade, and outside of the United States of America this is calculated by subtracting six from the age of the participant as per recommendations. For participants aged eight or 19, these were placed into the lowest grade or highest grade closest to their age. T-scores of 65 or above indicated scores at a borderline clinical threshold, scores of 70 or above indicate a high severity of symptoms above hte clinical threshold and scores above 80 are displayed as >80 as discriminations above this threshold are not clinically meaningful. T-scores are not given for extreme values, so the highest or lowest value was used and indicated with a greater than or less than symbol. The parent report scale has been found to be reliable and shows good convergent and discriminant validity with child samples on the RCADS-P (Ebesutani et al., 2012) and a systematic review, not completed by the authors who developed the scale, showed excellent mean reliability of the RCADS and good internal consistency across cultures (Piqueras et al., 2017).

The RCADS was presented as multiple-choice single answer questions, allowing respondents to select one item between 'never', 'sometimes', 'often' or 'always' in response to each individual question, as it is presented in the original questionnaire. The wording was altered from, 'please put a circle around the word that shows how often each of these things happens to you. There are no right or wrong answers' to, 'please put a tick to indicate how often each of these things happen to you. There are no right or wrong answers', for the online survey. This was displayed at the top of each web page spanning the RCADS. Analysis followed suggestions made by Weiss and Chorpita (2011), and the raw scores were exported into a spreadsheet, and total scores were calculated using the functions of the spreadsheet. T-Scores were calculated taking the raw score and hand-searching the conversion tables to identify the respective T-score for total anxiety and total anxiety and depression.

Tourette's Disorder Scale – Parent Rated (TODS-PR)

To capture a broad range of the effect of TS on the young person's life without causing measurement fatigue to the young person, the TODS-PR (seen in Appendix 8), a parent rated measure of tics and comorbidities was used (Shytle et al., 2003). The TODS-PR captures both tic severity and behavioural and emotional symptoms related to tics including inattention, hyperactivity, obsessions, compulsions, aggression, and emotional symptoms. The TODS consists of 15 items about symptom severity, which are each scored on a scale ranging from 0 to 10, (0 = not at all and 10 = extremely), to give an overall score of 150, with a higher score indicating greater severity. The TODS clinician rated scale suggests a score of above 60 indicates moderate to severe TS and was applied here (Hollis, Pennant, et al., 2016).

The parent rated scale has been described as internally consistent and valid whilst being intuitive and easy to administer, giving a parent-reported measure that allows for a good overview of behavioural problems YP may be experiencing (Storch et al., 2005). Further, it was recommended in a recent systematic review of scales for tics (Martino et al., 2017). Within the survey, the TODS-PR was presented as a scale question, allowing respondents to score each individual symptom on a scale from 0-10, which noted '0 = not at all', '5 = moderately' and '10 = extremely'. The survey asked parents to answer, 'In the past week, how much has [CHILDNAME] been bothered by the following symptoms?' which only differed from the original with the use of their child's name. Within a drop-down tab of the questionnaire, parents were directed to additional information on what an 'obsession' or 'compulsion' is and is not, using the original wording from the questionnaire but changing the word 'patient' to 'young person'.

Gilles de la Tourette Syndrome–Specific Quality of Life Scale (C&A-GTS-QOL)

The C&A-GTS-QOL was used to assess the young person's self-reported impact of having TS of a young person's life, across 27-items of four subscales including psychological, physical, cognitive and obsessive-compulsive (Appendix 9; Cavanna et al., 2013). The respondent rated the items from '0 = never a problem' to '5 = always a problem', with higher scores denoting poorer QoL. The total score on this scale is 135. A visual scale from 0-100 is included at the end of the measure, with '0 = extremely dissatisfied with my life' and '100 = extremely satisfied with my life'. The original version of the scale was developed for adults (Cavanna et al., 2008) however it underwent adaptations to make it suitable for Italian children using a clinician rated questionnaire for YP aged 6-12 and a self-administered questionnaire for 13-18 year-olds, where it was shown to have internal consistency, convergent and discriminant validity (Cavanna et al., 2013). The English-version met criteria of internal consistency and reliability on nearly all the subscales, and supported content, convergent and discriminant validity of the children's scale (Su et al., 2017). It is also described as being user-friendly due to its short nature, and recommended for use in clinical trials (Cavanna et al., 2013). It is notable that all studies measuring the reliability and validity of the C&A-GTS-QoL include the original researchers who developed the scale. On the online survey, automatic directing of the participant depending on their age was used to direct respondents to the C&A-GTS-QoL for YP under 12 or to the C&A-GTS-QoL for YP over 13. Respondents answered each individual statement which was presented as multiple-choice questions with a single answer of the following choices: never, rarely, sometimes, often, always. The wording for how to answer the questions was taken from the original questionnaires, however the sentence, 'this questionnaire addresses the issue of how your illness affects your well-being' was removed to simplify the wording because this had already been explained at the beginning of the survey. For the visual scale, a scale question was used with increments of 10 from 0-100, with 0 marked as 'extremely dissatisfied' and 100 as 'extremely satisfied'. The smiling and unhappy face icon could not be replicated on the scale and so this was not included.

Analytical Approach

Inductive Reflexive Thematic Analysis

The process of thematic analysis as outlined by Braun and Clarke (2006) was used as the foundation method for the thematic analysis approach applied to this research, and applied to Study 1 and 2 (Chapter 4, 5). As the aim of the research was open-ended and exploratory, it has been labelled an inductive approach to thematic analysis. Prior to conducting the analysis, the researcher decided they would approach the analysis at a semantic level, aiming to reflect the semantics used by participants.

In line with the above, the researcher spent time familiarising themselves with the data, which was achieved by being present during data collection, through transcribing the recordings and checking the transcripts with repeated active reading. Initial codes were generated from transcripts by succinctly labelling all relevant data in a form that is comprehensive enough to allow the researcher to group the codes without missing significant details, yet simple enough for this to be done efficiently. Between chapters, this was completed using NVivo, a software program for organising and structuring qualitative or mixed methods data, or a spreadsheet processing software. Attention was given equally and fully to aspects of the data that may be potentially relevant, including data that may contradict other findings. Once initial codes have been formed, the researcher searched for potential relationships between codes. Once candidate themes were proposed, the researcher looked through the themes to identify relationships between them. These were reviewed in a process of collapsing, removing, and separating themes, checking them against the codes that had been initially developed. At this point, some codes may have required recoding, and the themes reorganising, demonstrating the iterative process of thematic analysis. The analysis concluded by defining and naming the themes to ensure the titles included the essence of the theme and its pertinence to the research questions. For complex themes, hierarchy can be used to illustrate sub-themes within the theme and domains can be used to capture a shared topic, but not shared meaning (which would constitute a theme) (Braun & Clarke, 2019). Braun and Clarke’s (2006) 15-point checklist was used to ensure quality during the analytical approach.

To ensure the approach took an inductive method, principles from inductive approaches to analysis were also applied alongside this method. This includes Auerbach and Silverstein's (2003) bottom-up coding and Boyatzi's (1998) data-driven approach. The former suggests ‘making the text manageable’ through explicitly stating the research concern and keeping this in front of you when conducting the analysis and ‘hearing what was said’ by organising repeating ideas into common groups with a name that fits the text. The latter process suggests looking at codes that are prevalent across the data, opposed to looking for meaning within the data, to ensure the analysis remains at the manifest level and ensuring consistency across coding. Furthermore, both approaches suggest keeping a codebook of the analysis process which is believed to reduce ambiguity between researchers and helps to identify what is and is not part of the theme (G. Ryan & Bernard, 2000). Codebooks were used for consistency throughout the thematic analysis processes, however as noted by Braun & Clarke, 2019, codebooks can restrict the reflexivity of coding and so codebooks were less relied upon throughout the project, especially for inductive analysis. During research with multiple coders, codebooks highlighted discrepancies when interpreting the transcripts or coding, which enabled the researchers to consider different interpretations and capture this within the themes. Furthermore, functions within NVivo reduced reliance on codebooks due to the ability to add information to individual codes and themes, allowing coders to use this to support consistent coding. This was especially important for ensuring a priori coding was interpreted in line with the findings they had been taken from. Reflexivity is an important part of qualitative research, which includes understanding that all research is inevitably biased as a result of bringing their own experiences, assumptions, perspectives to research (Braun & Clarke, 2013). Reflexivity allows researchers to consider the subjectiveness of the data. To maintain a reflexive approach to qualitative data collection, keeping a research journal is recommended with thoughts relating to both functional reflexivity i.e. focusing on how the processes may have influences the research and personal reflexivity i.e. how our personal assumptions can influence the research (Braun & Clarke, 2013). These notes were kept and summarised in reflexive comments at the end of each empirical chapter. Other important elements of reflexivity include centring on the subjectivity of the researcher, an organic and recursive coding processes, and the importance of deep reflection on, and engagement with the data (Braun & Clarke, 2019) which were applied when possible to the data.

Hybrid Thematic Analysis

The hybrid thematic analysis approach incorporates both a data-driven inductive approach (Boyatzis, 1998; Braun & Clarke, 2006) and a deductive approach based on an a priori template of codes as outlined by Crabtree & Miller (1999), applied in Chapter 6 and 7. Such a position takes two contrasting philosophical stances. The latter is based on more positivist epistemologies which presume the data is already out there to be 'collected' as it is, whereas the former tends to be from social constructivist or interpretive epistemologies, that emphasise the involvement of the researcher, hence the data is 'generated' or 'developed' (Swain, 2013).

The hybrid thematic analysis process required developing a codebook of a priori codes. The themes from data collected in previous chapters were used as a template for the codes, some of which required segmenting into smaller codes for this process. These were assigned to the transcripts of the data during coding, linked with the relevant part of the transcript, with a few additional comments to explain if the code is in contradiction or agreement with the linked transcript, as in the template analytic technique (Fereday & Muir-Cochrane, 2006). The a priori codes can be used over multiple instances. In parallel, inductive codes generated from reflexive thematic analysis approach (using the same methods as outlined in Inductive Reflexive Thematic Analysis) are completed on the same transcript. This led to multiple a priori and posteriori codes linked to one part of the transcript. An example transcript with a priori and posteriori coding in parallel can be seen in Table 8. Ultimately, a codebook was developed consisting of a priori and posteriori codes. Relationships between these codes were identified, and the process of grouping the codes into meaningful units can start, leading to the development of themes and subthemes. Throughout this process, a priori and posteriori codes should not be merged, but must remain separately within the themes. This enabled the researcher to identify which themes or subthemes were deductive or inductive.

As with the thematic analysis approach, the researcher continued to code at a semantic level with the aim to reflect the participant's language, although it was recognised that the inclusion of previous researcher-led frameworks pushed this analysis further toward latent levels of analysis (Braun & Clarke, 2006).

A Priori		**Transcript**	**Posteriori coding**
Theme	**Coding**		
Theme 3 - Wellbeing for a young person with TS includes understanding and accepting their condition, engaging with and being able to manage life's demands and tics	Tics can make managing life's demands more difficult	Interviewer: What about having something inside the app that tells you about what you've got going on that helps you plan your day P1: like a calendar? Interviewer: yeah P1: yeah, cos then you get notifications through for it and you wont forget P2: I've never been able to do a calendar just cos, I don't know what it is for other people, but with like my Tourette's it's unpredictable. So like one morning I'll wake up and like I'll be ticcing really bad and I can't do the tasks that I like set myself that day, so that goes on hold 'til the next day and then it happens again and there's one free slot, where I do it all in one slot and it's all mix and match because you	The app should contain a calendar that gives notifications, so that YP will not forget If tics are really bad, YP cannot do the tasks they had planned, and must wait until their tics are better to do it
Theme 12 - Planning helps YP better manage day to day life leading to improved mood	Planning helps YP better manage day to day life leading to - *against*		

	never know what you're gonna be like.	

Table 8 An example transcript with a priori and posteriori coding in parallel. The a priori coding includes an example of the Theme being segmented into parts for ease of coding.

Reflexive Statement

Knowledge and experiences shape data collection and analysis, which can include the researcher’s thoughts on the subject, age, gender, professional status, class, culture, perceptions, and emotions (Braun & Clarke, 2006; Eakin & Mykhalovskiy, 2003; Mays & Pope, 2000). To minimize these biases and increase the credibility of the research, a reflexive approach was used throughout, where CB kept a journal and made field notes within 24 hours of conducting all interviews and focus groups, in line with thematic analysis recommendations (Braun & Clarke, 2006). In keeping with an awareness that the researcher’s experiences influence research, CB reflected that she is a white female young adult from a working-class family, and is a postgraduate, applied psychology student. Prior to the project, CB reported having no experiences of what it is like to live with tics or know anyone with tics. On starting the project, a friend known to CB for 7 years disclosed their diagnosis of TS. Inevitably, this led to discussions with the friend about living with tics. Prior to this, CB was not aware of having had any interaction with anyone with a TD. To learn more about the needs of YP with tics and to expand knowledge of what it’s like living with tics, CB volunteered at Tourette’s Action events, namely TicFest, a family weekend for YP with tics. Throughout the PhD, CB has attended multiple TicFest events annually (apart from final year where these events were cancelled due to Covid-19). These interactions will have impacted on CB’s awareness about living with tics.

Outside of research, CB has had varied experience volunteering with different mental-health related groups as a phoneline listener and support group facilitator for students with low mood, and as a coordinator for mental health campaigns. Through these roles CB has received and given a lot of training relating to mental health, including how to facilitate conversations with YP experiencing difficulties. It stands to reason that such training and experience will have impacted on the way CB approached interviews and focus groups, with a developed confidence in how to have similar conversations or how to facilitate group meetings about difficult subjects.

Aware that these experiences will develop and change throughout the project, CB made reflexive notes throughout, at each point of data collection, to capture the process of changing reflections and experiences with this project, documented in each empirical chapter. Alongside enabling CB to be sensitive to how researcher assumptions and experiences can influence the data, this journal was also used to note data saturation, and any areas where the transcript required correction or areas of focus for the next interview or focus group (Groenewald, 2004). These notes were shared with EN and GMJ at the end of analysis so they could be reflected on prior to the interpretation of the results.

Chapter 4 – Study One: Interviews with Children with TS

Introduction

To understand what YP with tics would find useful to include in an intervention aimed at improving their wellbeing, it is important first to explore YP's understanding and current management of wellbeing. This is in line with the PBA which aims to build an intervention from an understanding of the context and point of view of the end user (Yardley, Morrison, et al., 2015). The use of qualitative research is recommended for this, and whilst focus groups have previously been used to understand YP with tics' quality of life (Cutler et al., 2009), no research to date questions YP with tics on their perception of what wellbeing is, and what would be useful to them in an intervention for wellbeing.

The need for interventions to support the psychological wellbeing of YP with tics was previously highlighted (Chapter One). Nonetheless, current internal e.g., low help-seeking behaviour and external e.g., a lack of available specialists, barriers to accessing support for TS remain high. The introduction highlighted the potential for digital self-help interventions to overcome barriers to support and showed they are more effective than no intervention for YP with mental health disorders (Bennett et al., 2019). Yet, findings from the Systematic Review (Chapter Two) highlighted concerns around uptake and adherence in trials. Although reasonable retention was concluded from this review, another review of real-world uptake for DHIs for low mood, anxiety and depression found less than half of users engaged in moderate use, and concluded user uptake and engagement are the biggest challenges for the digital health world (Fleming et al., 2018). Therefore, the application of the PBA aims to identify issues with user engagement prior to intervention implementation, to overcome potential issues around adherence and engagement before resources are spent on the intervention (Morrison et al., 2018).

The first step of the PBA includes an understanding of the users and their context from in-depth qualitative research around issues relevant to the target behaviours, in this instance wellbeing (Morrison et al., 2018). Understanding how YP conceptualise mental health is important, as YP with a good understanding of mental health may be more able to adapt their behaviour to improve their wellbeing. This assumption is encompassed within the construct of mental health literacy (MHL), which refers to 'knowledge and beliefs about mental disorders which aid their recognition, management or prevention' (Jorm et al., 1997). Cauce et al.'s (2002) model of help seeking stipulates that problem recognition is the first step in help seeking behaviour, therefore MHL is a key driver in promoting health-driven attitudes. A systematic review looking into barriers for help seeking in YP found a lack of knowledge about mental health services was a barrier to seeking support (Gulliver et al., 2010). On the other hand, correct labelling of depression is believed to be a predictor of choosing the right support and getting timely treatment (Cheng et al., 2018). Research also suggests gender differences in MHL, with adolescent females being more adept at recognising depression (Burns & Rapee, 2006; Coles et al., 2016; Cotton et al., 2006) and anxiety (Hadjimina & Furnham, 2017) than males. In light of the increased prevalence of TS in males, it could be argued that a lack of insight into one’s problems, or ways to manage problems, could be contributing to the maintenance or exacerbation of difficulties in this population.

In addition, the impact of internal and external environments on tic severity was also previously reviewed. The relationship between tics and environments is complex and variable, however the physical impact of tics on QoL and wellbeing suggests that developing an intervention to support YP’s understanding and management of wellbeing could give them insights into better management of their internal states, whilst leading to improved tic severity.

Having a better understanding of how YP with tics perceive wellbeing will allow the intervention to be guided through the user’s view and understanding. How YP currently manage their mood and internal states more generally will also be important in determining what the intervention could include to be both engaging and useful to YP. Considering the person-centred approach recommends understanding the needs and views of the user to ensure interventions are engaging and effective, (Yardley, Morrison, et al., 2015), the overarching aim of this research would be to gain further understanding into YP with TS’s insight into wellbeing and the needs and challenges to be met. Enhancing this understanding would help the development of a self-help management approach that could be delivered as a technology-based tool for the management of YP with tics overall wellbeing. Therefore, the aim was to interview YP with TS or a tic disorder to explore how YP with tics understand wellbeing, and if they have any current self-management strategies for their wellbeing. Additionally, YP were asked what they would find useful and important in a technology-based self-help intervention for their wellbeing.

Study Aims and Research Questions

The main aim of the research was to explore what YP with TS or a TD would find useful in a technology-based self-help tool to improve their wellbeing. In particular, the research questions this study will aim to address:

1. How YP with TS or TS understand their wellbeing?
2. What YP with TS or a TD currently do to improve their wellbeing?
3. What YP with TS or a TD would find useful in a technology-based tool to improve their wellbeing?

Methods

Procedure

Parents or children responded to the recruitment call by completing online forms, as explained in the Methods Chapter (Chapter 3), and were given a participant information sheet (Appendix 10) or parent information sheet (Appendix 11). The researcher contacted parents after obtaining their contacts details to check the online forms had been completed by themselves and their children, to give an overview of the procedure and to develop a rapport between the parent, child and researcher. A familiarisation video (Chapter 3) was sent to all participants via a streaming link distributed to parent's email addresses.

The last two stages of the research included the interview and online surveys. The interview was either conducted face-to-face or through video call. Interviews were audio-recorded using two dictaphones, starting with a brief overview of the research aims followed by obtaining verbal consent from YP and parents to start recording, and then proceeding with the interview guide questions (see below). Some interviews were split into two separate parts for YP who struggled to concentrate throughout. Recordings were transcribed verbatim by CB, using the same processes as outlined in Methods (Chapter 3). The transcriptions were not returned to participants due to their age as it was felt this would be too labour intensive.

The interviews ended by completing the Yale Global Tic Severity Scale (YGTSS) (see below) and parents and YP were each sent a post-interview online form with wellbeing and tic-related clinical assessments: Parents received the RCADS-P and the TODS-P and children received the Revised Child and Anxiety Disorder Scale RCADS and the GTS-QOL-CA. More information about these clinical assessments are detailed in the Methods (Chapter 3).

YGTSS

Tic severity was measured through the YGTSS (Leckman et al., 1988) which was taken at the end of the interview. The YGTSS gives a total score for tic impairment, and a total score of tic severity, looking at both motor and vocal tics (Appendix 12). Vocal and motor tics are scored based on their type, frequency, duration, intensity, and the complexity of tics. These are each on a scale of 0-50, with higher scores indicating greater impairment. The global tic severity score accounts for the score of tic severity plus impairment of having tics, with a total score of 100. The YGTSS is reported as having good internal consistency, convergent validity and excellent psychometric properties (Leckman et al., 1988; Storch et al., 2005). The scale was recently evaluated and recommended in a review of scales for hyperkinetic disorders (Pietracupa et al., 2015) and for tics (Martino et al., 2017).

In this research CB was trained by experienced clinical researchers. Training included watching videos of YP undergoing the YGTSS with an experienced clinician plus practicing the scoring of the measure. To conduct the YGTSS in this sample CB had to achieve a score on the total tic severity, vocal tic severity and motor tic severity within 15% above or below the scores of the experienced clinician on all videos.

Development of Interview Guide

Interviews were semi-structured to allow for full exploration of the relatively broad aims and unexplored area of research. The interview guide (Appendix 13) was based on that developed by Babbage et al. (2018) where technology use and desires for a technology tool to increase wellbeing in a non-clinical sample of YP was explored. The interview guide was refined to include questions pertaining to what YP with tics think is important for their wellbeing. Care was taken to find ways to ask questions about wellbeing that would be suitable for a younger audience. As outlined in the Chapter 3, Ecocultural Theory influenced the development of the interview guide with questions centring around daily routines and action-focused terms, rather than starting with abstract questions. In response to difficulties exploring wellbeing with YP when the term is not conclusively defined, the interviewer used probing and follow up questions to get a sense of what the young person envisioned when they spoke about their wellbeing (Kvale & Brinkmann, 2009). Phrasing that may lead to a desired response were also carefully considered and avoided where possible (Grace & Bowes, 2011).

One pilot interview was run and included in the final analysis as few changes were made to the final interview guide. Minor changes included creating greater distinctions between moods and separating these questions when relating to mood, stress and tics to try and tease apart how these all may affect the individual at different levels.

Setting of Data Collection

Semi-structured interviews took place over video-call for most participants (Table 9) which was felt to be most in-keeping with the technology-user inclusion criteria. These YP participated in the video-call from their home. Two participants had face-to-face (in person) interviews at a University of Nottingham meeting room as this was more convenient for them. Parents nominated themselves to be available in the background of the interview, and some parents took a more involved role by sitting next to and joining in with the conversation. Whilst the researcher tried to direct most questions to the young person, there were overlaps between parent-child conversations.

The YGTSS was completed at the end of each interview and the other three quantitative measures were completed in the respondents' selected environment using a personal internet-connected device within 2 weeks of completing the interview.

Data Analysis

Data saturation was felt to be reached after interview 13, but two further interviews were completed to confirm. No new potential patterns or instances were felt to be identified in the final interviews and therefore data saturation was deemed sufficient (Glaser & Strauss, 1967).

All interviews were transcribed verbatim into a word processing software, and followed the 'data storage and protocols' processes (Chapter 3). Express Scribe Transcription Software (NCH Software PTY LTD, 2019) supported transcription. Transcripts were analysed using inductive reflexive thematic analysis, starting in April 2019 based on the guidelines of previous protocols (Auerbach & Silverstein, 2003; Boyatzis, 1998; Braun & Clarke, 2006) with the processes described in Methods (Chapter 3). The qualitative analysis software, NVivo (QSR International, 2019) was used to analyse the qualitative data and codes were removed from NVivo and placed into a presentation software to theme the relevant groups. Descriptive data was analysed using SPSS v24 for Mac (IBM Corp., 2016). During the theming stage, the researcher organised themes using visual mind maps and tables to help shape the themes and overarching categories. At one point these consisted of over 80 groups of codes, which were reorganised and aggregated to identify which themes were spoken about most frequently across participants and were most relevant to answering the research questions. Three categories were obvious categories to the researcher 1) understanding mental states 2) managing mental states and 3) features of the intervention. These categories were broadened to capture more themes, for example the first category was initially labelled 'understanding emotional states' but changed to 'mental' to embrace themes around tiredness and relaxation that would not have previously fit. The fourth and fifth categories became more apparent over time, initially starting as a category on 'living with tics', however this was felt to be too broad and could be divided into the fourth category 'mental states and tics', and the fifth category 'strategies and tics' which were felt to be more pertinent to the aim of this research. In the process of streamlining the themes, some themes were merged, and subthemes used to justify their position within the theme. Other themes had to be removed, as they did not constitute enough views from participants or meaning in relation to the aims of this research, for example on the day-to-day technology use of YP with tics. The codebook helped to outline what was and was not included within the categories and themes.

Reflective Statement

Prior to this research, CB had conducted a literature review on TS and attended TicFest. These experiences are likely to have been influential in how CB was beginning to understand the experiences of living with tics, in particular in relation to cooccurring conditions which had been a major theme of the literature review, and something that parents had frequently spoken about at the camp. YP were more reserved in talking to CB about their difficulties living with tics, however their difficulties were observed as YP struggled to complete activities at the camp or for those who were shy about their tics and interacting with others. Whilst CB was aware that these experiences gave a very small insight into how it is for families with tics, CB was mindful that these experiences gave them a much bigger insight into living with tics than had previously been understood. Through this, CB was a lot more relaxed about talking about and responding to tics as she felt more comfortable approaching the topic. This included knowing when to ignore tics or when to respond to them, for example learning that it was okay to laugh at tics sometimes.

Data Collection and Sampling

Overall, 15 YP aged 9-17 with a diagnosis of TS or TD were recruited through volunteer sampling. Recruitment was advertised through CB's personal social media (Twitter, Facebook, LinkedIn) using posts, posters, face-to-face from support groups, animation videos (https://www.youtube.com/watch?v=z4AQO0d5A7k&t=32s), and through the Tourette's Action research participants email register. To take part, participants had to be technology-users which was explicitly stated on recruitment posters and on the information sheets. Recruitment via online portals targeted those potentially more likely to be technology-users and reached a sample of YP who were accessing different types of support.

The days between the first interview and last interview totalled 80 days. Five participants were withdrawn from the study; one participant was too ill to complete the interview, two YP did not gain parental consent and two YP did not complete YP assent.

Ethics permission for carrying out this study was granted from the University of Nottingham Division of Psychiatry and Applied Psychology Research Ethics Committee, School of Medicine [Ref: 043], prior to recruitment (Ethics approval letter in Appendix 14). YP were required to give their assent to take part in the study, and parents had to give consent for children under 16 to take part. It was explained to participants and parents that YP could withdraw at any time and at various time points, including during conversations to schedule the time for interview with parents, on receipt of the familiarisation video and prior to the recording of the interview this was reiterated and verbal consent to record was asked prior to audio recording of videos. Please also see Methods (Chapter Three) for more information on ethical considerations taken during data collection.

Results

Participant Characteristics

15 YP were recruited between 9 and 17 years old, (IQR=11-15, median=3), four female and 11 male, six participants had TS-only, one participant had chronic motor tic disorder and seven participants had cooccurring conditions including ADHD (n=3), OCD (n=3), ASD (n=3), sensory processing disorder (SPD, n=2) and anxiety disorder (anx, n=3). Total researcher-rated scores for the YGTSS showed global tic severity ranged from 38 to 90 (out of 100) (IQR=56-76, median=66) with a mean tic severity score of 31.2, (SD=7.4) and a mean tic impairment score of 33.9 (SD=10.8). Parent rated RCADS showed average total anxiety symptom scores of 81.64 (SD=22.1) and total anxiety and depression symptom scores of 73.5 (IQR=68-100), where children had average scores of 61.1 (SD=16.1) and 61.8 (SD=17.9) respectively. One child's self-reported score reached above 65 indicating borderline clinical threshold for symptoms, and four children scored themselves above 70 indicating the clinical threshold for symptoms of anxiety and depression. 11 parents also scored their children above 70. The child-reported C&A-GTS-QoL showed an average rating of 53.07 (SD=23.4) and the VAS scored a median of 80 (IQR=48-83). Parent rating of the TODS gave a median of 84 (IQR=43-123) with 10 of the parents scoring their child above 60 indicating mild to moderate symptom severity TS (Hollis, Pennant, et al., 2016).

The total duration of recordings lasted on average 1 hour 19 minutes (shortest: 00:50, longest 01:46). Families were asked to complete assessment measures within a week of completing the interview however a technical error meant the RCADS scores file was corrupted and the researcher requested participants complete these again once this error was noticed. On average it took participants 1-day (IQR=0-6) to complete the C&A-GTS-QOL and TODS-PR, and 9 (IQR=3-37) or 12 (IQR=3-37) days to complete the RCADS-PR and RCADS-SR respectively.

Thematic Analysis Results

It was possible to organise themes into five distinctive conceptual groups. Three of these groups, 'Understanding Mental States', 'Management of Mental States' and 'Desired

Features of the Tool' were expected as they were similar to the research question of the current work; however two groups of themes were gained through analysis, i.e. 'Mental States and Tics' and 'Strategies and Tics'.

with increased scores indicating increased impairment. RCADS T-scores give total anxiety and depression and total anxiety for parent and self-report with scores above 65 indicating borderline clinical threshold and above 70 above the clinical threshold. The TODS-PR score gives an overall parent rated score for tic severity and behavioural and emotional symptoms. related to tics. Total possible score is 150, with higher scores indicating increased severity. Scores above 60 present moderate to severe TS (Hollis, Pennant, et al., 2016). The C&A-GTS-QoL total score is out of 150, giving the total across the psychological, physical, cognitive and obsessive-compulsive subscales rated by the young person with higher scores denoting poor QoL. The VAS scored separately, out of 100 and is the visual scale with higher scores showing greater satisfaction with life. * indicates missing data

Understanding Mental States

Themes	**Subthemes**
Theme 1 - YP understand general negative mood in terms of feelings and causes	
	Subtheme 1a - School is a major factor that leads to 'bad days'
	Subtheme 1b - Tiredness is a determinant of negative mood
Theme 2 - YP feel a good day enables them to engage in activities they enjoy	
	Subtheme 2a - Being energetic and not tired makes YP feel happy
	Subtheme 2b - When in a positive mood YP engage in mood congruent activities such as arts and crafts
Theme 3 - Having a difficult school day is understood to be a cause of stress	
	Subtheme 3a - Peers within the school context constitute a source of stress
Theme 4 - Anxiety is experienced physiologically and psychologically in the anticipation of negative situations	
Theme 5 - Anger is both understood in how it feels and what causes it	
	Subtheme 5a - Anger is experienced as annoyance or irritations

	Subtheme 5b - Losing in competitive games can be a cause of anger
Theme 6 - Tics disturb sleep leading to tiredness	

Codes were grouped around the most common mental states YP. These included general positive and negative moods (Theme 1 and 2), stress (Theme 3), anxiety (Theme 4), anger (Theme 5) and tiredness (Theme 6). The feelings and causes of these mental states were frequently discussed alongside the state. It is interesting to note that the YP in this sample did not seem aware of the impact having mental states had on their wellbeing, or the consequences of such states.

Theme 1 – YP understand general negative mood in terms of feelings and causes

The term general negative mood was ascribed when YP spoke about their days being bad or feeling down, but without applying a specific mental state, 'a lot of the time, I have like umm, I have like bad days and stuff' (LF81).

When talking about general negative moods, YP attributed feelings of sadness and isolation; 'I'm so grumpy' (ND93) or 'sad' (HE57) and 'I always think that people don't like me, umm, and so it can kind of like make you feel like nobody likes you' (LP24). Alongside being able to explain the feelings associated with having negative mood, YP recognised certain events made them feel more negative in particular tiredness (Subtheme 1b) and school (Subtheme 1a).

Subtheme 1a - School is a major factor that leads to 'bad days'

A large subset of the sample spoke about school being a trigger for negative mood. This regarded all aspects of schools including being in the classroom: 'you have to sit there all day' (LF81), peers upsetting them at school: 'yes one of the children upset me as well' (N9TT) and getting told off by teachers:

> 'Interviewer: What does a good day look like for you?
> BL19: Umm… oh when I, when I don't really get told off' (BL19)

Some of the YP remarked about school, 'I hate it' (FY78) and described non-school days being good because, 'we don't go to school at the weekends' (EO02).

Subtheme 1b - Tiredness is a determinant of negative mood

Tiredness was felt to be a main cause of negative mood, with YP recognising they ‘wake up in a very bad mood’ (LG64). YP understood feeling tired affected them ‘I feel really grumpy because I need to sleep’ (LF81).

Theme 2 - YP feel a good day enables them to engage in activities they enjoy

On a ‘good day’, YP referred to general positive feelings and associated such days with being able to engage in activities (Subtheme 2b) and feeling ‘free’ to do so: ‘I like being free so I don’t, I don’t like being restrained to what I can do’ (PA29) or, ‘I just do what I want really’ (EO02). This was often reported to be dependent on having the energy to do such activities (Subtheme 2a).

Subtheme 2a - Being energetic and not tired makes YP feel happy

YP implied on ‘good days’ they felt more energised and less fatigued, ‘a good day’s every day pretty much, like when I’m not tired and I’ve got all the energy’ (FL15) or, ‘I just want to get up and do everything’ (N9TT). Some YP suggested this was a result of sleeping well, ‘good days are usually, when to start with, I have a good night so I’m not super tired’ (LP24). Having more energy enabled them to have a good day and to feel more positive, one young person said, ‘on a good day I’ll be so energetic, and I’ll like be happy and say oh how are you and stuff’ (ND93).

Subtheme 2b - When in a positive mood YP engage in mood congruent activities such as arts and crafts

When referring to drawing, one young boy said: ‘I think the end result… like it makes me like really, it makes me feel really satisfied and happy because I really like… the art work’ (LF81) and another young person talked about art, ‘I like to do like art it’s, I’m in my zone so it’s quite fun’ (FL15). On good days YP can engage in activities that affirm their mental state of being positive.

Theme 3 - Having a difficult school day is understood to be a cause of stress

While in the earlier theme, school was believed to lead to a ‘bad day’, school was also identified as being a source of stress for YP, especially because of contact with peers (Subtheme 3a). YP rarely talked about the feelings associated with stress, but were able to recount that a lot going on at school led them to feel stressed, as this young person who explained:

> ‘It’s another school day, like, it’s you have to get up really early, you have to, do this, I, I’m not, like, free to do what I want, so it makes me stressed so, yeah (LF81)’

For some YP this caused them to feel stressed in certain lessons, one girl said, ‘but spellings, I’m scared if I get it wrong’ and ‘my timetables because my timetables are not really good’ (LG64). For some, the stress of school stopped them attending altogether, ‘umm I used to go to school and then I stopped because I, I didn’t go anymore because it was too hard for me’ (PA29).

Subtheme 3a - Peers within the school context constitute a source of stress

One of the aspects of school that YP were able to pinpoint as a cause of stress included peers, similar-aged children at school. This can include fallouts with friends, ‘they kind of decided they didn’t like me anymore which is fine… and I was a bit stressed about her mum coming in to collect her’ (LP24) or generally being around peers, ‘I uhh, normally walk later so there’s not a lot of people there’ (FY78). Stress can also escalate when there are other problems such as bullying, ‘he’s stressed about something else, he’s being bullied in school’ (Mum of XY70).

Theme 4 – Anxiety is experienced physiologically and psychologically in the anticipation of negative situations

When describing how anxiety feels, YP often talked about the physiological sensations that accompanied feeling anxious, ‘it feels like I can’t breathe… and it makes me panic’ (PA29) or ‘lots of noises and feeling sick’ (HE57). Such physiological symptoms were associated with the anticipation of something negative happening, ‘because I didn’t think my teacher was going to be in’ (ND93). Some of this was exemplified by YP who were worried about what would happen if they were alone, ‘because I don’t like, like, being on my own and watching stuff’ (PA29) and ‘if I go to the toilet… alone’, (BL19) or:

> **‘Mum AM58: You don’t like being on your own do you?**
> **Interviewer: What’s that, what’s the feeling you get with that?**
> **AM58: I don’t really, just, like being scared and anxious’**

This example created a sense that the anticipation of negative situations causes anxiety-related feelings.

Theme 5 - Anger is both understood in how it feels and what causes it

YP selected specific words when describing feeling angry, such as ‘frustration’ or ‘irritation’ (Subtheme 5a). As forms of anger, this suggests YP understand how anger feels. Furthermore, the main cause of anger was seen when playing games where there was a competitive element (Subtheme 5b).

Subtheme 5a - Anger is experienced as annoyance or irritations

Being annoyed or irritated by someone was often a cause of feeling angry. One of the YP described a situation where her friend was irritating her:

> ‘BB39: I didn’t really feel down I felt a little bit like irritated with one of my friends because she was just being like really annoying umm…
> Interviewer: So, when your friend was irritating you, how did you feel at that time?
> BB39: Angry’

Subtheme 5b - Losing in competitive games can be a cause of anger

A cause of anger YP shared repeatedly related to competing in games, where YP found themselves becoming angry as a result of not winning, ‘I lost a game of football and I sweared[sic] at A***… because I get really angry if I, if I don’t win’ (BL19). This competitive element was shown by a desire to beat others in games, ‘yeah so I like to out-do them and be better than them, it’s part of me’ (FL15).

Theme 6 - Tics disturb sleep leading to tiredness

As noted in Theme 1, tiredness effects mental states but it was also noted that tics can cause tiredness, mainly due to making it more difficult to get to sleep at bedtime, ‘for about a week or two I couldn’t get to sleep until about one because of my Tourette’s were [sic] quite bad’ (MR38). A mother and daughter recollected:

> **‘**Mum LG64: I mean because you get quite fidgety don’t you and she struggles sleep as well, and she’ll kind of start throwing her body about or sometimes you get your neck tic don’t you

> LG64: And sometimes I even cry’

Tics also can affect the quality of sleep during the night, ‘sometimes I don’t sleep very well because of my tics’ (LP24).

Management of Mental States

When YP spoke about ways they managed their mental states, there were strategies they noted as useful for states or more general moods, such as ‘bad days’ (Theme 7). These strategies included interacting with others, relaxing the body or mind (Theme 8), actively engaging with activities (Theme 9 and 11) or pastimes (Theme 12) and having support networks (Theme 10) which all helped to alleviate, lead to or away from certain states. YP also reported the use of distraction and avoidance for anger and anxiety respectively (Theme 13 and 14) and relaxation to support sleep states (Theme 15).

Themes	**Subthemes**
Theme 7 - Interaction with others helps deal with bad days	
Theme 8 - Videos, films and music is a way of relaxing when having a bad day or to improve negative mood in general	
Theme 9 - Engaging in Games and Music helps relieve negative mood	
Theme 10 - Having a support network helps maintain positive mood	
Theme 11 - Engaging strategies help relieve stress	
	Subtheme 11a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress
	Subtheme 11b - Engaging with des-stressing activities reduces physiological symptoms associated with stress
Theme 12 - Pastimes maintain a soothing state	

	Subtheme 12a - Passively listening to sounds and watching videos sustains a calm and relaxed mood
	Subtheme 12b - Actively engaging with arts and games fosters a calm and relaxed mood
Theme 13 - YP use strategies to avoid anticipated anxiety	
	Subtheme 13a - Being accompanied reduces anxiety
	Subtheme 13b - When possible YP add comforts to their anxious contexts, otherwise they remove themselves from it
Theme 14 - When experiencing anger YP engage in activities which shift their focus	
Theme 15 - Engaging in relaxing activities to facilitate sleep helps avoid negative mood caused by sleep deprivation	

Theme 7 - Interaction with others helps deal with bad days

During days where YP described being in a negative state, YP discussed how spending time and interacting with others helped improve their mood:

> ‘Interviewer: What do you do to make yourself feel better on those days when you’re feeling grumpy?
>
> ND93: Uh maybe play Minecraft and play with all my other friends on it’

A couple of YP said they would talk to their friends about how they were feeling, ‘Interviewer: Would you talk to them if you weren’t feeling that good? AM58: Yeah’ (AM58) whilst others suggested that the presence of friends helped them deal with their negative mood, ‘yeah, I try and go out with my friends’ (FL15). Whilst friends were the main source of interaction, family also acted as support for some of the YP:

> ‘I was in a really horrible grotty mood but when I came back my mum gave me like lots of hugs and we watched a bit of a movie, and stuff like that and I really cheered up’ (N9TT).

Theme 8 – Videos and films are a way of relaxing when having a bad day or to improve negative mood in general

When YP had negative mood, relaxing strategies included watching videos or films to improve their mood. For some YP, films were used to relax, ‘yeah like really fun things, like, relaxing, like watching movies or something’ (LF81) whereas other YP would use videos as a method for improving mood, ‘umm I like to watch YouTube when I’m down and low’ (PA29) which included videos such as, ‘oddly satisfying videos’ (HE57).
Two YP explained how videos them feel better: ‘I just watch them and then my brain goes, oh I’m feeling better now!’ (N9TT) and more relaxed:

> Interviewer: So do you tend to watch slime?
> BL19: Yes…
> Interviewer: And what is it that’s relaxing?
> BL19: When they scrunch’

Theme 9 - Engaging in Games and Music helps relieve negative mood

Certain activities enabled YP to become completely preoccupied and distracted by the activity, alleviating general negative mood. Such engagement was apparent with activities such as playing games and music. With games YP explained that they had a positive effect on their mood, ‘sometimes it just makes me feel good and changes my mood’ (N9TT) and explained they were intensely engaged in the activity,

> ‘Interviewer: what are you thinking about during the game?
> BB39: Uh levelling up’

Regarding music, YP engaged through playing instruments, singing and editing music. When engaged in this, YP explained the process that makes them feel better:

> ‘it sort of goes, I start off the song thinking about it, thinking about the situation, and then, after I get more and more into the song, once it gets to like the solo, I’m just more into the song again then, and then breaking out of it [the negative mood]’ (XY70)

> Interviewer: Do you do anything that makes you feel better?
> ND93: Yeah, playing drums …

> Interviewer: What is it about playing your drums that makes you feel different?
> ND93: I don't know
> Interviewer: You don't know?
> ND93: Because of the loud noise'

Theme 10 - Having a support network helps maintain positive mood

Having a support network was about having a community of people the young person knew were there, even when they weren't interacting with them. For the YP, just knowing they had this community acted as a buffer against negative mood or helped to sustain positive mood,

> Interviewer: 'Do you get any bad feelings like this when you're at school?
> AM58: Mmm, no, my friends are there and stuff'

YP sometimes talked about the support network being there to stand up for them. 'she'll [friend in class] turn around to them and say you don't always have to look' (HE57). Having allies and social support helped YP to maintain a positive mood, 'it makes me feel like, relaxed and like, that me and that person have something in common, like, it makes me like [sic] I am not the only one, sort of' (LF81).

Theme 11 – Engaging strategies help relieve stress

YP engaged in a varied selection of activities that can be viewed as providing distraction from a stressor. Providing a relief from the stressor meant YP experience decreases in both psychological symptoms (Subtheme 11a), and physiological symptoms (Subtheme 11b) including those experienced as physical sensations.

Subtheme 11a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress

YP spoke about a variety of activities that would preoccupy them when feeling stressed, and hence help to manage mood, including puzzles, 'I use this app and it's just on my phone and I use it when I'm a little bit stressed out, and it's basically like, I guess it's kind of like a number Sudoku but it's with colour (LP24)', creative activities:

> ‘Interviewer: when would you write a story?
> N9TT: Just any time when I’m feeling stressed?’

game consoles, ‘I play Fortnight and then that helps’ (PA29) and music, ‘when I’m sat in an actual exam, I’m in a separate room, so I’m on my own with my PSA and I have little rest breaks where I can play my guitar, and I’m allowed to do that, so that’s the main thing I do isn’t it’ (XY70).

Many of these activities acted as diversions from the psychological symptoms of stress, enabling them to de-stress or relax:

> ‘To relax umm I use my iPad so like a tablet, umm to sort of, it kind of like keeps my mind occupied almost, so sometimes I’ll have to like watch something, or put something on my iPad so then I can do other things so whether it’s you know drawing or doodling or something a little more constructive’ (LP24)

Suggesting that amusements or strategies help YP manage stress by reducing the psychological symptoms of stress.

Subtheme 11b - Engaging with de-stressing activities reduces physiological symptoms associated with stress

On the other hand, some YP employed activities that enabled them to feel less stressed through the act of managing the physiological symptoms one can experience from feeling stressed. Physiological symptoms can include feeling hot, ‘I like to create stuff to help me to cool me down’ (PA29), or having nervous energy,

> ‘BL19: I sometimes play with a ball
> Interviewer: You play with a ball, what ball is it?
> BL19: It’s a squishy

And, ‘walking with my music’ (FL15), or having sensory over-stimulation, ‘like when we go to parties, I, I bring my ear defenders’ (PA29). These strategies helped to counteract the negative physical sensations the young person was having.

Theme 12 - Pastimes maintain a soothing state

YP talked about pastimes, activities they described as being relaxing, that soothed the mind and body. Such activities included listening to sounds and watching videos

(Subtheme 12a) or playing games and doing arts (Subtheme 12b), with the former activities being more passive in their nature and the latter requiring more active participation.

Subtheme 12a - Passively listening to sounds and watching videos sustains a calm and relaxed mood

The types of sounds YP listened to varied from the radio to nature sounds or music and ASMR sounds, which lead to an autonomous sensory meridian response (ASMR) often caused by watching and listening to specific visual or auditory stimuli. The act of listening to these sounds calmed the young person, 'we listen to like relaxing music and like, clear out our minds of all the stuff that's like, maybe a problem' (AM58),

> 'Interviewer: when you put the radio on how did that make you feel?
> N9TT: Really calm'
>
> 'BL19: I like the sound of water falling
> Interviewer: So, what sort of, what does that music, what do those sounds make you feel?
> BL19: Calm'

In trying to explain how music makes you feel relaxed, this young person said, 'umm I guess it kind of relaxes me, umm and it, puts everything in a, I don't know it keeps my mind occupied in a certain way' (LP24).Y

When talking about videos some YP felt like how they felt when listening to music, in that watching videos was a way of relaxing, 'yeah it's just as relaxing playing video games as it is watching other people play them' (LF81). When watching ASMR videos one young person explained how they, 'have flashlights and you just follow the light and stuff' (FY78) which was their way of using videos to relax.

Subtheme 12b - Actively engaging with arts and games fosters a calm and relaxed mood

Whereas subtheme 12a included passive engagement, the practice of being more actively involved in an activity helped YP to feel calm and relaxed, such as through playing games and doing art. When asked what activities they do to keep calm, one young person reported, 'I play on my phone' (PA29), and another described that gaming, 'just calms me'

(N9TT). Similarly, with artistic activities YP talked about the impact art had on how they feel, with some using art apps, ‘I have lots of drawing apps. And, yeah, umm, I find that quite calming’ (LP24) and others talking about drawing, ‘Interviewer: What do you like about drawing? ND93: Oh it calms me down’ (ND93).

When asked how drawing helps to relax the self, YP explained it is the creative side they enjoy, ‘the imagination, and concentration’ (PA29), or the freedom of choosing whatever they want that helped YP manage their mood:

> ‘umm, doing stuff, like, like drawing, it takes time, but you’re not rushing and… you can stop and do it, whatever picture you want, you’re not, um, like stuck doing one thing’ (LF81)

Theme 13 - YP use strategies to avoid anticipated anxiety

YP employed strategies when apprehending an anxiety-provoking situation. They would put into place strategies to overcome the anticipated anxiety, such as ensuring they were accompanied (Subtheme 13a) or making adaptations to that environment (Subtheme 13b). In situations where the young person was unable to make such changes, they removed themselves from that context to reduce their angst. Notably, most of the YP who were coded to this theme experienced comorbid diagnoses of anxiety and OCD.

Subtheme 13a - Being accompanied reduces anxiety

When the young person was worried about doing something, having a person or pet accompany them reduced their anxiety, ‘I’m not really sure what the cat would do just because I know it’s there, but like dogs, can protect me, like if anything did happen [when going upstairs]’ (AM58). Anxiety provoking situations could include going upstairs, ‘I don’t like going upstairs on my own’ (PA29) or going outside, ‘he wouldn’t go anywhere without any adult supervision’ (EO02 Parent). Completing the anxiety-provoking act was made more manageable through the company of another person or animal.

Subtheme 13b - When possible YP add comforts to their anxious contexts, otherwise they remove themselves from it

Another way a young person was able to continue despite their anxiety was by changing the environment to make it less anxiety-provoking. An example of this was with night lights, ‘any light really just not really dark ones because I don’t like the dark’ (AM58), or glow in the dark stickers in a bedroom:

> ‘Interviewer: So, are there any other things that would help you feel less scared about being in your room?
> PA29: Umm, I do, umm, want, I’ve asked mum about this like a night light that projects stars onto your roof
> Interviewer: Oh yeah
> PA29: And I like them because then, I, I just, feel more calmer’ (PA29)

Those YP who were feeling anxious but unable to make changes to their environment talked about leaving the situation. One young person said they, ‘just try to go home’ (EO02) or, ‘I usually just use my legs and then go’ (LP24).

Theme 14 - When experiencing anger YP engage in activities which shift their focus

YP talked about engaging in a variety of different activities when feeling angry, including strategies that could be considered relaxing or interacting with others. A commonality amongst the strategies YP executed when feeling angry was distraction, shifting focus away from the feeling of anger. Some YP used drawing, counting or listening to music which calmed them through focusing:

> ‘Interviewer: what do you do when you’re calming down?
> BL19: Count to 10’

> ‘AM58: Umm, yeah like when like, I’m, say I had a rage, usually I just stay downstairs for a bit
> Mum AM58: You draw
> AM58: Yeah I draw’

Other YP referenced playing games, ‘umm, sometimes when I feel a bit angrier I like to just go on like, an easy game, and like, just play through the levels’ (PA29) or, ‘the puzzles game will stop it [the anger] in its tracks’ (XY70) with the suggestion that completing the game or playing puzzles acts as a means of distraction.

Finally, YP sought interaction with their parents after being angry, through cuddling leading to feeling, ‘happy’ (AM58) or, ‘more calm’ (XY70) and helping to replenish their physical needs after having an anger outburst:

> 'Mum EO02: what do I do to make you feel better?
>
> EO02: Give me a drink'

Theme 15 - Engaging in relaxing activities to facilitate sleep helps avoid negative mood caused by sleep deprivation

Sleep was reported as a cause of negative mood and disturbed sleep can be caused by having tics. Therefore, it appears YP attempt to engage in relaxing activities to help counter sleep difficulties. Some YP recounted using music or audio to facilitate falling asleep, 'I told my Alexa dot to play Radio 1 last night and I just fell asleep listening' (N9TT) and, 'I like the audio books... at nighttime' (PA29). Other YP used different sounds to help them get to sleep at night, including ASMR, 'it just relaxes me umm, and makes me sleepy' (FY78) and nature noises:

> 'Oh yeah that was, yeah like natural sounds, like rain, umm, like in, like, in, like in a forest… Yeah, I used to listen to that and it would make me feel more relaxed and it should make me feel really sleepy on them, and make me go to sleep' (LF81)

Other YP used games to relax before bedtime, 'I just play games but then like a while [sic], a couple of hours I get tired and then I just fall asleep' (LG64) or, 'I use umm… [sic] group of games, they're probably for like much younger children, but it doesn't matter' (LP24) or watching videos:

> '[if] I really need to get to sleep but I can't because of my tics, what I do, is I'd put something on my iPad you know through my ear phones and I'd watch something and then I'd be able, and then I'd get, and then it would calm me so I wouldn't be ticcing so then I'd feel really tired so then I'd switch it off and go to sleep' (LP24)

And, 'sometimes I just watch YouTube and then when mum comes up, and, turns the light off I like to umm, just go to sleep' (PA29). Using such strategies could prevent the onset of negative mood the next day from as a result of tiredness.

Desired Features of the Tool

Any codes pertaining to features desired in the tool were grouped to gather the features desired by YP. These codes were only grouped if YP talked about wanting such an aspect to appear on the tool, which included ways to learn more about TS (Theme 16), activities that help to keep the young person calm (Theme 17) and functions that help YP to organise their activities (Theme 18). One of the YP summed up many of these activities succinctly as:

> 'this is what I want on it okay; music slash relaxing, TS videos about get over tics, and then games to help you with your tics, a schedule that helps me as well' (BL19).

Themes	**Subthemes**
Theme 16 - There is a need for psychoeducation derived from interacting with others' lived experience of Tourettes	
	Subtheme 16a - Interaction with others enables learning more about Tourette Syndrome
	Subtheme 16b - Normalisation of experience is gained through sharing
Theme 17 - Being able to select music, sounds and games will help YP to be calm	
Theme 18 - Need for a function that acts as a reminder for the day's activities	

Theme 16 - There is a need for psychoeducation derived from interacting with others' lived experience of tics

Psychoeducation includes having understanding and knowledge of the condition. Through speaking to those who have their own experience of living with TS and tics, psychoeducation could enable YP to learn more about tics (Subtheme 16a) and feel more normal about their condition (Subtheme 16b). Psychoeducation in this context included finding out about how to 'manage and control their tics' (XY70), or to 'see how they're doing' (LG64) and gain 'tips and tricks' (BL19) from speaking with others.

Subtheme 16a - Interaction with others enables learning more about TS

One of the main sub-themes found was that YP feel having social support from those with experience of TS could increase their understanding of their condition. One of the YP suggested a forum to learn strategies for their tics:

> 'a forum might be yeah because I've gone online a few times, well I say, once or twice trying to look for different ways people manage to try and

> to control their tics, I haven't actually found anything I've just found NHS website explaining what Tourette's is, you know in general, a very abrupt summary of what thing is but not any techniques or anything' (XY70)

This suggests YP are looking for more in-depth information than what is currently available, with YP suggesting that members of the Tourette's community aid the forum. Similarly, another young person said, 'I was thinking… we can message other people with Tourette [sic]' (BL19) enabling them to ask for 'tips and tricks' and 'advice' about their TS. These views show YP were hoping to gain advice about managing their TS and tics through conversations with others who may have similar experiences.

Subtheme 16b - Normalisation of experience is gained through sharing

Sharing your own lived experience of having a condition also creates a normalisation of the observers own experiences. Many YP feel alone, so talking to people who share commonalities with them would help with 'knowing that it's not just you' (LP24). Setting such standards of experience across communities with the same conditions can help YP who may be experiencing shame or embarrassment, 'just like seeing what happens to them, what they've got and like embarrassing things that they've done' (FY78), or feeling different to other people, 'I think HE57 is quite keen to meet other girls that have got Tourette's, we don't seem to [meet any girls at TS support meetings]' (HE57 Parent). Such normalisation could also positively impact on families who are worried about their children feeling isolated by their condition, 'then you'd think, I'm not alone in this, oh god that explains why I'm feeling like this' (FY78 Parent).

Theme 17 - Being able to select music, sounds and games will help YP to be calm

Many YP desired activities that would keep them calm on the intervention, these calming activities mostly consisted of sounds and games. Such sounds felt to be calming included a variation of nature sounds like, 'noises of like rain and maybe the sea' (FY78) or music, 'if I was feeling angry, like, like, then you can, if I put like calm music on then I feel calmer' (PA29). These quotes exemplify how YP would intend to use the intervention, so in the present moment when they feel music would help to relax them they could access it:

> 'If there, if someone had like, a certain, like song, or something that helps them, when that happens [experiencing sensory overload] or when

> they’re in a space like that, that, that’s on that app, so you can keep it there, so whenever you need it, if you had your headphones or whatever, if you listened to that and you know that you’re like, safe or whatever, so, I don’t know, kind of like, something to keep, reminders so you know that actually you know everything’s okay you know’ (LP24).

In terms of games, this was also a feature YP felt would make them feel calm and therefore would desire on such a tool, ‘maybe a calm concentrating game that would take your mind off it or something… Like a mystery kind of game’ (MR38). YP had an idea of the type of games that would be calming and those that would not be, ‘maybe not like a you-know like a robot game when you tap and when you jump cos that might make me angry’ (BL19) and non-stressful games, ‘put games on that are not as stressful’ (FL15), highlighting the importance of calming game genres if they were a feature of the tool.

Theme 18 - Need for a function that acts as a reminder for the day's activities

The final theme that YP desired for the self-help tool included a feature that would remind the young person of the activities they had planned for the day. This would be useful for YP who struggle to remember what they are meant to be doing: ‘a schedule that helps me as well… because people with like tics have like, memory loss and forget things’ (BL19). YP reported they do not currently have the support available to them to be reminded of such things:

> ‘yeah, if someone’s like, was reminding us you know that would be good for them to help me, but then you know, they [the teacher reminding them] would distract the whole rest of the class, and, yeah, if the teacher did it, she’d have to do it every second of the day’ (LF81).

Such a function could help the young person feel more able to manage day-to-day activities: ‘I don’t know, kind of like, something to keep, reminders so you know that actually you know everything’s okay you-know’ (LP24).

Mental States and Tics

The relationship between tics and mental states was spoken about so frequently it constituted a theme in itself. This theme related to when YP talked about the relationship between their mental state and their tics. As tics and mood have an impact on wellbeing, it was important to include these experiences.

Themes	**Subthemes**
Theme 19 - Anticipation or experience of tics is associated with negative mental states	
	Subtheme 19a - Excessive tics make it a bad day
	Subtheme 19b - Minimal tics are associated with a calm or relaxed state
	Subtheme 19c - Anticipation of tics causes anxiety
	Subtheme 19d - Ticcing, or anticipating tics is associated with stress

Theme 19 - Anticipation or experience of tics is associated with negative mental states

During a day that YP felt was negative, YP often stated that tics were the cause (Subtheme 19a). On the other hand, if a day was not overruled by tics, YP reported feeling calmer or more relaxed (Subtheme 19b). Similarly, YP showed signs of stress when they had tics (Theme 19d) and were stressed and anxious by the thought of having tics (Theme 19c).

Subtheme 19a - Excessive tics make it a bad day

YP felt it was very hard to make a day that was characterised by excessive tics a good day, therefore such days were often bad. One young person explains that having tic attacks in the morning suggests they will have tic attacks for the rest of the day leading to a worse day as explained:

> 'When I do have loads and loads of tics, like, some days I have loads of tic attacks so I tic the whole entire day, when I only one or two, then it, yeah it's quite a good day' (LF81).

Instead, a good day is often felt to be characterised by having few tics, 'yeah like today was a good day because like in class I like didn't make any noises' (HE57).

Subtheme 19b - Minimal tics are associated with a calm or relaxed state

There appears to be a circular relationship between tics and calm states, whereby on days when YP have fewer tics they also report feeling more calm, and being more calm led to fewer tics. In line with the former statement a young person reported they had fewer tics at the farm and said this was due to the, 'the calmness and stuff like that' (N9TT). Another young person explains how when things are going smoothly, the tics are also calm, ‘everything like fits in to place, and my tics are very calm and they’re not violent at all and everyone’s happy with me and all that’ (MR38). The opposite appears to also be true, that on busy days tics seem to also be busier, ‘so whenever my mind is busy, then my body will also be busy, whether it’s even just excitement’ (LP24) suggesting a mind-body relationship with tics.

Subtheme 19c - Anticipation of tics causes anxiety

It is not always necessary to actually tic to be anxious about tics, as YP in this subtheme explain that being worried about tics can be enough to cause anxiety, ‘uhh I feel anxious because I’m worried about people judging me on my tics and I’m just embarrassed… And like, that’s why I’m anxious around, like, everything’ (FY78). Being worried about what will happen when ticcing in front of people can cause anxiety, with some YP leaving the room to tic:

> ‘At my old school because I don’t go to school anymore, I used to hold it
> [the tics] in and then ask if I could go to the toilet and then shout it’
> (PA29)

For similar reasons, YP explained they were anxious about going to new environments, ‘yeah I find that if I’m going to a new thing or things like that, I worry about my tics and going to see new people and things like that’ (LP24).

Subtheme 19d - Ticcing, or anticipating tics is associated with stress

Similarly to Subtheme 19b’s cyclical cycle of tics, being stressed was often noted as a causal factor of tics, and being worried about ticcing also caused stress. The cause of the stress was variable between participants but feelings of stress led to a young person ticcing or having more tics than usual. Two YP summarise the effect stressful days have on their tics: ‘a good day is when I’m not stressed and then my legs don’t get tingly but when I am stressed my legs get tingly and I have to shout stuff’ (PA29) and, ‘not having a too stressful day, cos like [if] everything’s a bit more stressful and you’ve already got your bad tics, they don’t really mix together very well’ (LP24). The impact feeling stressed has on YP with tics life was explained:

> ‘LG64: Yeah, it feels different and uhh, and I feel really really sad, and stressed at the same time, but I feel much[sic] angry because it gets on my nerves
> Interviewer: Is that, so your tics make you feel angry, stressed and sad all at the same time?
> LG64: Yeah, I sometimes I even cry’
> ‘FY78: It’s really stressful and I don’t like just doing, I find it really hard to get through the day
> Interviewer: Mhmm, is that because of how you’re feeling?
> FY78: That’s because of my tics’

Strategies and Tics

YP talked about strategies they engaged with which helped them manage their tics. Managing tics included spaces they felt comfortable to tic in (Theme 21), or that distracted them from their tics through pastimes (Theme 20) or physical activity (Theme 22), as well as times where they felt a reduction in their tics.

Themes	**Subthemes**
Theme 20 - Engaging in pastimes can increase an awareness of a reduction in, or shift focus away from tics	
Theme 21 - A 'tic-friendly' environment provides a private space for the free expression of tics	
Theme 22 - Physical Activity is a distraction from tic monitoring	

Theme 20 - Engaging in pastimes can increase an awareness of a reduction in, or shift focus away from tics

Different pastimes were recognised by YP to alter tic expression, including through the reduction of tics, ‘I just don’t do it as much’ (FY78) or a shift of focus, which makes YP less bothered and aware of their tics, ‘I never really noticed when I play’ (FL15). Such pastimes rarely led a young person to be more aware of their tics or to have increased tics as a result of engaging in them, suggesting being engaged in these activities is a way to help YP manage their tics. The pastimes YP referred to included activities that required both active engagement such as playing instruments:

> ‘It [the cello] kind of like rings out and you can feel the vibrations, and of course when you play percussion there’s vibrations, so I guess there’s that part. It somehow occupies my brain in a certain way, so that my tics, don’t, I guess kind of like when I use my iPad, umm I don’t tic’ (LP24)

> ‘See when I’m playing my guitar I just tic less, I don’t know why’ (XY70) or those activities that appear to be more passive like watching videos ‘because I watch football videos as well it’s obviously what I like doing so I’m, even though I’m not doing I still like watching it and it still calms my tics down in a way’ (MR38)

Listening to music also had a similar effect, ‘it’s just, I don’t tic when I listen to music, I’m just relaxed and in my own world’ (FY78). Whilst it is hard to determine the levels of engagement the young person has, it appears that the pastimes do ‘pass the time’ for the young person where their time is not preoccupied by or with tics, ‘because it’s like, concentration, yeah, concentrate, I’d concentrate on it a lot and concentration stops my tics’ (AM58).

Theme 21 - A 'tic-friendly' environment provides a private space for the free expression of tics

Certain environments are not tic-friendly, in that YP do not feel comfortable to tic in these environments due to fears of being judged or feeling embarrassed as explained here: ‘uhh just people looking at me, giving me weird faces, puts me in an uncomfortable mindset or whatever’ (MR38) and ‘because it’s a quiet still space it makes me tic more, and then stressed out, so it’s kind of like a circle’ (LP24). As a result, YP find ‘tic-friendly’ environments where they could tic freely without having the need to suppress, ‘you can do anything in there… I’m allowed to go in there whenever I want to, to tic’ (LG64) or where others aren’t around, ‘there’s no one around and I can just do it and be myself’ (FY78). Some YP create such safe spaces by informing others about their condition:

> ‘I know that there’s going to be some supply teachers who are going to be funny about things… and they’re like, sit still, I can’t, yes you can, and I just show them the card [information passport card] then and when they’re like never mind it you can’t’ (XY70).

Having this space or creating it is a strategy as it enabled the young person to tic in a place they feel safe to do so.

Theme 22 - Physical Activity is a distraction from tic monitoring

Many YP notice that through doing physical activity, such as team sports, walking or keeping active, the tics are not as noticeable to them. Noticing tics or monitoring tics, means they are aware and conscious of them. During physical activity, conscious monitoring may be reduced through a shift in focus to the activity instead. Some YP explain this as forgetting, '[when I] play rugby I just forget about my tics and it just doesn't happen, I'm just focused on that' (FY78), or being distracted by sport, 'I like what I'm doing and its fun, and with football I'm running around getting distracted' (MR38) and, 'so it [playing football], because sometimes it helps me, it distracts me' (BL19). Furthermore, many of the YP replied they do not notice their tics when asked about different activities including, 'walking the dogs' and 'climbing' (HE57), 'mountain biking', (XY70), 'in the gym'(FY78) and whilst playing, 'tig' (BB39), suggesting such activities also help to distract from tic monitoring.

Discussion

Together, 15 YP were recruited to explore what YP with TS or a TD would find useful in a technology-based self-help tool to improve their wellbeing. The demographics of the YP in the small sample suggest it is fairly representative of YP with tics as a range of tic severities and wellbeing measurements were reported. The ratio of girls to boys was as expected with reports indicating a dominance of males to females somewhere between 3:1 to 5:1 (Hirschtritt et al., 2015; Yang et al., 2016). The age of the sample mainly congregated around early adolescence, however there was a wide range of YP from either end of the recruitment criteria from 9 to 17 years old. The global tic severity scores from the YGTSS suggested a range of YP experiencing moderate to high impairment as a result of their condition had been recruited, although it was noted that the average total YGTSS score from this sample was higher than reported in other qualitative studies with similar samples (Edwards et al., 2017; H. Smith et al., 2016; Wadman et al., 2016). This was supported by the TODS-PR scales, with parents indicating their children have at least moderate to severe TS. The parent rated RCADS suggested YP in this sample had, on average, above the threshold for anxiety and depression symptoms, whereas YP reported themselves as being just below the clinical threshold for borderline anxiety and depression symptoms. Nonetheless, this indicates a sample of relatively high anxiety and depressive symptomatology. Whilst the sample showed varied high and low QOL scores and satisfaction with life on the C&A-GTS-QOL scale, on average YP scored highly on the VAS indicating relatively good satisfaction with life.

From the interviews, 22 themes were generated and organised into five categories. This included six themes on YP's Understanding of Mental States' and nine themes on 'Management of Mental States'. Two further categories were defined, relating to one theme centring on how YP see the relationship between their 'Mental States and Tics' and three themes around YP's 'Strategies and Tics'. Finally, the last group of themes related to participants 'Desired Features of the Tool'. Both what YP said, and what YP did not say, will help to form a basis for the proposed intervention.

Understanding of Mental States

Within this category, six themes were developed showing the mental states YP frequently spoke about and showed understanding of. In terms of negative mental states, YP were able to characterise general negative mood or anger, and what would cause such moods (Theme 1, 5). Furthermore, YP identified the emotions: anxiety (Theme 4) and stress (Theme 3), also being able to pair these emotions with potential causes and feelings associated with them. Additionally, YP made the connection between tiredness as a result of having tics and the impact this had on their mental state (Theme 6).

Management of Mental States

Nine themes were identified within this category relating to how YP manage mental states. Some of these were specific depending on the state or mood of the YP, for example for anxiety YP used avoidance strategies (Theme 13), for anger YP used distraction (Theme 14), or for sleep YP engaged in relaxing activities (Theme 15). For states that were more general, such as positive and negative mood, YP used strategies that helped to maintain or boost mood (Theme 8, 9). It is notable that of the mental states highlighted in the above category, these were also identified here as those YP showed management of.

Within their management strategy repertoire, YP often talked about the use of entertainment which they found to be relaxing (Subtheme 12a) and helped with emotions such as relieving stress (Subtheme 11a). However, with nearly three-quarters of YP reporting to watch TV and play games for over 12 hours a week (Dubicka & Theodosiou, 2020), and 72% of YP streaming music daily (Statista, 2017), it is difficult to disentangle whether YP are actively drawing upon these activities to intentionally change the way they feel, or if it is part of their daily routine. This is a similar finding to previous research conducted by this group with a non-clinical sample of YP. It was found that YP tended to use the same digital technology they would use on a daily basis for relaxing and distracting purposes (Babbage et al., 2018). While YP with tics have displayed a better understanding of mental states in the current research, their coping strategies are relatively similar to typically developing children who all desired features of a wellbeing intervention to provide distractions, relaxation and social support (Babbage et al., 2018). Although these activities are coping strategies, they may not always be the best form of coping in the circumstances. Distraction is believed to be a better form of mood management than rumination, however only in the short-term as it could lead to increased negative emotions in the long run (Broderick, 2005). Relaxation is often incorporated within CBT approaches for mood management, which can include structured relaxation practices such as progressive muscle relaxation, but can also be experienced by people within daily life such as through recreational activities like watching TV (Luberto et al., 2020). However, mindfulness is now more commonly used within CBT approaches and is thought to be superior to relaxation (Sedlmeier et al., 2012). These findings suggest YP could benefit from developing further mechanisms for coping with negative mental states.

Social support has often been reported as an important aspect of coping for people with tics, with YP rating parents as most important for coping, which continues into adulthood with family and friends being the top two factors to help with coping in a survey of adults with tics (Byler et al., 2015). This is backed in qualitative research where themes denoted the ‘importance of friendships’, ‘caring relationships’ and ‘the value and negative impact of TS on interpersonal relationships’ (Grace & Bowes, 2011; H. Smith et al., 2015). The findings confirm this, with support from friends and family being noted as a strategy that both supports positive mood maintenance (Theme 10) and improvement when days have not been good (Theme 7). This latter theme also highlights how YP with tics often experience social difficulties, with peer victimisation and struggles with friendships being heavily reported in the literature. Tics can cause embarrassment, shyness and social isolation and ultimately struggles with friendships (Lee et al., 2016) and bullying (Malli et al., 2016).

Mental States and Tics

In addition to understanding mental states, YP talked about the relationship between mental states and tics. This consisted of one theme (Theme 19) with four subthemes. This theme highlights the impact mental states can have on tics, and tics can have on mental states, with YP becoming anxious in anticipation of tics (Subtheme 19c) whilst a reduction in tics can allow YP to be calm and relaxed (Subtheme 19b). This cyclical relationship has been documented in previous reviews, as people with tics reported a 'need to manage emotional responses associated with tics' (Hollis, Pennant, et al., 2016). If YP develop an understanding of the relationship between their tics and mental state, YP may be more inclined to use mood management strategies for intervention on both their mood and their tics.

Strategies and Tics

Of the category, 'Strategies and Tics' three themes were identified pertaining to techniques YP used specifically in the management of their tics. Whilst YP stated these were tic-related strategies, many of these activities are similar to those this sample reported for managing their mental states. For example, 'Engaging in pastimes can increase an awareness of a reduction in or shift focus away from tics' (Theme 20) is similar to the pastimes YP reported they used for maintaining a soothing state (Theme 12) and the use of distraction (Theme 11, 14). Furthermore, exercise was found to be a distraction from tics as it prevented YP from noticing their tics (Theme 22). Findings from a systematic review of physical activity found light intensity activity was associated with a reduction in tics, with the suggestion this was due to reduced anxiety and stress (Kim et al., 2018). Finally, YP also reported how different environments impacted their tics and how 'A 'tic-friendly' environment provides a private space for the free expression of tics' (Theme 21). As previously mentioned, external contexts have been found to impact tic expression, with responses to the tics such as being told to stop ticcing or being looked at, laughed at or asked about can lead to further increased tics (Himle et al., 2014). Such reactions make it difficult for YP ticcing in public where they do not feel they can tic freely despite the urge being high. Therefore, it is not surprising that YP seek out 'tic-friendly' contexts where they can tic in private. Previous themes from qualitative research have also noted that 'home was a place they can let everything out', suggesting YP may withhold their tics until they can find a place they feel they can freely express them (Edwards et al., 2017).

Desired Features of the Tool

On the topic of what YP would like to see on the intervention, YP requested psychoeducation from those who have tics (Theme 16), entertaining features that would keep the young person calm (Theme 17) and a function to remind YP of their activities for the day (Theme 18).

Although YP had already displayed relatively proficient understanding of mental states from the first category of themes (Understanding Mental States), they also showed a desire to learn more about their tic condition as a feature of the intervention. This is in line with recent qualitative research in which YP were found to rarely understand the cause of their tics (Edwards et al., 2017). Psychoeducation interventions improve MHL (Jorm, 2011) and are a first-step in many treatment guidelines for TS (Martino & Pringsheim, 2018; Murphy et al., 2013; Steeves et al., 2012; Verdellen et al., 2011). Many behavioural treatments for tics also include psychoeducational components (Woods et al., 2008). The European guidelines propose that psychoeducation provides the young person with relevant information which has a supportive function in relieving any potential anxieties about the condition. It is fundamentally important that YP with tics have excellent MHL, which will allow them to understand their emotions and learn how to better manage their mood (Verdellen et al., 2011), therefore such a feature would likely be highly recommended by stakeholders, irrespective of YP views, albeit this means YP may be more inclined to engage with the requested feature.

Previously, YP highlighted the importance of social support in maintaining and boosting their mood (Theme 7, 10). This was furthered by the desire for social support as a feature of the intervention to learn more about their condition (Subtheme 16a). YP expressed how socialising with others with tics is a normalising experience (Subtheme 16b). It was found that neurotypical YP perceived YP with TS to be part of an outgroup, using 'them' and 'us' terminology (Malli & Forrester-Jones, 2017). If YP with tics are not treated by their peers as equal, having social support on the intervention by those that do treat them as 'normal' could be a rewarding experience.

An unexpected, desired feature included the reminders for the day's activities (Theme 18). YP with tics and their caregivers often report an impairment with independent functioning or managing life's demands. For example, a survey exploring non-tic related problems found at least 30% of the parent sample reported difficulties in YP's ability to concentrate on schoolwork and homework, while over a quarter of the sample were not prepared for class. Outside of school, parents also reported high levels of impairment in YP doing household chores, making new friends, sleeping and being with strangers (Storch et al., 2007). Such difficulties managing everyday life are known as adaptive functioning problems. From the known research, findings suggest co-occurring conditions are a predictor of adaptive impairment, especially ADHD (Taylor et al., 2018). These interviews suggest that YP are aware of difficulties they have with planning or remembering their daily activities. While this does not directly relate to mood management, putting a structure into daily life and managing one's day could be enhancing one's sense of being in control of their internal and external environments.

Of note, YP appeared to show some assumptions that this intervention would be in the format of a mobile phone application. Although this did not develop as a theme, field notes from the researcher showed that YP had already created such an expectation even prior to the interview, 'he had made his own paper-version of an app which he told me all about'. Furthermore, in their references to the intervention YP often referred to an app, or compared features from other apps that they thought should be integrated into this tool.

Limitations and Strengths

Some limitations of the present research included the time difference between the clinical assessments collected resulting from the corruption of the online survey data. The RCADS scores were taken on average 11 days for children and 8 days for parents after the other measurements. This means the depression and anxiety symptom scores may not be as reflective of the young person's mood during the interview as the other measures. The only known study to explore measurement stability of the RCADS found the anxiety subscales measured anxiety symptoms comparably across time in a general population of adolescents using self-report (Mathyssek et al., 2013). This implies over the week it is unlikely the delay in returning the scores will have had a large impact on how they will have responded on the scale. Furthermore, one participant and their parent did not return their online survey.

Another potential limitation for this research was the involvement of parents. Whilst parents were invited to be present during interviews for personal and safeguarding reasons, this differed hugely between participants with some YP being very dependent on their parents throughout the interview and other YP removing themselves from their parent's supervision altogether. While the advantage of online interviews included YP being in control to make the decision that felt most comfortable to them, it also meant there could be some variation in how much YP disclosed. Other limitations pertaining to completing online surveys for clinical assessments of wellbeing or the use of online interviews can be found in the Methods (Chapter 3).

Conclusion

These findings suggest that YP with tics could benefit from the use of a digital intervention to support their existing understanding of wellbeing and coping strategies. By conducting this research, a better grasp of the needs and challenges for YP, and what they would want from the tool, to support a PBA to developing the intervention is had. This has included distracting and relaxing activities, the ability to learn about tics from others with their own personal experience of tics and features that help with YP's daily routines. Further, YP have expanded on how they currently manage their mental health and how their mental health impacts their tics, supporting the rationale that mood management would be useful to support their mood and indirectly the symptoms of TS. These aspects make this tool unique to others currently available which are not aimed at YP with tics and their wellbeing. Future research should seek to understand what strategies are currently being used with YP with tics to support their wellbeing. The inclusion of professionals who have worked with YP with tics would likely expand on whether such strategies could be implemented onto a self-help tool and any additional features they feel would be supportive to wellbeing. Furthermore, the PBA approves of the inclusion of experts who have much experience of supporting YP with tics who may also identify the needs and challenges such an intervention should address.

Chapter 5 – Interviews with Professionals

Introduction

The inclusion of professionals when developing interventions can provide greater insight into the intervention needs (Knowles et al., 2018). Health professionals are adept at highlighting appropriateness and safety issues in interventions (Band et al., 2017). Furthermore, as they are often gatekeepers to the target group, it is important professionals have confidence in the intervention being developed. Research has suggested interventions not including professional insight lack an evidence base or fully developed rationale for helping to manage conditions. In a systematic review of anxiety applications, 67% of more than 5000 apps neglected using professional insights. This majority did not conceptualise the condition, symptoms or treatment of anxiety in line with any literature (Sucala et al., 2017). Similar findings have been shown in other reviews, for example of 279 self-care pain apps, only 43 reported any healthcare professional involvement (Lalloo et al., 2015). These findings are concerning as most are intended to be self-help where there is little or no professional support. The inclusion of multiple stakeholders, i.e. end-users and professionals increases the richness of the intervention (Knowles et al., 2018) and is recommended by the PBA, arguing all relevant perspectives can help to enhance the benefits of the intervention (Yardley, Ainsworth, et al., 2015). Such a view has been taken in qualitative research to understand the broader issues affecting YP with tics at school by including parents, professionals and YP's viewpoints but this approach has not been applied to developing an intervention for tics and wellbeing (Rivera-Navarro et al., 2014).

Currently, no research exists to show what professionals who work with YP with tics think would be useful in a self-help tool for their wellbeing. As previously noted, the only known qualitative paper to take the viewpoints of health professionals was interested in learning about the experiences of YP with tics at school. This study highlighted that professionals felt tics cause social maladjustment, consistent with previous quantitative findings that have shown YP with tics have impaired social functioning, form insecure peer attachment relationships and experience increased problems within their friendships compared to typically developing YP (Rivera-Navarro et al., 2014). Additionally, professionals felt tics cause academic disturbance to YP especially concerning coprolalia, also supported by previous literature which found increased academic interference with tic severity (Conelea et al., 2011). Professionals also noted that YP with tics experience stigma as a result of their condition, which is felt to be a result of TS's misrepresentation and mocking in the media (Calder-Sprackman et al., 2014; Fat et al., 2012). This is worrying as stigma is believed to act as a further barrier to accessing treatment (Hollis, Pennant, et al., 2016). Considering the wide experiences professionals will have with YP with tics, including them within this research could provide further evidence for what would be useful to support YP with tics.

Such research is expected to highlight recommendations from current best practice guidelines, which suggest using psychoeducation. American (Murphy et al., 2013), European (Verdellen et al., 2011) and Canadian (Steeves et al., 2012) guidelines include psychoeducation as the first step for treatment. In its first instance, psychoeducation was presented as a model for therapy (C. Anderson et al., 1980) but has since been streamlined as a self-contained approach in light of the need for therapy to become compact and efficient. Components of psychotherapy include 'active communication of information, exchange of information among those afflicted, and treatment of general aspects of the illness' (Bäuml et al., 2006, pp. S3) and psychoeducation is commonly integrated as an essential element of tic therapy (Capriotti, 2015). Psychoeducation is believed to improve QoL by improving self-management, communication and involvement of care providers (Day et al., 2020). Systematic reviews of psychoeducation interventions have shown promise for adolescent samples with, or at risk of depression (Bevan Jones, Thapar, Stone, et al., 2018) and ADHD (Dahl et al., 2020). While the reviews should be interpreted cautiously due to variable psychoeducation components, risk of bias and different variables for measuring efficacy, a further controlled meta-analysis using 12 RCTs found a small but significant effect (standardised mean difference of 0.14, 95% confidence interval 0.06–0.23) of psychoeducation for physical chronic paediatric conditions on QoL (Day et al., 2020) suggesting it's efficacy.

Following the principles of stepped-care, psychoeducation offers a low intensity intervention. Rapee et al. (2017) compared individual therapist-led CBT sessions, usually offered as a second or third step in treatment of depression for YP (NICE, 2019a) to a stepped-care approach, including parent-assisted bibliotherapy or self-help initially. The stepped care also included CBT, as in the control group and finally the last step included an individualised interventions developed by the therapist. The findings showed stepped-care was as effective as the CBT group, and achieved with significantly less time investment (Rapee et al., 2017). Intervention delivery costs were also significantly lower than CBT from a societal perspective, which included health sector plus parent time required or lost productivity (Chatterton et al., 2019).

While psychoeducation is often proposed as a first-line treatment, it is also anticipated that professionals will suggest the use of CBT strategies to support mood management. CBT is recommended in the NICE stepped care approach for anxiety disorders and depression (NICE, 2011b; Shepherd & Parker, 2017) making it likely that professionals would view this effective strategy should be implemented. Additionally, as already identified in the systematic review (Chapter 2), CBT-based self-help interventions were found to be the most efficacious, with good retention and follow up rates. This is also supported by other systematic reviews of DHIs for YP with elevated mental health difficulties (Calear & Christensen, 2010; Ebert, Zarski, et al., 2015; Hollis, Falconer, et al., 2016; S. L. Rice et al., 2014; Richardson et al., 2010; Rooksby et al., 2015; Ye et al., 2014). Moreover, the NICE guidelines for social anxiety suggest the use of CBT-based supportive self-help for YP who are emotionally and cognitively able to undertake this treatment and recommend self-help groups and materials for children with depression during their assessment (NICE, 2014, 2019a). Together, the evidence suggests that while CBT interventions can be effective, self-help as a first step in treatment for YP with tics may be more plausible and remain beneficial. Integrating the evidence and guidelines with professional input could lead to better understanding of whether a self-help intervention could act as a first step in treatment for YP with tics experiencing wellbeing difficulties.

There is a well-documented dearth in professionals trained to give behavioural therapy to YP with tics (Chapter 1: Accessing healthcare for YP with tics). This is further complicated by the structure of the health services in the UK, where a young person can often see-saw between neurological and psychological services, taking an average of three years to receive a diagnosis for their tic disorder (Hollis, Pennant, et al., 2016). Including professionals could provide an aid for families, equipping them with tools, skills or signposting them to more support without making further financial or time demands from professionals.

Embracing all stakeholders is important to develop a well-rounded intervention that accounts for different people’s experiences of what is important for YP’s wellbeing. Not only do professionals have a wide understanding of what would support YP’s wellbeing from their daily practice, but the intervention could also seek to increase access to professionals who find there are many barriers to providing support. Furthermore, it is important to gauge professionals' view of such an intervention in order to assess its perceived acceptability by those who would likely be involved in developing the intervention, and further down the line, signposting to it.

Study Aim and Research Questions

The main aim of this research is to understand, from the experiences of professionals who work with YP who have TS or a TD, what would be important in a technology-based self-help tool to improve their wellbeing. This study is intended to address the following research questions:

1. How do professionals perceive wellbeing to be in YP with TS or TD?
2. What are the professionals' views on the factors that determine wellbeing in YP with TS?
3. What strategies or techniques do professional feel are most useful for YP to manage their wellbeing?

Methods

Procedure

Professionals could directly access the consent and demographic information online forms from advertisements or could be directed to the online forms via expression of interest to the researcher (CB) where they would be emailed a link to complete the online forms. Please see Chapter 3 for a detailed process of how the consent procedures were completed.

Once consent was obtained, the online form directed participants to a demographic information page where they were asked to input their date of birth, gender, ethnicity, contact details, job title, highest level of qualification, working hours (part-time/ full-time), years of experience working with TS or TD and years of experience working with children. An open-ended box allowed participants to detail any further training achieved for children with tics. Using the contact information given, the researcher contacted professionals individually via their preferred communication preference and organised a date to talk. For the interview, participants were given the option to have a video call, phone-call, or face-to-face interview. Interviews were voice-recorded using two dictaphones for verbatim transcription after verbal consent was given by participants, followed with the semi-structured interview guide questions. Post-interview, professionals were emailed a transcription of the interview and asked to detail any changes they would like making with two weeks of receipt of email.

Datum was stored in accordance with the University of Nottingham's Research Data Management Policy, further details of which are noted in the 'Data Storage and Protocols' section of the Methods (Chapter 3).

Development of interview guide

The interview guide (Appendix 15) was developed from previous interview guides from a participant population of clinicians talking about online mental health resources (Sinclair et al., 2013) and from those who had interviewed parents and staff working with YP with TS (Wadman et al., 2016). Prompts were used to encouraged thinking about the young person's wellbeing holistically, considering the young person's mental health alongside their social and academic worlds. Further, prompts about YP who were coping well and not coping well were used to understand what could lead toward or away from good or poor wellbeing. The bulk of the interview time was intended to be around question four and five, which aimed to make participants think about strategies they used with YP for their wellbeing and which could be applied to the intervention, but also wanted participants to consider indirect strategies that may lead to improved wellbeing. It was also important to ask about what resources professionals are currently using and signposting YP with tics to, and to understand how acceptable such an intervention would be to professionals. One pilot interview was run and included in the final analysis as no changes were made to the final interview guide.

Setting of data collection

Semi-structured interviews took place in a location convenient for the participant as they chose the platform for their interview. Prior to the interview, professionals were asked to think about the following, 'what strategies or activities (e.g., psychoeducation, mood monitoring, hobbies) do professionals feel could be usefully implemented onto a technology resource, such as an intervention or a website for the daily self-management of mood for YP with YP or tics’. Two interviews took place face-to-face at the place of work for both participants, seven took place through phone call and seven were on video call platforms. Participants were invited to check their transcript after the interview for authenticity.

Reflective Statement

The current piece of research began a little after the previous research with YP with tics (Chapter Four), which gave CB an opportunity to develop some confidence in how YP with tics were experiencing TS and in running interviews. However, this also had the potential to change the researcher's knowledge about professionals as many YP and families had reported difficulties. This had also been discussed in the supervision prior to completing the interviews to make CB aware of the potential bias from families at both TicFest and previous interviews. The power dynamic between interviews with professionals felt very different to that with children, as the current interviews included a sense of trying to appear competent and confident to gain the respect of professionals. Further, being aware that professionals were talking about patients whom they work with was really important, and assuring them that names and identifiable characteristics would be kept anonymous helped professionals to become more comfortable during the interview. There were no notable differences between talking to professionals on either of the platforms.

Data Analysis

Data saturation was felt to be reached after interview number 15 and one further interview ensured this was the case, where no new patterns or instances were felt to be identified (Glaser & Strauss, 1967).

Recordings were transcribed verbatim into a spreadsheet processing software using Express Scribe Transcription Software (NCH Software PTY LTD, 2019). One professional checked their interview transcription, and all the suggested corrections were made to their transcript.

Transcripts were analysed using inductive reflexive thematic analysis based on the guidelines of previous protocols (Auerbach & Silverstein, 2003; Boyatzis, 1998; Braun & Clarke, 2006); further details of the process followed can be found in Methods (Chapter 3). A spreadsheet processing software was used to analyse the qualitative data and generate themes. Descriptive data was analysed using SPSS v24 for Mac (IBM Corp., 2016).

Initial codes were generated into the spreadsheet processing software in columns alongside the transcript. Codes were identifiable to a professional through the use of fonts and coloured cells. Codes were grouped and given headings. These were checked to ensure there were multiple professionals and numerous codes to support the group. Some groups were split into further groups whilst others were merged. Those that were not thoroughly supported by enough initial codes or across participants were collated into their own group, and returned to later on in the process. As groups were diverse, topics begun to develop leading to seven topics including: app, mental health strategies, treatment, Tourette Syndrome, wellbeing, comorbidities and environments. Initial codes within these groups were refined and developed into initial themes. After the initial themes had been developed, these topics were removed and the themes were considered without their topics. It was felt that topics were needed, and this led to the development of three overarching categories: Rationale, Strategies and Treatment, however these categories underwent further refinement to fit all the themes comfortably. 'Treatment for TS' became 'Support for TS' to be able to include other aspects of accessing treatment and support. 'Strategies for the Intervention' evolved into 'Features of the Intervention' to capture non-therapeutic strategies and 'Rationale of the Intervention' was split into 'Format and Rationale' to cover themes on how the intervention should look and the purpose of the intervention. During this process, many of the themes were merged and subthemes were created to capture the complexities of the theme. Subthemes that were not as strong were removed, for example 'Implementing strategies at home can be beneficial for YP and their families' although had previously been part of Theme 1. Initial codes that had become redundant within their previous groups were checked, and any matching the new themes were reintegrated to that theme. For an example of the coding process for theming, see codebook (Appendix 16).

Data Collection and Sampling

Professionals were recruited for semi-structured interviews via a flyer posted on the author's personal social media (Twitter, Facebook, LinkedIn) and emailing a database of professional bodies through the Gatekeeper, Tourette's Action with a participant information sheet (Appendix 17). Purposeful sampling was used as professionals were actively targeted on the grounds that they had a professional background working with YP (under 18) with tics or YP e.g., clinicians, mental health nurses, specialist teachers or therapists. No limitations were placed on how much professional experience they needed to have had to be involved in the study. An initial sample of 18 participants were recruited. One participant dropped out as a face-to-face interview could not be organised and another participant was removed as they were based outside of the UK, totalling 16 professionals who were interviewed.

Ethical permission was granted by the University of Nottingham Division of Psychiatry and Applied Psychology Research Ethics Committee, School of Medicine [ref: 043] (see Appendix 11 for ethics approval letter) prior to recruitment.

Results

Participant Characteristics

16 professionals with a median of 6.5 years (IQR=2.8-10) experience with TS, and a mean of 16.9 years (SD=9.2) professional experience of working with children were recruited. All professionals had at least Level 6 or equivalent qualifications (e.g. BA hons/ BSc hons/ graduate diploma), four had Level 7 qualifications or equivalent (e.g. integrated masters degree/ PGCE/ MA/ MSc) and five were educated to Level 8 (e.g. PhD, DPhil). Two professionals disclosed a diagnosis of TD or TS and three professionals disclosed having close family relatives with tics. 15 of the professionals were British and 14 were White British. Interviews spanned six months, from the dates of December 2018 to July 2019. Interviews lasted on average 1 hour 10 minutes.

Thematic Analysis Results

From the interviews, 17 themes were categorised based on the data. They were each organised into one of four groups: Format, Rationale, Features, Support. Three themes were grouped into the format of the intervention which related to how features and elements of the intervention must function to be acceptable to professionals. Rationale themes included five themes that helped to explain the need for such an intervention, and eight themes centred on the features of the intervention which gave examples of what professionals thought would be necessary to include to improve wellbeing for YP with TS.

The final group of five themes refer to how professionals feel the wellbeing of YP with tics can be supported.

Support for TS

Several themes centred on the understanding professionals have around what support YP with TS need for their wellbeing. Support themes included those that related to the environment the young person was in and how accepting environments were more supportive (Theme 1) as well as the impact of social support on improving YP's wellbeing (Theme 2). Professionals also noted that a young person was more likely to be better supported if they understood their own condition (Theme 3), were able to manage life's demands and had confidence. Finally, professionals felt they are better able to support YP if the treatment they give is holistic and individualised (Theme 4).

Themes	**Subthemes**
Theme 1 - Understanding environments can help with acceptance of tics and allows for adjustments to be made where strategies can be implemented	
	Subtheme 1a: Society is not accepting of TS
Theme 2 – Social support provides inspiration to YP	
	Subtheme 2a: Role models provide hope that YP's lives can still be fulfilled
	Subtheme 2b: Knowing other YP with tics can reduce isolation and share advice although can increase tic symptoms
Theme 3 - Wellbeing for a young person with TS includes understanding and accepting their condition, engaging with and being able to manage life's demands and tics	
	Subtheme 3a: Improved self-esteem is a desired outcome of treatment
	Subtheme 3b: Improved wellbeing can be gained through better self-regulation and self-esteem
Theme 4 - Professionals want treatment for TS to be holistic and centred on the needs of the young person and family	
	Subtheme 4a: Developing a trusting relationship in order to understand YP is important

Theme 1 - Understanding environments can help with acceptance of tics and allows for adjustments to be made where strategies can be implemented

Professionals commented that understanding environments make a difference in how YP come to accept and manage their tics. One professional explains how environments are as important as helping the young person: ‘YP are entwined with their family, but actually you can try to help the child but ultimately if the parents and the school aren’t on board then you can’t change that’ (HD84). Families with a better understanding of the condition at home make it easier for the young person to accept their tics:

> ‘I think it’s families where the tics are not focused on… around umm, actually you know what, sometimes they’re worse, sometimes they’re better, they come and go, they’re just part of him, they’re, now there’s a narrative around this is just part of normal life, and you can hear the young person really internalizing that’ (NS62)

Along the same lines, families that were not accepting could lead to poorer management of tics for the young person, ‘just stop making that noise, you just would and actually it’s about that, and I suppose not that negative reinforcement, because the more you pick up on it the more it will happen’ (HD84). Similarly, schools can have a huge impact on how well the young person manages their condition, ‘I think that in terms of what makes a difference to managing well and not managing so well, I think the school environment and how things get responded to is hugely important’ (NS62). Schools that had better understanding were more likely to help with adaptations such as: ‘now he’s got a really lovely positive teacher who times her activities so he doesn’t have to sit for very long’ (SY46) or allowing the young person to leave the classroom early, ‘liaising with school and saying can this pupil just leave five minutes early before the end of the lesson and make their way to the new classroom which then means that actually then there not as stressed about it’ (BI28). In order for environments to be accepting, they need to be understanding and professionals urge that both families and schools need to be told and educated to be able to help the young person manage their condition: for families, ‘you want them [the parents] to learn the strategies because it’s them that’s going to carry on with it after’ (IN73) and for schools, ‘so the child has to be involved but so do the teachers because if you don’t educate the teachers nothing will ever change’ (SY46). However, professionals also noted that it is difficult to achieve accepting environments at home and school when society is not accepting of tic disorders (Subtheme 1a).

Subtheme1a: Society is not accepting of TS

Professionals commented on the frequently reported difficulties YP had with going out in public; one professional explained this and its consequences leading to social isolation: ‘it’s a condition which isn’t very accepting in society, so how, how do you deal with that? You know, because it is a very socially isolating condition’ (KC73). Another professional felt the word ‘Tourette’s’ has stigma attached, which causes them to modify their language, ‘I suppose there is just a bit of stigma attached [to the word], so don’t want to put people off really’ (JE04). Many professionals summed up how societies’ attitudes impact the young person, with two professionals noting society’s lack of acceptance to be disabling for YP, ‘the biggest disability is not the Tourette’s but other people’s attitudes’ (BG73). ‘in the middle of a job interview or college interview… how can you how can you sit there whilst ticcing because it’s not a socially acceptable’ (KC73). This stigma was attributed to the media by a few professionals, one of whom said ‘a lot of the media has a lot to answer for the way that Tourette’s is presented it’s very rare, they represent people with Tourette’s who are completely functioning in life, and are able to manage and do great things despite Tourette’s and comorbidities’ (RQ74). Unaccepting attitudes towards ticcing are also noted within schools, with many professionals noting that bullying is a problem, but that often this was due to a lack of awareness, ‘bullying at school its very much working with the class rather than individuals… It’s more awareness for their awareness really, because you don’t very often have bad children’ (IN73).

Theme 2 – Social support provides inspiration to YP

Knowing other people with TS, and knowing others who have done well despite their condition, is inspirational to YP with TS. Professionals felt YP have gained hope from knowing or seeing role models with TS as shown in Subtheme 2a and knowing other YP with tics is important to reduce isolation and provide a place to learn from (Subtheme 2b).

Subtheme 2a: Role models provide hope that YP's lives can still be fulfilled

Role models can be both famous people and people, with whom the young person feels a connection with, and who provide the young person with hope that they can overcome their condition to live out their potential. One professional explained that role models can be helpful, ‘I think seeing people who manage their, their condition and still manage to have purposeful and meaningful lives, I think is really helpful’ (BI28) and another talked about their personal experiences of having TS and a role model and what it taught them:

> ‘there’s no reason umm, physically as to why I can’t be a mental health nurse, and that was helpful to know, so maybe have [on the intervention] these conversations that YP need to have with peers, umm, about umm, about the facts[sic] that Tourette’s isn’t the end of your life’ (RQ74)

Another professional felt that doing group work was useful for YP, where ‘the 10-year-olds can see the 18-year-old and how things got better for them at 15, 16, [that] there’s hope’ (AB95). Similarly, another professional with tics talked about having ‘love[d] to have had someone growing up who was like older than me but also doing like, having similar value[s] to me’ (NI36) showing how role models can be inspiring and could have a beneficial impact on YP’s wellbeing.

Subtheme 2b: Knowing other YP with tics can reduce isolation and share advice although can increase tic symptoms

Interacting with other people who have tics can help to break feelings of isolation, which is often experienced by those with TS, ‘there is something about umm, support as well, connecting with other, I think it [TS] can feel quite isolating’ (BI28). Professionals report that YP who attend group meetings are beneficial, ‘psychoeducation groups are quite good because people get to see that they’re not the only one’ (JE04). This was similar for professionals who had run group therapy, ‘we found that the groups were a massive help to that and I think it was often to do with meeting other YP who also had tics so they often didn’t feel on their own’ (BC84). Although professionals did mention that tics can be suggestible, ‘the problem was because there was more children there with Tourette’s than not, she would pick up on everyone else’s Tourette’s, hers would be worse and she'd come back with new ones’ (IN73), it was also noted that the benefits of meeting others could outweigh the potential increases in tics:

> ‘So, even when we’re sitting together our tics kind of increase and kind of bounce off one another, he’ll smile about that instead of being really frustrated, you know, he’s not sitting with Tourette’s, and his Tourette’s his actually worse in that moment, but not annoyed by it, and his parents have said that he’s gained a bit more acceptance of it and a bit more confidence to be out and about with his Tourette’s, and I think that’s a really powerful thing umm that I needed at one point and that I think he’s starting to feel as well’ (RQ74).

Theme 3 - Wellbeing for a young person with TS includes understanding and accepting their condition, engaging with and being able to manage life's demands and tics

Professionals felt wellbeing included YP understanding and accepting their tics, whilst being able to engage with daily demands and manage these alongside having their tics. Understanding one’s own condition, and cooccurring conditions, was believed to help with acceptance, as one professional explains:

> ‘[YP] end up leaving that psychoeducation session going alright I’m a Ferrari, I’ve got a Ferrari that struggles to slow down rather than I’m broken weird, crazy and stuff and that to me is a change in wellbeing, you know the way you see yourself’ (AB95)

Similarly, understanding one’s own condition enables YP to better manage their emotions: ‘[YP who] seem to be coping well umm, they’ve, they kind of understand the condition or, or at least… they don’t feel too worried about it or anxious about it’ (JE04). On the other hand, YP who do not accept their tics can lead to feelings of frustration and stress, ‘whenever you’re trying constantly to change the symptoms, of something that you can’t control umm, and you’re constantly frustrated with yourself and be frustrated with your illness’ (RQ74), ‘a lot of the time it’s kind of how they view their tics… there are quite a few YP who who don’t mind the tics they just feel they’re part of them and so it’s not a big deal’ (BC84). This acceptance can lead to a confidence, further detailed in Subtheme 3a, that enables YP to manage their symptoms better, ‘that they’re not seen as their tics, but they then come out the other side and when they get that magical balance they dovetail and then you have a very confident person’ (BG73).

The other aspect of wellbeing professionals mentioned was being able to manage life's demands, which professionals felt was important so YP were not limited by their condition, 'it's the ability to take what's wrong with you, or what feels painful or challenging and being able to say, okay I've got this but I'm not going to let it affect me here' (AB95), physically or mentally:

> 'wellbeing is something about participation, being and feeling well enough to take part in school, friendships, sports, and feel valued in these activities. Feeling and being able to meet their potential in life, rather than being stopped by being anxious etc. and enjoying it' (JE04).

This self-management may relate to being able to self-regulate their emotions, as explained in Subtheme 3b.

Subtheme 3a: Improved self-esteem is a desired outcome of treatment

Professionals felt that self-esteem was so important for YP with TS that one of the goals of treatment should be to improve confidence: 'I think the end goal should probably be like, umm, confidence, umm, just a self-esteem, a more improved self-esteem, and also a kind of, uh, an acceptance of Tourette's Syndrome,' (RQ74). This may enable the young person to not feel defined by their condition, 'so it's [TS] not the be all and end all of life, it doesn't define him, he wants to be a pilot, great, go for it' (AB95) and to remain ambitious despite their condition, 'for the main part it's just about giving the young person confidence about umm, that they still can do what they want to do with Tourette's' (RQ74). Examples of confidence-building activities could include helping a young person to voice their diagnosis to others, 'they [parents] weren't so scared about the outcome for the child because she'd actually voiced it in front of others, and she was quite confident about it (IN73).

Subtheme 3b: Improved wellbeing can be gained through better self-regulation

Professionals recognised the importance for YP to be able to self-regulate their own emotions, to be able to have good wellbeing, something to help YP, 'kind of self-manage their, their symptoms in a way and take control of things' (JE04). This was described as resilience by some, 'a resiliency to be able to deal with the demands of life' (JS82), or functioning by others 'so they can function daily' (IN73), and management by others, 'so how can we help them with general stress management' (NS62).

Theme 4 - Professionals want treatment for TS to be holistic and centred on the needs of the young person and family

Professionals were certain the main goal of treatment should be congruent to the needs of the young person and their family:

> ‘Umm I think the end goal is actually what that young person and family come to you in order to try and, I suppose they have a goal in mind, you try and get to find out what that goal is in your first assessment with them, and then you work towards that goal’ (HD84).

This means YP are at the core of the treatment which is achieved through developing an open relationship with one another (Subtheme 4a). Underlying many of these responses was the idea that professionals didn’t want their own opinions to steer the way the young person’s therapy should go, ‘the best kind of interventions and treatments are guided by the young person themselves identifying what they want to get from it, as opposed to some predetermined idea that we as clinicians or researchers have’ (JS82). As part of reaching the goals of the young person, professionals recognised that family’s views need to also be accounted for, ‘very much working in collaboration with the young person and their family umm because sometimes the family might have an expectation of what somebody’s wellbeing is that they're at a detriment but actually the young person may not agree with that they may say that they’re fine’ (KC73). To elicit information about YP’s goals, professionals described some techniques they used, including, ‘sometimes you don’t do it overtly as goals, you know there’s that technique, if you had three wishes what would you wish for?’ (SO95) and ‘you know creating a plan sort of for themselves and what needs to be in that plan, what are there trigger points you know, is it getting up in the morning, is it you know in certain lessons, what they need to put in place’ (NC74).

Subtheme 4a: Developing a trusting relationship in order to understand YP is important

Professionals recognised the importance of their relationship with the young person. The development of trust was highlighted as an important aspect within the dynamic, ‘it’s quite difficult when you[sic] first meeting YP with Tourette’s because they’re quite guarded… once they realise you understand the Tourette’s and they realise you can help; we eventually can get to that but it’s sort of very softly’ (NC74). Trust between YP and professionals enables open conversations ‘it does depend on that close working relationship really where the person feels able to tell somebody about what’s going on really’ (UI93), in particular with someone outside of the family home, ‘they just want to whinge… YP don’t want to upset their parents, by saying actually this is awful… you can be an audience but not that you’re losing a night sleep over it, because parents do’ (SO95). Through a trusting relationship, professionals can better understand the young person to help them reach their goals.

Format of the Intervention

Three themes related to the format of the intervention which explained in what ways professionals thought the intervention needed to be formatted in order to be useful and acceptable. Formatting suggestions would involve all elements of the intervention, for example for Theme 5, ‘The intervention must be safe to use, which can be achieved through thorough research before publishing’ this would then require every aspect of the intervention to be safe to use. Such themes included requirements that the intervention is safe to use (Theme 5), and that as an app it is engaging and flexible to different needs (Theme 6) and can be disseminated across different levels of support (Theme 7).

Theme	Subtheme
Theme 5 - The intervention must be safe to use, which can be achieved through thorough research before publishing	
	Subtheme 5a: Whilst screens are likely to be a desired feature by YP, they should be regulated
Theme 6 - The format of the intervention as a mobile phone application will engage YP and can be flexible to different needs	
Theme 7 - The intervention needs to be disseminated across different levels of support, but especially as an adjunct to therapy	

Theme 5 - The intervention must be safe to use, which can be achieved through thorough research before publishing

Safety was regarded by professionals as an important format necessary for this intervention to be acceptable for use by YP with TS, with one professional highlighting: ‘obviously safety is a priority’ (NI36). Safety issues included apprehensions about the digital world, ‘I think because of my experiences tend to be around those very vulnerable groups, it’s just how you keep those people safe online really’ (UI93). Professionals were especially worried about screen-time which became a subtheme (5a). Concerns that did not constitute sub-themes included safeguarding worries, use of inappropriate advertisements and data protection. To overcome such concerns, professionals expected the intervention to be thoroughly researched to ensure it was of high quality before implementation, highlighted by a few professionals who said, ‘I’m always conscious of, I guess, feeling that apps have been developed with some quality’ (BI28) and ‘as far as possible just making sure the information like, is quality’ (NI36). Thorough research included RCTs as the goal ‘ultimately’ (BI28), efficacy tests ‘will it be effective? But definitely worth trying’ (JS82) and by asking YP with tics their thoughts, ‘because they’d even be able to say some of the things’ (RQ74). Without such testing, professionals felt this would need said explaining to families, ‘I think you could explain couldn’t you, if you knew that it’s being tried out and you think it’s helpful’ (SO95).

Subtheme 5a: Whilst screens are likely to be a desired feature by YP, they should be regulated

Professionals understood the allure for YP to a digital intervention as, ‘screens are more attractive to that group of children and YP, it’s often quite an easy way to engage somebody’ (UI93), yet in the same essence, the use of a digital intervention adds to worries parents and professionals have around YP’s over-engagement with screens. For example, this professional explains using an app to help with sleep may be counter-productive: ‘it might be a bit, dubious asking them to go on the app… you could have advice about sleep but don’t necessarily have to access [it] at midnight or something’ (JE04). Reasons for wanting screen time to be regulated included: parents being unaware of what their children are doing with their phones, ‘you do really get parents saying no I don’t want to use an intervention because I don’t want my child on the screen because I don’t know what else they’ll be doing’ (SO95); to research suggesting YP are becoming addicted, ‘our brains are affected by, by interactive screens... they’re becoming addicted’ (BG73); or not feeling educated enough to know whether screens are good or bad, ‘I can’t make a value judgment’ (SO95). The operation of how regulation should look was not corroborated by most professionals, although one suggested using time limits, ‘your app will have to regulate screen time and any games like that’ (BG73).

Theme 6 - The format of the intervention as a mobile phone application will engage YP and can be flexible to different needs

Professionals were enthusiastic about the format of the intervention, ‘it sounds fab it really does’ (BC84), especially as the intervention is something they feel YP would engage with: ‘I think many people have smart phones umm, and may be more willing to read information on an intervention rather than a book (JS82)’. One professional explained that an intervention is engaging due to its intuitive nature, ‘a general app is lovely… you can touch it, you can hear it, you can see the difference in the bits, it’s bright, it’s colourful’ (AB95). Furthermore, professionals highlighted the suitability of the app for different ages and needs:

> ‘I could see the teenagers accessing one type as we talked about with videos umm and maybe a forum for asking questions, having some mindfulness exercises, umm having some prompts and reminders which I think would be hugely helpful for teenagers and then younger kids maybe a more fun based umm, computer game as reward, doing certain tasks’ (JS82)

As an app, the intervention needs to be suitable for younger people, but also for older YP transitioning from primary to secondary school, where cooccurring conditions can begin to present themselves and when they have access to phones, ‘when they start having more anxiety, so you, that’s probably when, I'd be thinking of something, then you’d probably need more of a phone intervention because they’ve all got phones’ (HD84).

Theme 7 - The intervention needs to be disseminated across different levels of support, but especially as an adjunct to therapy

> ‘For me, the ideal tool would be one where I could do the kind of initial input, where I could talk to staff, and I could talk to the young person themselves and then leave them with a tool that gave them some strategies and a bit of control’ (SY46).

Many professionals felt such an intervention would be useful to provide alongside therapy. Some professionals felt YP could access it straight away, whilst others questioned whether families would need an introduction first, as explained by participant JE04, ‘that might be too much for them to take in before they’ve really sat down and had a conversation about a diagnosis, in which case it would definitely be useful I think after seeing them the first time'. The view as to why the intervention would be useful was to aid the young person to continue with strategies outside of therapy sessions: 'I like to be able to give them something to go away with, to do, umm, and they need to be reminded, of what to do' (IN73).

Rationale of the Intervention

Professionals were aware of the need for an intervention for YP with tics, and they talked about this with regard to tics being difficult to live with and manage (Theme 8), being further complicated by co-occurring conditions (Theme 10). They also spoke about the need for more support for tics, relating to the current healthcare climate, where accessing treatment is difficult (Theme 9), especially relating to support for tic related conditions and for professional training to give this support (Theme 10).

Theme	Subtheme
Theme 8 - Tics are often embarrassing and debilitating although many YP can learn to cope well with their tics	
	Subtheme 8a: Transitions cause difficulties in the management of tics
	Subtheme 8b: Suppressing tics is often dependent on the environment
Theme 9 - The intervention should provide accessible support to YP with TS as getting treatment for TS is difficult	
	Subtheme 9a: The structure of the healthcare system complicates receiving treatment and does not prioritise TS
	Subtheme 9b: The intervention should be able to signpost those who need further support
	Subtheme 9c: Getting a diagnosis is often the first step in accessing treatment
Theme 10 - Having a cooccurring condition can impact on emotional and tic functioning, reducing quality of life and impacting on treatment options	
	Subtheme 10a: Comorbidities may lead to requiring a different approach to treatment

	Subtheme 10b: YP with TS have a propensity toward anxiety, which often makes the tics worse
Theme 11 - Professional training is not part of the curriculum, but is specialised or developed through personal experience	

Theme 8 - Tics are often embarrassing and debilitating but many YP learn to cope well with their tics

Professionals recognised that YP find their tics difficult to live with due to their nature, which can be embarrassing. Some professionals shared personal insight on the embarrassing nature of tics, '[I] do feel quite uncomfortable with my own tics… I do feel really distressed by them' (NI36). Another professional commented on the impact tics can have on life, 'you come across quite a number of umm YP with tics and you see how debilitating that would be, how hard that must be for them in a social setting especially something like school' (NC74). Furthermore, tic therapy was not reported to be a treatment option for everyone, notably because tic therapy can be difficult to apply, requires dedication and YP must feel it is worth the effort: 'when your tics wax and you're struggling… they think about kind of doing behavioural therapy, probably habit reversal or exposure response, it's really tricky, so they try it, they don't like it' (AB95). Professionals spoke about how the effort required must be worth the outputs from completing therapy, as tic therapy is not easy to practise:

> 'I generally say to parents that habit reversal um, ERP is often mostly dependent on whether the young person wants to change the tics or manage the tics themselves, so it's really difficult to do it if they have no interest in, in changing them or managing them' (BC84)

Yet, despite tics being debilitating and difficult to learn to manage, professionals tended to say, 'I'm always really impressed by how well a lot of youngsters cope with having Tourette's' (JS82) and suggest this is a result of learning to live with the condition. The sub-themes relate to how transitions are a particularly difficult period for YP in the management of tics (8a), which can be dependent on the environment the young person is in (8b).

Subtheme 8a: Transitions cause difficulties in the management of tics

Transitions for YP moving from primary to secondary school was recognised as causing great difficulty for YP with tics. One professional noted an increase in families visiting the clinic at this time due to worries about the transition, 'we often see people who come around that time, just around that summer before they go to secondary school umm, because they're worried about their situations they're going to come up in their new class' (BC84). This was affirmed by other professionals, explaining the cause of stress being due to meeting new people:

> 'They then feel they've got to start with a new group of people who might not have seen people with the kind of tics they have, they've got to explain about it, umm, or say something at some point, they might not want to and that's something that comes up a lot, how do YP tell their peer group about what's happening and how much they disclose about that, yeah so transitions can be harder' (SO05)

In addition, there are biological and social changes which may exacerbate the transition process:

> 'Yeah, young kids care less and they're aware of it less, you get to that, teenage, tween age, 11, 12, 13, you become more socially anxious or you become more socially aware, you go through puberty, your body changes, you have every other difficulty around for kids as they go through puberty plus you're more self-aware, more self-conscious and more bothered and frustrated amid all of that' (AB95)

Overall, professionals suggested the intervention would be particularly well-suited to YP going through transitions.

Subtheme 8b: Suppressing tics is often dependent on the environment

Professionals had different views about whether YP should learn to suppress tics, with arguments that YP should be able to tic freely and other stances expressing being able to control tics is useful: 'I just think it is what it is, if you need to tic, then you tic, and that's okay… but what they [other professionals] were saying is… she needs to be able to control them' (KC73). However, in general, professionals seemed to feel the latter was important, as YP with tics may feel they need or want to suppress in certain environments which can act as a buffer for how embarrassing or debilitating tics can be.

One professional with tics themselves recounts their personal experience of suppressing or not suppressing, depending on who they're working with:

> 'the only time that I have deliberately not suppressed is when I work with a young person who has Tourette's and is really, has a diagnosis, and, is really frequently very distressed by their tics, umm, and umm, finds [it] normalising that myself and one of the nurses both have a tic' (NI36).

Certain environments such as being at home are noted as places YP do not feel the need to suppress in, 'before bedtime it wasn't about suppression, they could tic, allow tics in, but actually give themselves time to relax, just give themselves the permission to take time' (IN73).

Theme 9 - The intervention should provide accessible support to YP with TS, as there is a lack of available treatment for TS

Professionals feel an intervention would make YP feel better supported, 'having something with people with tics means someone's thought about it and behind that is, you're worth it, you're worth my attention to make you an intervention specially for you' (AB95), as professionals highlighted a current lack of support for YP and families with TS, 'I just think there's such limited resources and such great need and the resources we have are not the[sic] meeting the need' (JS82).

Reasons for not being able to access support are highlighted within Subtheme 9a about how the healthcare system creates barriers to support, with the structure of services creating difficulties with accessing support especially pre-diagnosis, where it was also commented that receiving a diagnosis is often the first step to getting treatment (Subtheme 9c). Professionals revealed other barriers to accessing treatment including not reaching the criteria, 'your chances of being seen, unless your tics are painful or are causing you to be not accessing education, the chances of you making the list in the first place are minimal' (SY46) and a lack of age-appropriate support, 'you know otherwise it's what they read, which is adult led, or the information that you can get, so it would be like Tourette's Action so that's also written by adults for adults the majority of the time' (IN73) or the support is inaccessible to those with more complex needs:

> 'Sometimes many resources are developed for just that group, that are cognitively able, that are able to engage in apps and websites and so on, and so I just have my own personal frustration, that group tends to get focused on than what is a much larger group that has complex comorbidities that can't access those kind of resources, that kind of tend to get a bit left out, that would be it really, in designing an app, whether, they've just, thinking about whether it is just for those that are very cognitively able that can manage a complex interface rather than those that can't... at a very minimum it could just follow the accessible information standard' (UI93)

This theme highlights a need for 'easily accessible, easy to use, really straight forward' (KC73) interventions which can be adapted depending on accessibility needs and if the intervention is unable to provide that support, it should signpost on so that appropriate support can be accessed (Subtheme 9a).

Subtheme 9a: The structure of the healthcare system complicates receiving treatment and does not prioritise TS

> 'It does fall between often umm, I would say paediatric neurology and CAMHS and because it's not necessarily thought of to have mental health problems, often that is one of the driving forces for these children, I notice they're always anxious and we might come onto that, but essentially people see it as a movement disorder and therefore a neurological disorder, but actually there's a lot more to it than that, but that's my experience' (HD84)

As explained by this professional, the nature of TS as both a psychological and neurological condition means YP are often redirected between departments, not reaching the criteria to access either service despite professionals feeling the YP needs further support. This could be the result of no dedicated pathway existing for TS, 'there's no sort of dedicated pathway within our country for children with YP in that they, they might get seen by the neuropsychiatry service in CAMHS but actually it that was never a formalized commissioned pathway' (NS62) which often means different areas of the country offer different support, 'it's like a postcode lottery for support' (IN73). Likewise, there are often threats to funding for TS, 'CAMHS is going through a restructure in **** so it might all be changing and it might even be that Tic and Tourette's therapy isn't seen as a priority at all and I might have to stop that completely' (NC74), which means professionals often struggle to find resources for TS, 'I couldn't really find anything [for TS]' (NC74), or have developed their own support groups which became oversubscribed to due to need:

> 'So, we were looking at interventions to manage our waiting list but of course what happened was, as soon as people found out that we did this group umm, our referrals from the neurologists within the county went up by about 30%' (NS62).

Subtheme 9b: The intervention should be able to signpost those who need further support

Some professionals explicitly reported the intervention should signpost YP on to further support, 'look at this website, or if you feel you need treatment and stuff speak to your parents about it or your GP, ask for a referral here… think about getting this book' (AB95) and, 'maybe a list of contact details' (KC73). The use of signposting was mainly deemed to be important to offer protection to YP who are at risk and may need immediate signposting, 'you've also got to think about what might cause risk to the young person and children and teenagers with low mood are more at risk of self-harm and suicidal ideation' (JS82).

Subtheme 9c: Getting a diagnosis is often the first step in accessing treatment

Most professionals were pro-diagnosis for TS, with one professional using a metaphor, comparing not having a diagnosis to being left in the ocean, 'if you're left without a diagnosis label you haven't got anything to cling to its like being in an ocean and nobodies throwing you your…. Line' (BG73), suggesting that receiving a diagnosis opens up a lot of options for families and YP with TS. Professional HD84 explains how having a diagnosis can further support for that young person or enable adaptations to be made: 'Then they can have like help in class and people then know what the problem is' (BC84). This often referred to increased support at school Emotionally, professionals also reported a relief for the young person and families in receiving a diagnosis, 'though her assessment and diagnoses has, has really you know been such a relief I think [to the family]' (KC73) and, 'it just validates a lot of things, up until then you're questioning am I just not trying hard enough' (RQ74).

Theme 10 - Having a cooccurring condition can impact on emotional and tic functioning, reducing quality of life and impacting on treatment options

YP with TS are likely to have a co-occurring condition alongside their TS, ‘it wouldn’t be very often that I would just see a young person with a tic’ (UI93). Many professionals recognised they would rarely see a young person with TS only, ‘it’s unusual that there isn’t something co-occurring’ (SO95) and, ‘most of them that have had other problems’ (IN73). Professionals often described these cooccurring conditions to be more difficult to live with than the tics:

> ‘I mean having the tics on their own, anyone you talk to with Tourette’s will tell you, Tourette’s is the tip of the iceberg, it’s what people say, it’s all the stuff underneath it, it’s all the internal stuff that’s the biggest kind of hurdles to overcome’ (RQ74).

Reduced functioning as a result of cooccurring conditions was also related to a range of conditions, ‘you know undiagnosed autism, ADHD, OCD, specific learning disorder, I think, you know, everyone recognises the chances are they may have more impact on the child than the tics’ (JS82), and in particular were felt to be the cause of impaired functioning as this professional relays some findings from their research:

> ‘Adaptive behaviour is a proxy for wellbeing in many ways because if you can go to school and see your friends and do your homework, and talk to your parents and not be in arguments all the time, you know, that is wellbeing… and what came out of that study was that the co-occurring conditions had quite a profound impact on the capacity to, to regulate, which then had an impact on the adaptive behaviours’ (JS82).

Furthermore, professionals highlight the difficult cycle of TS and functioning, as YP who continue to struggle will develop low mood, ‘again, so all of the comorbidities that come along with Tourette’s, he just wants to change, don’t want to feel different, umm, and that’s a big part that’s affecting his wellbeing and leading to feelings of depression as well’ (RQ74). This can lead to other problems such as withdrawal, ‘low mood is that it often happens as a result of isolation or withdrawal, which, can happen because they feel anxious initially about doing certain activities, and then they start reducing what they’re doing' (BC84) or negative social comparison, 'everything's so much easier for a sibling than for them, and you know that feeling that it's not fair' (SO95).

This theme further encapsulates other complexities resulting from comorbidities within the Subthemes, including treatment options (10a) and the cycle between anxiety and tics (10b).

Subtheme 10a: Comorbidities may lead to requiring a different approach to treatment

Co-occurring conditions often meant professionals experienced difficulties when trying to treat the young person, 'it just adds an extra layer of complexity… so some of the difficulties are around thinking about what interventions you might provide because we've got this added layer of managing' (BI28). Co-occurring conditions can cause therapies to be less effective, 'so children with significant ASD issues for example might struggle in the group setting' (NS62) or, 'the CBT wasn't working was because of the ASD' (KC73). Professionals highlighted the need for adaptations such as 'visual aids rather than lots of words (HD84)', or for ADHD:

> 'Any good clinician knows that you, you know, keep the appointments shorter, you write down instructions, you train their parents up as well, you get them to do star jumps 20 minutes into the appointment, umm, you know there's all sorts of adaptations that you can do' (JS82)

Professionals also found helping YP learn how to manage the comorbidities alongside their tics was important for their day to day functioning, 'managing comorbidities as well would be a really helpful way in terms of people saying they're more confident in their management of Tourette's in day to day life' (RQ74).

Subtheme 10b: YP with TS have a propensity toward anxiety, which often makes the tics worse

A range of professionals highlighted a view that YP with tics have an underlying propensity toward anxiety disorders:

> 'What were they like beforehand [before the tics started], because often personality and psychiatric disorder are often related, so if you're, sort of an anxious predisposition, you're more likely to get one of the anxiety

> disorders actually, you're more likely to get any disorder, so, um, that's useful to know' (HD84)

Whereby the relationship of increased anxiety and stress was always detrimental to tics, 'they're going to have tics regardless of umm how stressed they feel, they are all going to have tics, but they're much much worse when they're anxious' (SY46) and, 'I do think that anxiety, it makes the symptoms of Tourette's worse, because when she's anxious in community, her Tourette's is worse, and that's very obvious' (KC73). A cyclical relationship between anxiety was noted, with professionals recognising a 'chicken and egg' effect, 'yeah I actually think it's an interplay between the two and it's again, it's a chicken and egg thing first, the more engaged you manage to get YP with everyday life, you often see their symptoms of their Tourette's decrease because their perhaps less anxious' (BI28). Professionals advocated the need to try to help YP overcome their anxiety, which included improved confidence around tics, 'so the children aren't fearful of them, they know that they want, make small changes but they don't fear them' (IN73) and understanding causes of anxiety, 'it's looking at what's happening in their life, are they at a very high achieving school, are they perfectionistic' (SO95).

Theme 11 - Professional training is not part of the curriculum, but is specialised or developed through personal experience

The suggestion from all professionals was that training for TS was not inherent as part of training for the professional position they were in. Some professionals even highlighted that they had not received any training for TS, 'so admittedly I've never umm had any umm official training, umm about, about supporting with them' (NI36). Those professionals who had received training obtained it through attending an organisation where it was delivered, this included specialist hospitals or Tourette's Action, 'I've done the CBITs training, I did that with… Tourette's Action' (SO95). Other professionals accessed private training at a huge cost, 'when I was looking into what, what to do, I spent over £20,000 on private training and therapies and such because I just couldn't find anything you know' (BG73). Interestingly, some of the professionals in this sample had personal experience of tics which they used to help them manage the YP they work with. These professionals described having an increased amount of empathy with their patients, 'you know when I give things and say things which umm, which I feel are supportive, I'm not saying as a lay person… I have some awareness of what CBIT involves' (NI36). Professionals who had relatives with tics also emphasised their ability to understand how to support the young person which they felt aids their role within their profession:

> 'My dad's got tics, he's fairly autistic as well so I've always had an interest, why he's doing that with his arm, what's he doing with his face, my sons 12 now and since the age of 6 he's showed motor tics and had Tourette's for about 3 years, so from a personal point of view, it was important to get better at this and to know what I was talking about to have a frame of reference for people, so I could then pass it on to my lad, but then also having a lad with tics and having two other lads without tics, made me able to see some of the differences which I assume is tic related. So, you can never say that it is but then I bring that back into clinic, so I come with multiple hats on' (AB95)

Features of the intervention

Professionals had several ideas about the features they felt should be included on the intervention in line with the main aim of this research i.e., to help YP improve their wellbeing. Many of the features suggested were practical strategies that could be seen to help a young person in day-to-day life, and were grouped into the following themes around planning, therapeutic self-help strategies, psychoeducation and features that help with tics in particular.

Theme	Subtheme
Theme 12: Planning helps YP better manage day to day life leading to improved mood	
	Subtheme 12a: Planning helps YP to decide what they should and shouldn't do
	Subtheme 12b: Maintaining sleep hygiene helps the young person have a better day
	Subtheme 12c: Prompts in the intervention could instruct YP to employ strategies
	Subtheme 12d: Timetabling helps YP implement routines and remember to-do's
Theme 13: Therapeutic strategies could be implemented on the intervention that would help to improve wellbeing	
	Subtheme 13a: Different forms of mindfulness can help YP to relax

	Subtheme 13b: Strategies can be employed to improve self-esteem by changing the way the young person thinks about themselves and their tics
	Subtheme 13c: Mood Diaries help YP to notice emotions, which can help identify and control feelings to lead to more positive outcomes
	Subtheme 13d: Challenging thoughts can improve mood
	Subtheme 13e: For anxious YP the intervention should include CBT approaches
	Subtheme 13f: Distractions allow a change in focus from negativity and should be fun and engaging
Theme 14: Psychoeducation includes understanding the biology and psychology of one's own tic-condition, which makes the young person and their family better able to cope with it	
	Subtheme 14a: Being able to tell others about Tourettes can empower YP
	Subtheme 14b: Being well-informed about one's own condition can make YP feel more normal
	Subtheme 14c: Understanding one's own feelings is an important part of managing one's condition
Theme 15: Tic Strategies help to reduce tics or to understand them better	
	Subtheme 15a: Distraction from tics helps stop the tic cycle, especially when combined with movement
	Subtheme 15b: Environments can be tic-triggering
	Subtheme 15c: Tic diaries can be helpful in giving information about tics
	Subtheme 15d: Focusing on symptoms can lead to a vicious cycle of tics and mental health

Theme 12 - Planning helps YP better manage day to day life leading to improved mood

The first theme included features around planning that a young person could employ within their daily lives that may enable better management of mood. These activities included planning to foresee potential challenges (12a), helping to maintain one's sleep routine (12b), timetables to remember the day's events (12d) and finally, employing features that prompt YP to use the features that have been suggested for the intervention (12c).

Subtheme 12a: Planning helps YP to decide what they should and shouldn't do

Professionals felt YP may be able to employ strategies that allow them to think about upcoming activities or events and consider ways they may overcome potential challenges surrounding that activity. For example, one professional said, 'I always say plan ahead, so J*** umm wears his headphones a lot, so he plays music to play in the background so… work out what the sensory challenges are going to be, and then work out how you are going to combat those challenges' (BG73) showing how they encourage the young person to consider ways to overcome potential challenges. Being able to make these decisions requires helping the young person consider their environment and select ways to avert problems to, 'help[s] people develop their own tool kit for managing their health condition' (AB95).

Subtheme 12b: Maintaining sleep hygiene helps the young person have a better day

Sleep hygiene is an aspect of planning as it requires maintaining a bedtime routine. One professional described sleep hygiene as:

> 'Having a set bedtime, not too late, umm, sundown, not having Facebook etc. in bed… not trying to catch up on all your sleep at the weekend, try to have a fixed sort of set bedtime… getting fresh air and exercise through the day, drinking enough through the day can also kind of help' (JE04)

Strategies professionals suggested for sleep hygiene included, 'doing relaxation and breathing exercises each night, a lot of mindfulness… So it was aroma therapy, some of the techniques like umm the bands around the wrists' (IN73) or, 'I have always recommended the [sleep] app' (NC74). The importance of sleep hygiene was felt to be 'massive' by professionals: 'its sleep it's massive, you know cos if you don't sleep you're gonna be absolutely exhausted, irritable, snappy' (KC73).

Subtheme 12c: Prompts in the intervention could instruct YP to employ strategies

Prompts in the intervention have been suggested to have multiple purposes. One of these purposes could be to help YP complete tasks set by professionals in-between sessions: ‘I like to be able to give them something to go away with, to do, umm, and they need to be reminded, of what to do’ (IN73). Another purpose of the prompts could be to help the young person to employ strategies at the moment they’re currently feeling stressed, ‘it’s [SAMApp] got some sections on it that have got strategies for what you can do in the moment if you become very stressed and lots of my students have found that very useful’ (SY46). Another professional elaborates:

> ‘That’s something that I think an intervention would help him in terms of his wellbeing, is giving him one less thing to worry about, like kind of getting instruction from an intervention or getting kind of reminders from an app, that maybe you don’t need to worry about what other people are saying or how they’re looking at you or even just something that draws focus away from other people around them that just kind of’ (RQ74)

Many professionals noted that such prompts would be really useful for YP with attentional difficulties, ‘I suppose they’ll have an option to like, click or unclick if they want prompts and buzzes and all this sort of stuff, so yeah I'd put that one in for the ADHD children’ (HD84).

Subtheme 12d: Timetabling helps YP implement routines and remember to-do's

Professionals have said that timetabling is a needed function for YP with tics as they often struggle with executive functioning and attentional problems: ‘Self-help strategies for ADHD include executive functioning, planning organising, time-management as they often get in trouble for being late or forgetting things, leading to stress’ (JS82). As this professional points out, such difficulties can be stressful, but such a feature is believed to support feeling stressed: ‘well a lot of the symptoms [for stress] so that may be, again, it’s looking at timetabling, I know that sounds odd but how much time do they get for homework, do they have a break afterwards or are they working the whole time’ (SO95). Problems with planning can lead to a cycle of negative mood, ‘you know once it’s slipped, you’re behind in your work, you haven’t got your, you know, your coursework in whatever, it really is, affects your mood' (SO95) and therefore professionals believed a function helping YP timetable their activities would have a positive effect on mood.

Theme 13 - Therapeutic strategies could be implemented on the intervention that would help to improve wellbeing

There were several strategies professionals suggested as types of self-management a professional might use within their usual practice. These strategies are all considered to be appropriate for the young person to complete alone in a self-help intervention, including mindfulness practices (13a), self-esteem boosting techniques (13b), mood diaries (13c), reframing negative thoughts (13d), CBT approaches (13e) and the use of distractions (13f).

Subtheme 13a: There are different forms of mindfulness that help YP to relax

In general, professionals said, 'I think maybe some mindfulness' (KC73) would be useful. Some participants spoke about YP already accessing mindfulness strategies elsewhere, 'headspace is kind of, the kids of mentioned that's come up, I've heard that so many times in clinic' (JS82). More specifically mindfulness personalised to tics or the young person was felt would be appreciated:

> 'Obviously mindfulness is all the rage and we do try and suggest mindfulness apps for the YP, even if it's not connected to tics, if there was one that was more specific, it might be helpful, where they could feel like yes this was for them rather than so generic' (HD84)

Another professional suggests personalised mindfulness, so it works for the individual, is important:

> 'Talking somebody through muscle relaxation if it's a strange voice doesn't always work and some of the voices can be quite strange on the mindfulness CDs and I even say that to adults, you've got to find the right voice otherwise it just won't work' (IN73).

Furthermore, there are a range of different forms of mindfulness and YP may prefer what helps them most, 'for some people breathing exercises would be great, for some people progressive muscle relaxation' (AB95). Professionals most frequently talked about the mindfulness approaches; grounding, 'the, umm, mindfulness techniques, the grounding techniques I find some people really benefit from' (JS82), breathing 'you can definitely do a you know the breathing, the relaxation, there's um, you know there's a lot of apps out there anyway for that sort of thing' (NS62)' and muscle relaxation, 'I think definitely having progressive muscle stuff on there but not very long, so just literally tensing and relaxing the major muscles, and having prompts for that would be really helpful for YP with tics' (BC84).

Subtheme 13b: Strategies can be employed to improve self-esteem by changing the way the young person thinks about themselves and their tics

Professionals noted that YP with tics are embarrassed about their condition for a range of reasons, which can include how their tics are responded to, what they think of their tics and if they've been bullied or have anxiety:

> 'Input from an early age of what is tics and Tourette's, so the children aren't fearful of them, they know that they want, make small changes but they don't fear them. Even if they come for therapy because they want to make small changes, they've, they're still not scared of showing you how they tic, its its part of them, it's not a problem, and I find, I've found with the anxiety comes from the people around them rather than themselves or their response, so if there's been bullying with the tics then they're more likely to be ashamed' (IN73)

A variety of strategies were suggested by professionals who felt these would work to improve self-esteem. Each of these strategies aimed to change the way the young person thinks about themselves, including recognising that everyone has differences, 'everybody's different, you're in an inpatient ward and every single one of you are having difficulties, umm, you're completely unique to everyone else around you but they're also unique and their experience too' (RQ74). Positive logs of personal attributes or a 'gallery of assets' was a way YP could improve their self-esteem including, 'what's good about your body, umm, what do people see as your positives, you know why would people like you? Understanding the positives about themselves, umm, what they're good at' (NC74). Some professionals also highlighted how strategies need to be worded so that one is, 'not bringing someone's success down to their talents, or to their abilities but also to their personal qualities as well' (RQ74). YP may struggle with such activities and so helping them is important: 'sometimes people find it really difficult to think about positive things about themselves and you could also put, you could also have like you know you swipe the page and there are examples' (NC74).

Subtheme 13c: Mood Diaries help YP to notice emotions, which can help identify and control feelings to lead to more positive outcomes

> 'If there's a mood diary for anxiety where they can track that with their tics and then they can see how they're doing then that might be useful, so you're not teaching them how to control their tics but what you're doing, you've got this anxiety and you've tracked it and look oh yes the tics are gone' (HD84)

Diaries can help YP think about how they have been feeling and reflect so they can monitor and prepare for potentially reduced moods. Adaptations may be needed to support YP who may struggle to understand and identify feelings, 'I think I would be saying that kind of having that emphasis on that visual support so not everything is written down, there is use of pictures and visual support, it would seem very useful' (UI93).

Subtheme 13d: Challenging thoughts can improve mood

Professionals felt challenging negative thoughts would affect how YP feel about themselves and their situations and in-turn, their behaviour, 'they need to change it from a negative to a positive, and do you know all about how thoughts effect how you feel, about how you behave, so we always do about that as well, quite early on' (NC74). Furthermore, they continue to highlight how, 'that [also] has a big impact on the tics and getting them under control'. Positive reframing, which involves restructuring a negative thought or feeling so that it becomes positive, can improve the way YP consider themselves and their actions:

> 'It's about making people feel proud of who they are, good about what they're doing, and positive reframing… I've got all of these problems and actually I think 3 of them are all gifts, so you're sensitive so you're a loyal friend, you know you're good at knowing when your mums poorly and doing jobs for her, oh he's very sensitive, he's very good at that and then you start to reframe those things about these are your strengths as well' (AB95).

These could be completed at home, ‘that would be a home activity for them, is by next session I want a list of everything that’s made them happy that week’ (NC74) suggesting such techniques could be applied to a self-help tool.

Subtheme 13e: For anxious YP the intervention should include CBT approaches

Professionals recommended use of CBT approaches for YP experiencing anxiety and OCD. These included a variety of methods, such as systematic desensitisation:

> [A] ‘very staged approach so, you know they’ll often talk with mum or a close family member, and you sort of work on stages, where okay, you can do that with mum, I’ll sit in and listen, can you write what you want to say down… it’s that classic desensitisation approach’ (UI93)

Others suggested preparing for the situations that were preventing the YP from carrying out the action:

> ‘In terms of the anxiety it would also be really helpful to help YP with situations that they were avoiding because of their tics or to try and pick up on coping behaviours that they could use to kind of confront those situations… preparing in advance for the worst case scenario, say if they did accidentally hit someone if they had a big arm tic, what they could do about that, what they could say about that, so kind of having some examples of what they could prepare in advance’ (BC84).

Further, considering the chances of the event they were avoiding from happening:

> ‘What is the probability of something happening, actually happening, could you even see it because the line might be so fine you wouldn’t even see it, so the CBTs a lot of these practical exercises with drawing things, and then the behavioural bit too, the actual doing it or the exposure response prevention’ (SO95)

Such techniques are based on CBT but have a range of applications that professionals think could be useful for symptoms of anxiety.

Subtheme 13f: Distractions allow a change in focus from negativity and should be fun and engaging

The use of distractions was something professionals felt were important to stop YP dwelling on negative thoughts. The best distractions were noted to be fun and engaging in order to be distracting, ‘if they’re distracted with something, then they can you know, I’ve distracted from an anxiety because something interesting has happened, you have to take their minds off it’ (SO95). Some professionals noted the use of distraction techniques may allow a young person to remain in a stressful situation: ‘distraction techniques, so apps on their phone, umm music, umm you know, friendship groups, anything that at that time what can they distract them from, that, that, that stressful situation’ (KC73). Such distractions can become part of the young person’s individual toolkit to help them when they need it, ‘you know all these things… it’s one, isn’t it, one of your toolkit’ (AB95).

Theme 14 - Psychoeducation includes understanding the biology and psychology of one’s own tic-condition, which makes the young person and their family better able to cope with it

This theme around psychoeducation shows professionals recognised the impact having a good understanding of your condition can have on wellbeing management. Psychoeducation was explained as a first-line treatment, ‘they would prefer people to have access to psychoeducation behavioural therapy as a first line’ [AB95], reflecting the importance granted to psychoeducation by professionals. This professional noted how psychoeducation is often given to families:

> ‘So let’s say for parents, you’re told your child has tics, and you’re instantly flooded with the fear of what that means… so you’re trying to take in the information at the same time as you are really frightened and I think for children it’s the same… so you might be sat in a room being taught about something, and midway through you have a tic and you get distracted and you don’t take it all in’ (SY46)

Explaining the need for further psychoeducation to be available to families throughout the journey of the young person’s condition was another point made. Professionals felt understanding is empowering for YP (Subtheme 14a), who are then able to explain their condition to others. This also has the effect of normalising how the young person feels about having a diagnosis (Subtheme 14b). Furthermore, having this knowledge can increase awareness of how to manage aspects of having tics and emotions, which can also be useful in helping to manage the co-occurring conditions YP have (Subtheme 14c).

Subtheme 14a: Being able to tell others about Tourette's can empower YP

As this professional explains, it is important to a young person's wellbeing to educate others about your tics:

> 'So what I tend to focus on is empowering YP to feel like, they can control how people think about them and they can control how people perceive them umm, so the first things I do as part of that is that I teach YP about Tourette's' (SY46)

Being able to tell people about their condition gives the person a sense of control and confidence as they can talk openly and with knowledge about their condition, 'I think communicating, and having a confidence, just to describe what the tics are can be hugely helpful' (JS82). Furthermore, being able to educate others also helps those close to the YP with tics:

> 'The parents become quite nervous how the people are going to respond to their child… we designed, umm, for her to do a PowerPoint at school and invite her parents along, and she did that and her parents felt a lot better' (IN73)

Subtheme 14b: Being well-informed about one's own condition can make YP feel more normal

Understanding the condition that you are living with, be it tics or a co-occurring condition can have a positive effect on normalising the experiences of the young person. Professionals explain information alone is not enough to make a difference, and that information has to be 'normalising' to have a positive effect on the young person:

> 'Access just to information isn't it, but, what you really want is to normalise it, everyone with this feels this way… it might have a psychoeducation section on there about how many kids have got Tourette's, if you're likely to grow out of it that kind of stuff' (AB95)

Furthermore, as another professional explains, understanding a condition could replace the need for seeking further support for those people with moderate need: ‘I think the psychoeducation could be sufficient to normalise it enough or give them these small coping strategies, as opposed to having to go and have 12 sessions of umm therapy with the community specialist’ (JS82).

Subtheme 14c: Understanding one’s own feelings is an important part of managing one’s condition

Professionals recognised that YP often struggle to identify and understand their feelings, which can make it harder to change how they’re feeling, ‘there’s something there about identifying feelings and understanding them, so understanding when things are difficult and sort of feelings of stress and being able to identify those’ (UI93). Certain conditions like autism can create further difficulties in recognising emotional states: ‘I didn’t know she had autism, so when I’m trying to explain around her thoughts and her emotions, she has not[sic] insight to her emotions or experiences’ (KC73). As a result, the intervention could help YP to better understand their feelings which may help them to have better self-management:

> ‘I think there could be something really useful about an app, you know as a resource around you know what different feelings words, what those feelings might look like, or, how they might be described, those kind of rating scales where a child or young person could rate their moods and their feelings and show that to to other people’ (UI93).

Another professional describes a way of teaching YP to manage feelings through helping them understand how feelings influence behaviours:

> ‘You map out things like, your early life experiences, anything that impacted on you, umm, your current triggers, umm, your current thoughts, your current feelings, your current behaviour… then you map that onto their feelings, so obviously that makes you feel stressed out, what are the behaviours that you do to manage that, umm, so manage that and you try to help them identify where the cycles are helping them and where the cycles are hindering them’ (NS62)

Theme 15 - Tic strategies help to reduce tics or to understand them better

Professionals also desired the tool to have features that help YP to learn how to manage their tics better, which is believed to indirectly improve wellbeing. These could include methods that lead to a direct reduction in tics, such as through distractions (Subtheme 15a), or changing one's environment (Subtheme 15b), or through methods that help YP to understand their tics better, including tic diaries (Subtheme 15c) and learning about the relationship between tics and mental health (Subtheme 15d).

Subtheme 15a: Distraction from tics helps stop the tic cycle, especially when combined with movement

Distractions from tics have been noted to help reduce the number of tics the young person is having. In particular, movement was often spoken about as providing a distraction from tics as you have to focus on the activity you are performing, 'you need something to do which helps your motor centres to feel busy and you need to cognitively be aware of it rather than thinking about your pink elephant [tics]' (BG73) or sensory workouts provide a similar relief: 'he really umm benefits from the sensory workout because that little break I think kind of gives his brain a break and distracts his brain from the tics and allows him to go back to work' (SY46). One professional coined their own equation for the effect movement has on tics: 'I have this equation and its movement, plus focus equals tic break' (BG73). On the other hand, YP display difficulties when having to sit still, 'now when he's moving around the classroom and he's busy his movements aren't so severe, but when he's concentrating on sitting still they get much worse' (SY46), and suggests movement can provide relief for YP: 'I think it's really enjoying the activity and umm the movement, because you know a lot of what YP are doing at school is that they sit still, you know at the desk, so something like drumming isn't about sitting still is it?' (SO95).

Subtheme 15b: Environments can be tic-triggering

Environments are often reported to cause tics. These can be a result of aspects of the environment, such as noise and lighting leading to more tics, 'umm, noise is a massive one, going into supermarkets at certain times of the day, the lights in some sort of supermarkets have made it worse' (IN73), or other environments halting tics, 'yeah because it's not a real life environment so to speak, you're sat in a lovely calm white room in a in a hospital with somebody who is willing you to do it' (SY46). Alongside environment being triggering, professionals also recognise that different environments can lead to extreme emotions which can introduce tics like anxiety or excitement which can in turn cause a vicious circle of ticcing:

> 'The actual concept of trying to find a parking space, then walking across a car park… because she's already [anxious] then her anxieties heightened, then her Tourette's will flare up then people stare then that makes her worse because then she becomes quite vocal' (KC73)

Similarly, excitement can affect tics too: 'when they're having a really good time, and they get really annoyed because their excitement sets off some of their, some of their symptoms' (BI28).

Subtheme 15c: Tic diaries can be helpful in giving information about tics

Tic diaries can be useful at different stages of diagnosis, from those awaiting diagnosis and for those who may be receiving treatment, as described here: 'for people who aren't getting diagnosed with Tourette's, so they can keep a diary, a monitor, and their tics so they have evidence to provide if they ever do go in for an assessment or anything like that' (RQ74) and 'when we do HRT stuff it would be really helpful if there was a way of like tallying how many tics they're doing in like a 5 minute period, like a tally chart that they could do on the intervention' (BC84).

The above examples show how a tic-diary feature could work for YP and families alongside professionals, diaries can also help YP recognise their tic triggers by formulating patterns of where tics occur. One professional talked about how they started gathering this information and then how they could use it to improve the young person's life:

> 'So I often do a day in the life of, so we talk through in quite a lot of detail about umm what happens in everyday life, so what time do you wake up, how do you wake up, whose there when you wake up… beginning to think about when some of those symptoms might be more prevalent than others, so looking at some patterns across the day, looking at some patterns across the week… because it might be that we need to change something in the environment, umm, it might be about they need to think about a way that they umm, distract themselves, it might be

> thinking about that's particularly stressful part, so is there something we can do reduce that stress' (BI28)

Subtheme 15d: Focusing on symptoms can lead to a vicious cycle of increased tics and decreased mental health

Professionals explained how the relationship between tics and mental health can pose difficulties for a young person with tics. When YP start to be concerned about their tics, it increases the likelihood they will tic, which further increases their worries, hence starting a vicious cycle: 'if you're worried about it, you know, worrying about it makes you tense up and it [tics] more likely to come out' (AB95). This viscous cycle can cause YP to withdraw from activities, negatively affecting their wellbeing:

> 'So they might have a flare up of their symptoms, which then means they stop doing things because they might be embarrassed for example… we then see YP whose Tourette's has got worse so I'm now not seeing my friends, I'm not getting out the house, I'm not seeing my friends as much, I'm not going to school as much, you know I'm having problems with my behaviour and all of that seems to feed into them, the fact that the symptoms get worse, um and so, there that's the cycle of doing less' (BI28)

Whilst professionals recognised focusing on one's symptoms is characteristic for many YP with health conditions, they see this being particularly hard to manage due to tic's outward facing nature: 'I guess some of the difference with the Tourette's is some of the manifestations of Tourette's you can't hide' (BI28). This is important to note within the features of the intervention as, 'it can be a double-edged sword so talking about tics increases them a bit more' (RQ74) and helping YP recognise that managing their worries around their tics could improve their relationship with tics, would help to prevent this cycle being maintained.

Discussion

The current research conducted semi-structured interviews with a group of professionals who have experience of working with YP with tics. The aim of the research was to understand how professionals conceptualise wellbeing for YP with tics, to learn what techniques professionals think are and would be useful for YP to manage and improve their wellbeing. Finally, it was also important to assess whether a self-help intervention for YP with tics would be considered as acceptable by professionals. Themes were found relating to four superordinate categories: format, rationale, features of the intervention, and support for TS. These covered how professionals felt the intervention should be set-up, the basis of the need for the intervention, what aspects the intervention should include and themes about what is important to support a young person with tics' wellbeing. These will be discussed below, together with a comparison of noteworthy findings from the previous chapter on interviews with YP (Chapter 4).

Rationale of the Intervention

Initially, it was important to ensure professionals felt there was a need for an intervention and to assess whether professionals viewed the idea of a self-help intervention to be acceptable or useful to YP with tics. Regarding themes relating to the rationale for an intervention, these highlighted how challenging it can be to access treatment for TS (Theme 9), how behavioural treatments are not suitable for everyone with tics (Theme 10) plus underlining how difficult TS and the cooccurring conditions can be to live with (Theme 8). Based on these themes, it has been assumed that professionals see a need for an intervention to support wellbeing in YP with tics. These findings confirm those from previous literature about the dearth of available treatments (McGuire, Ricketts, et al., 2015; Scahill et al., 2013), the complications of accessing support for TS which borders neurological and psychological services and the lack of training for professionals (Marcks et al., 2004). The current research also emphasises how transitions are especially challenging for YP with tics, which was also found to be a factor in increasing tics for 68% of a large surveyed sample (Bornstein et al., 1990) and reported in interviews with parents and YP as 'anxiety provoking' (Silva et al., 1995). Further, the professionals in this study showed an awareness of the difficulties of living with tics and that cooccurring conditions can cause. This is somewhat contradictory to other findings which have highlighted a perceived lack of understanding from non-specialist healthcare professionals by individuals with tics (Cuenca et al., 2015; Hollis, Pennant, et al., 2016) such as feeling TS was not especially stigmatising compared to other conditions (Rivera-Navarro et al., 2014). This observation could be due to collecting perspectives from small focus groups of professionals, where the current sample is three times the size. Furthermore, focus groups can be vulnerable to social desirability bias whereas the current methods utilised individual interviews which may have reduced this bias. It is also possible this sample is highly attuned to the needs of YP with tics due to their specialities or interest in the area, or that whilst healthcare professionals do show empathy with what YP are experiencing, this is not being portrayed to those with tics and their families.

In addition to professionals viewing a need for a self-help intervention for YP, it is likely that such an intervention would also provide support to healthcare workers. Although a dearth in professionals trained to give therapy for tics had been recognised (McGuire, Ricketts, et al., 2015; Scahill et al., 2013) it was not anticipated that the training for 'specialists' would be so low. This study identified that some professionals had not had any access to professional instruction for TS (Theme 11). Considering this, the intervention could act as a resource in addition to therapy (Theme 7), as it could provide professionals without training suggestions for ideas of resources to provide to YP.

Support for TS

It was important to understand how professionals viewed wellbeing for this population of YP, to further understanding of what could affect or improve wellbeing, which could potentially be applied to the intervention. One theme identified wellbeing as understanding and accepting one's condition and being able to function in daily life (Theme 3), such as completing daily activities independently. Similar themes also related to the need for social support (Theme 2), understanding environments (Theme 1) and individualised and holistic therapy (Theme 4) as all being important to support a YP with tics' wellbeing. Social support has been regarded as a buffer against negative experiences, discrimination and stigmatisation, often experienced by adults with TS (Malli et al., 2019). Interestingly, analogous themes were found by YP (Chapter 4), where social support was identified as a desired feature for the intervention and tic-friendly environments were noted to help YP with their tics. These findings all note the importance of supportive homes and friendships. Difficulties with peers have been commonly noted as a problem for YP with tics, and are documented in quantitative (A. S. Carter et al., 2000; Stokes et al., 1991) and qualitative studies (Cutler et al., 2009; Lee et al., 2016; Wadman et al., 2016). Social difficulties also extend to the classroom, such as with teasing, and with teachers not being supportive of YP with tics causing some of the most vexing issues for YP at school (Wadman et al., 2016). Family functioning has also been described as integral to emotional stability in children with TS (A. S. Carter et al., 2000), yet families with TS show increased caregiver burden compared to families of children with asthma (Cooper et al., 2003), higher levels of parenting stress compared to families with typically developing children (Stewart et al., 2015) and lower overall family functioning with a sample of over 300 children (Vermilion et al., 2020). As the current findings are consistent with previous research, and have come from both stakeholder groups YP with tics and professionals, applying these principles of supportive wellbeing should lead to a better-rounded intervention, in line with the person-centred approach (Knowles et al., 2018).

Features of the Intervention

Furthermore, an aspect of the wellbeing definition given by professionals regarded the importance of YP being able to carry out daily activities for their positive wellbeing (Theme 3) and consequently, a similar theme professionals requested as a feature on the intervention was to help YP with planning their daily activities (Theme 12). This was also noted in the suggested features by YP, according to which YP desired a way for the intervention to help them remember their daily activities (Chapter 4, Theme 18). Concepts such as concentration, inability to complete important tasks and forgetfulness are all encompassed within the cognitive domain of QoL (Evans et al., 2016). Adaptive behaviours are behaviours that help someone to manage everyday life and gain independence, relative to their age (Taylor et al., 2018). Similar definitions have also been given to functional impairment, as the inability to complete age appropriate tasks at school home and socially (Storch, Lack, et al., 2007). A recent body of literature has started to emerge about the potential implications TS and comorbid conditions could have on such adaptive behaviours, although the role of adaptive functioning in TS is still being characterised (Rose et al., 2019). A comparison of adaptive behaviours between a sample of older adolescents with TS and case-matched controls were found to be more impaired for the TS group. Whilst cooccurring ADHD could explain some of the impairment, there was still impaired functioning for YP with TS alone (Gorman et al., 2010). Recent evidence suggests a diagnosis of ADHD and having two or more comorbidities can significantly impair adaptive functioning (Taylor et al., 2018), which was also found to be significantly related to executive functioning. The correlation of perceived QoL with functional disability was found to be higher in the TS group than in healthy individuals and individuals with chronic illness, indicating higher dissatisfaction for those with TS as a result of functioning (Conelea et al., 2013). In all, whilst this literature is still developing, it suggests that such a feature, advocated by both professionals and YP, could support YP with their wellbeing through daily functioning.

As expected, psychoeducation was identified within the category of features desired for the tool (Theme 14). As stated previously, psychoeducation can improve QoL by improving communication and involvement of care providers (Day et al., 2020). In support of this, professionals recognised psychoeducation was for both the YP and their families, with the theme highlighting that, 'psychoeducation makes you and your family more able to cope'. Previous research has suggested the development of family interventions to improve knowledge would be useful to understand the characteristics of TS (Rivera-Navarro et al., 2014). Furthermore, the ability to communicate your condition to others was a subtheme (14a), which had also been identified in the previous literature. The validation of psychoeducation as a desired feature by both YP and professionals implies YP would engage with the feature. Furthermore, professionals frequently reported that applying strategies to manage tics could also enable YP to learn about how to manage them (Theme 15). YP in the previous chapter requested that psychoeducation would be from others with experience of living tics, which included learning more about managing to control tics (Chapter 4). Professionals recognise YP's needs in learning about both mental health management and tic strategies for YP to gain true wellbeing whilst living with tics. Some of these tic strategies were similar to ones YP had proposed, for example professionals noted distractions were useful especially those including movement (Subtheme 15a) which relates to Theme 22 from YP, 'physical Activity is a distraction from tic monitoring' (Chapter 4). These complimentary themes suggest features would be supported by both parties.

Whilst CBT had been anticipated as a therapeutic strategy professionals may suggest, they also offered a broad range of other therapeutic ideas to improve wellbeing (Theme 13). One of the features to help YP manage mood was the proposal of a mood diary or tracking element on the intervention (Subtheme 13c), with the main idea to enable the YP to reflect on their mood states. In the first step of the stepped care approach to depression, professionals advise the patient to actively monitor their mood (NICE, 2009), which provides subtle, low intensity care. As found in the systematic review (Chapter 2), studies using mood monitoring continued to show effectiveness at follow-up, and might improve emotional self-awareness, supported by professionals who felt mood monitoring would improve emotion identification and management (Kauer et al., 2012; Reid et al., 2011). Furthermore, an alternative strategy was the use of mindfulness (Subtheme 13a) which has been found to be useful for adults with tics, reducing their tic severity and overall impairment (Reese et al., 2015). In addition, mindfulness has been found to be effective for many cooccurring conditions of TS, including OCD (Hanstede et al., 2008; Patel et al., 2007) and ADHD (Harrison et al., 2004; Zylowska et al., 2008). It has been posited that mindfulness may help with tics due to its links to improving attentional control and ability to decrease physiological arousal (Lutz et al., 2008; Rubia, 2009). Both mindfulness and mood tracking are considered emotional regulation strategies, termed as processes with 'a goal to up- or down-regulate either the magnitude or duration of the emotional response' (Gross, 2013, pp. 359). Many of the proposed features by professionals could also be considered as adaptive emotion regulation or emotional awareness strategies, which include cognitive reappraisal (Subtheme 13d), problem solving (Subtheme 13e) and distraction (Subtheme 13f; Volkaert et al., 2020). These methods have been found to reduce rumination (Hilt & Pollak, 2012) and decrease negative mood (Rood et al., 2012) in adolescents. As depression and anxiety symptoms are negatively associated with adaptive emotion regulation strategies (Schäfer et al., 2017), their inclusion on the intervention could be supportive to YP's wellbeing.

Format of the intervention

Finally, regarding the format of the intervention, professionals advocated for a mobile phone application (hereon referred to as 'app') believing such a platform would be engaging and flexible to the needs of this age group (Theme 6). This is interesting as a theme that explicitly said an app would be wanted was not found when interviewing YP (Chapter 4), although the researcher did note an implicit assumption that YP thought the intervention was going to be an app. This finding suggests YP would find the format of the intervention as an app to be both expected and intuitive to them, agreed with by professionals. Furthermore, professionals also shared their expectations that the intervention would have to be safe for use (Theme 5), highlighting this could be achieved through thorough research. Safety is a likely caveat of how acceptable such an intervention would be, as a lack of safety would likely reduce how acceptable professionals would perceive the intervention.

Limitations and Strengths

As a result of recruiting professionals with a background in TS and those who responded to a recruitment advert about improving wellbeing for YP with TS it is likely this sample is a somewhat homogenous sample of TS-educated and understanding professionals, as previous research has shown a lack of understanding about TS by physicians and psychologists (Marcks et al., 2004) and a perceived lack of understanding from healthcare professionals (Cuenca et al., 2015; Hollis, Pennant, et al., 2016). Furthermore, the sample of professionals was mainly White British, which is not representative of the NHS healthcare population whereby 1 in 5 are not from white ethnic groups (NHS Digital, 2020). Nonetheless, interviews with professionals who have the best intentions for YP with tics are likely to be the most useful for this stage of developing the intervention. Furthermore, this sample included professionals who had a great range of professional experiences, supplemented with a variety of professionals with experience of tics in their personal life which is felt to have enhanced the findings.

A further possible limitation is that the professionals interviewed in this sample may not be part of a regulated professional board, as this was not specified on the recruitment criteria. This means professionals may not meet criteria to be a regulatory health professional, such as those employed by the NHS. Whilst most professionals in this sample did report working within the NHS or private healthcare, this was not checked and may mean they are not following standard guidelines from regulated bodies as other papers have ensured (Lalloo et al., 2015). This limitation would be overcome through thorough checks of the safety of the intervention later in its development which would adhere to development guidelines such as those proposed by NICE (NICE, 2019b).

Conclusion

Overall, this paper presents a novel piece of research exploring what features and formats professionals with experience of tics believe would be useful in a self-help DHI for YP with tics. The current findings imply professionals are on board with such an intervention being developed for YP with tics notably due to a feeling that there is a need for greater support for this population of YP who are contending with managing a difficult condition. Professionals made many suggestions for features of the intervention, and most of these were in line with suggestions given by YP, an encouraging finding that gives promise for YP engaging with such an intervention. A range of the features suggested centred around improving adaptive functioning and emotion regulation techniques, which have aptitude for supporting wellbeing and QoL. Finally, professionals advocate for the format of the intervention to be an app and to be safe. Further research should verify whether the proposed features would be acceptable to further groups of YP with tics to ensure they would be viewed as acceptable with a wider tic audience.

Chapter 6 – Focus Groups with YP and parents

Introduction

The previous research findings have advocated for a range of features to be included in the intervention, proposed by YP with tics (Chapter 4) and professionals (Chapter 5). Furthermore, these findings have also supported a better understanding of TS and YP's needs. The array of components proposed for the desired tool from both YP with tics and professionals were variable, consisting of entertainment features (games, music, sounds, puzzles, videos, art), socialising (interaction with others with TS, support networks), learning about TDs (tic strategies, psychoeducation), mood-improvement features (relaxing strategies, therapeutic strategies), executive functioning (schedules and planning) and how the intervention should function (safety, app-based format, accessibility). By returning to YP at this point in the research, the current findings can be endorsed by attending to a different group of YP with tics to confirm the proposed features are desired across end-users. Furthermore, the components proposed by professionals have not yet been endorsed by the target group, hence it was also necessary to refer these with YP Previously, themes from professionals highlighted that they expect a self-help intervention to include therapeutic techniques for managing YP's mood. These included strategies such as developing skills in mindfulness, improving self-esteem, keeping, and reflecting on mood diaries, or using CBT approaches. These strategies can be thought of as active therapeutic methods that could be employed to support mental states. This is somewhat different from YP, who did recognise the importance of features such as relaxation and planning, but not the use of activities focused on active mental state management. Outside of those activities YP already engaged with in daily routines, they did not show an awareness of, or desire for, active management strategies. Similar themes were uncovered in previous research conducted by CB with neurotypical YP on desired features of an intervention (Babbage et al., 2018). These activities, in therapeutic terms, tend to include distraction techniques or escape-avoidance, which are useful in the short term but may become maladaptive over time (Compas et al., 2001; R. Lewis & Frydenberg, 2002). Problem-focused coping strategies are helpful and associated with positive health outcomes (Gonzales et al., 2001), but YP with tics may not realise that such strategies could improve wellbeing, or they may not have the repertoire of coping strategies to call upon. Therefore, the inclusion of professional's opinions has been important. Systematic reviews of interventions have shown that therapist guided interventions or interventions based on therapeutic approaches e.g. CBT, are the most effective (Bennett et al., 2019; Grist et al., 2017). For this self-help intervention to be as effective as possible, it must integrate expert opinion and evidence-based approaches.

Focus groups are an effective method to enable production of multiple views and exploration of a topic (Braun & Clarke, 2013) and can be used to determine the components of an intervention by exploring the end-users perspectives, as recommended in the PBA (Chapter 3; Ferrey et al., 2018). The PBA advocates for iterative development, returning to target users who can inform decisions about content and design during the development stages of an intervention to ascertain the intervention components that are relevant and useful, and others that may be rejected (Howarth et al., 2019). Focus groups were used as a method 'which allowed new ideas to be generated in a safe forum, where participants could build on each other's perspectives' when developing a psychoeducational intervention for adolescents (Bevan Jones et al., 2018, pp. 3). Furthermore, the use of focus groups will help to ensure a comprehensive exploration of the phenomena of interest through the use of multiple methods to combine data sources, known as triangulation (R. Johnson et al., 2007). Sequential triangulation allows the former findings of previous methods to support the planning of the next study, helping to build comprehensiveness through multiple sources and different methods (Mays & Pope, 2000). In summary, the use of focus groups may be an effective way to comprehensively explore whether the currently proposed features of the intervention are viewed as acceptable and useful to the target group, as suggested by the PBA.

To progress through the stages in line with the PBA, the previously identified themes need to be supported by YP with tics. Whilst YP formally came up with some features for the intervention in Chapter 4, this only included the following four suggestions: reminders (Theme 18), music and sounds (Theme 17) and psychoeducation (Theme 16). The other features have derived from building a greater understanding of how YP with tics manage and understand their mental states, derived from themes that do not necessarily relate to 'features desired on the tool'. These included how YP with tics manage and understand their mental states and how they cope with tics (Chapter 4, Themes 1-15) and features proposed by professionals and their insights (Chapter 5). Therefore, corroborating the proposed features with YP with tics will ensure such components would not be viewed as useless and irrelevant, but engaging, attractive or useful to YP. Referring to this group also helps to ensure the research is following the correct trajectory in terms of developing an intervention to improve wellbeing targeted for that population. The application of focus groups to this research is especially suitable for building on and gaining a variety of perspectives, whilst also enabling triangulation which should further the comprehensiveness of the research.

Study Aims and Research Questions

The aim of this research was to explore whether the proposed features from previous interviews with YP and professionals were supported in focus groups of YP with tics and their carers. For features that YP supported the inclusion of, gaining further information on how the features would look and function is important to increase understanding of how to develop an engaging wellbeing tool. This study aimed to address:

1. If YP with tics and their parents support the previously proposed features and functions from YP with tics?
2. If YP with tics and their parents support the previously proposed features and functions from professionals?
3. How YP with tics and their parents feel the supported features should function or look?
4. How YP with tics and their parents experience living with tics?

Methods

Procedure

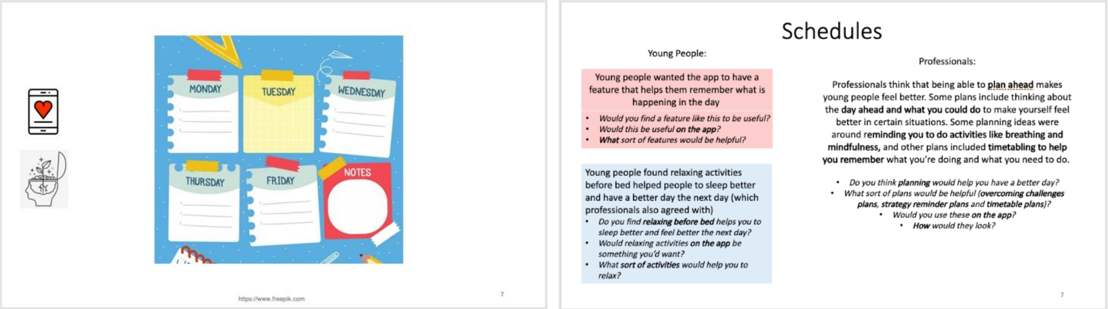
Focus groups took place at support groups around the country after contacting gatekeepers and group leaders about conducting research at the support group. A support group was also set up and advertised in one of these locations for the purpose of the research.

Prior to the focus group, information sheets (resembling those given in Chapter 4, Appendix 10 and 11, but only including part two for those who weren't involved in Chapter 4) and a familiarisation video were distributed via the support group gatekeeper to any families that indicated they were attending the support group. At the start of the focus group, this video was replayed, and information sheets redistributed for any support group attendee who may not have received the information. Participant consent forms were given to parents and YP over 16, and participant consent forms were given to parents of YP under 16. For consenting participants, the focus group began with ground rules. Participants were informed they could leave at any time. CB asked questions listed on the focus group guide (see below) and the research assistant supported this through prompts, follow up questions and ensuring all questions had been covered. Focus groups were recorded using two dictaphones, and a microphone was used.

After each focus group, parents and YP were requested to complete post-focus group online forms and in receipt would be emailed a £10 shopping voucher. The form included the RCADS-P and the TODS-P for parents, and children received the RCADS and GTS-QOL-CA. An open response section at the end enabled feedback to be given about their experiences of the focus group and involvement in the research. More information about these measures can be found in Chapter 3.

Development of focus group guide

App-relevant themes from interviews with YP (Chapter 4) were used as a framework for the focus group guide (Appendix 18). This led to the following broad features being identified: *Psychoeducation*, *Games*, *Support Networks*, *Videos*, *Music and Sounds*, *Puzzles*, *Arts*, *Interaction with others*, *Relaxing Activities*, *Schedules*. To make these more concise, *Puzzles* and *Games* were collapsed into one group and *Relaxing Activities* were subdivided across groups where relevant. This created nine feature-based themes from the previous



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Schedules

Young People:

Young people wanted the app to have a feature that helps them remember what is happening in the day

- *Would you find a feature like this to be useful?*
- *Would this be useful **on the app**?*
- ***What** sort of features would be helpful?*

Young people found relaxing activities before bed helped people to sleep better and have a better day the next day (which professionals also agreed with)

- *Do you find **relaxing before bed** helps you to sleep better and feel better the next day?*
- *Would relaxing activities **on the app** be something you'd want?*
- *What **sort of activities** would help you to relax?*

Professionals:

Professionals think that being able to **plan ahead** makes young people feel better. Some plans include thinking about the **day ahead and what you could do** to make yourself feel better in certain situations. Some planning ideas were around **reminding you to do activities like breathing and mindfulness,** and other plans included **timetabling to help you remember** what you're doing and what you need to do.

- *Do you think **planning** would help you have a better day?*
- *What sort of plans would be helpful (**overcoming challenges plans**, **strategy reminder plans** and **timetable plans**)?*
- *Would you use these **on the app?***
- ***How** would they look?*

Figure 3 Example of one of the slides from the focus group guide, showing the picture (left) that would have been shown to the focus group participants and the questions that were viewable to the researchers (right). The questions are separated into previous findings from YP and professionals, and exploratory and validating questions.

research that required exploring further. It was also important to explore the features professionals had suggested (Chapter 5). This was achieved by mapping feature-based themes from the previous research onto the nine feature-based themes developed from interviews with YP. One theme, *Therapeutic Strategies*, suggested by professionals could not be mapped onto the features proposed by YP and was therefore created as a further theme, leading to ten overall feature-based themes. For each feature-based theme, we printed a slide with picture and text on alternate sides. The participants could see the picture and the text held the focus group guide, which could be seen by the researchers, an example can be seen in Figure 3. The focus group guide was separated into corroborating questions (pink in Figure 3), where a previous theme had explicitly requested the feature and exploratory questions (blue in Figure 3), where a feature hadn't been explicitly requested by YP and further information was needed. For all features, further questions were asked on how a feature would function. Each slide contained a reminder that features needed to be relevant to an app for wellbeing, using a picture of an app, heart and brain. Table 9 includes an overview of the topic of each slide, and how the previous themes influenced the development of the focus group guide for the feature it related to. Each focus group began with ground rules, giving an overview of the research, and general rules were covered such as taking it in turns to speak, using name badges, recording devices and consent, confidentiality and respect, and completing post-group questions.

Setting of data collection

Focus groups were held at support groups for YP with tics around the country, in Hull, York, Nottingham and Manchester. These support groups were usually inside community halls and the focus group was carried out in an adjacent room (Manchester and Hull), or within the hall where the support group was running (York). At Nottingham, a support group was set up in a University building, and the focus group ran in an adjacent room after the support group.

The post-group online survey including the other three quantitative measures were completed in the respondents' selected environment through a personal device within 2 weeks of completing the interview.

Feature-based themes (slide)	YP themes	Professional themes:
Games and Puzzles (1)	**Theme 17** - Being able to select music, sounds and games will help YP to be calm **Theme 9** - Engaging in Games and Music helps relieve negative mood **Subtheme 11a** - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress **Subtheme 12b** - Actively engaging with arts and games fosters a calm and relaxed mood **Theme 20** - Engaging in pastimes can increase an awareness of a reduction in, or shift focus away from tics	**Subtheme 15a**: Distraction from tics helps stop the tic cycle, especially when combined with movement **Subtheme 5a**: Whilst screens are likely to be a desired feature by YP, they should be regulated
Videos (2)	**Theme 8** – Videos and films are a way of relaxing when having a bad day or to improve negative mood in general **Subtheme 12a** - Passively listening to sounds and watching videos sustains a calm and relaxed mood	**Theme 14** - Psychoeducation includes understanding the biology and psychology of one's own tic-condition, which makes the young person and their family better able to cope with it
Music/ Sounds (3)	**Theme 9** - Engaging in Games and Music helps relieve negative mood **Subtheme 12a** - Passively listening to sounds and watching videos sustains a calm and relaxed mood **Theme 17** - Being able to select music, sounds and games will help YP to be calm	**Subtheme 15a**: Distraction from tics helps stop the tic cycle, especially when combined with movement **Subtheme 15b**: Environments can be tic-triggering **Subtheme 13a**: There are different forms of mindfulness that help YP to relax
Arts (4)	**Subtheme 12b** - Actively engaging with arts and games fosters a calm and relaxed mood	
Interaction with others (5)	**Theme 16** - There is a need for psychoeducation derived from interacting with others' lived experience of tics **Subtheme 16a** - Interaction with others enables learning more about TS **Subtheme 16b** - Normalisation of experience is gained through sharing	**Theme 2** – Social support provides inspiration to YP **Subtheme 2a**: Role models provide hope that YP's lives can still be fulfilled **Subtheme 2b**: Knowing other YP with tics can reduce isolation and share advice although can increase tic symptoms

Professional Strategies (6)		**Subtheme 3b**: Improved wellbeing can be gained through better self-regulation **Theme 13** - Therapeutic strategies could be implemented on the intervention that would help to improve wellbeing **Subtheme 13a**: There are different forms of mindfulness that help YP to relax **Subtheme 13b**: Strategies can be employed to improve self-esteem by changing the way the young person thinks about themselves and their tics **Subtheme 13c**: Mood Diaries help YP to notice emotions, which can help identify and control feelings to lead to more positive outcomes **Subtheme 13d**: Challenging thoughts can improve mood **Subtheme 13e**: For anxious YP the intervention should include CBT approaches **Subtheme 13f**: Distractions allow a change in focus from negativity and should be fun and engaging **Subtheme 3a**: Improved self-esteem is a desired outcome of treatment **Subtheme 3b:** Improved wellbeing can be gained through better self-regulation
Schedules (7)	**Theme 18** - Need for a function that acts as a reminder for the day's activities	**Theme 12** - Planning helps YP better manage day to day life leading to improved mood **Subtheme 12a**: Planning helps YP to decide what they should and shouldn't do **Subtheme 12b**: Maintaining sleep hygiene helps the young person have a better day **Subtheme 12c**: Prompts in the intervention could instruct YP to employ strategies **Subtheme 12d**: Timetabling helps YP implement routines and remember to-do's **Theme 3** - Wellbeing for a young person with TS includes understanding and accepting their condition, engaging with and being able to manage life's demands and tics
Support Network (8)	**Theme 10** - Having a support network helps maintain positive mood **Subtheme 13a** - Being accompanied reduces anxiety	**Theme 1** - Understanding environments can help with acceptance of tics and allows for adjustments to be made where strategies can be implemented **Subtheme1a**: Society is not accepting of TS

Relaxing Activities (9)	**Theme 8** – Videos and films are a way of relaxing when having a bad day or to improve negative mood in general **Theme 12** - Pastimes maintain a soothing state **Subtheme 12a** - Passively listening to sounds and watching videos sustains a calm and relaxed mood **Subtheme 12b** - Actively engaging with arts and games fosters a calm and relaxed mood **Theme 15** - Engaging in relaxing activities to facilitate sleep helps avoid negative mood caused by sleep **Subtheme 19b** - Minimal tics are associated with a calm or relaxed state	**Theme 12** - Planning helps YP better manage day to day life leading to improved mood **Subtheme 13a:** There are different forms of mindfulness that help YP to relax **Subtheme 15b**: Environments can be tic-triggering
Psychoeducation (10)	**Theme 16** - There is a need for psychoeducation derived from interacting with others' lived experience of tics	**Theme 14** - Psychoeducation includes understanding the biology and psychology of one's own tic-condition, which makes the young person and their family better able to cope with it **Theme 3** - Wellbeing for a young person with TS includes understanding and accepting their condition, engaging with and being able to manage life's demands and tics

Table 9 An overview of themes taken from findings of Chapter 4 and Chapter 5 that influenced the development of the focus group guide. The number in brackets represents the number of the slide in the focus group guide.

Data Analysis

Data saturation, defined in Methods (Chapter 3), was felt to be reached after conducting all focus groups. Recordings were transcribed verbatim into a spreadsheet separating speaker by column and speaker-timings by row, using different font colours to represent speakers, by the research assistant (ES) under the guidance of CB, using Express Scribe Transcription Software (NCH Software PTY LTD, 2019) and following the 'data storage and protocols' processes, as outlined in the Methods chapter. Transcriptions were then member checked by CB and edits were made directly to the transcripts.

A hybrid approach to thematic analysis was chosen for this study, as it incorporated both a data-driven inductive approach (Boyatzis, 1998; Braun & Clarke, 2006) and a deductive approach based on an a priori template of codes. For more information on both these approaches, see Methods. This strategy was chosen to incorporate data from Chapter 4 and 5 into the data collected from the present study, enabling corroboration of previous findings whilst being open to exploring how features would be used for the intervention. A priori codes were based on themes from Chapter 4 and 5, relevant to the research questions for the present study. These themes matched those used to develop the focus group guide, outlined in Table 9. Where subthemes were included, the main theme was also taken to fully capture the theme.

The transcripts were simultaneously coded with a priori and posteriori codes, into separate, adjacent columns alongside the transcript. An online shared spreadsheet allowed the researchers to do this in parallel. Theming followed a similar process to the previous studies, where relationships between codes were identified and grouped, in a continuous process of regrouping and forming new groups until more stable themes are developed. Throughout this process the a priori and posteriori codes are kept separate within their groups, enabling the researcher to identify deductive and inductive themes. Similarly, codes from parents and codes from YP were noted throughout the themes to identify if themes were representing one group more.

Reflexive Statement

CB had visited all the support groups previously to disseminate information about the research, and therefore some of the participants included in the focus groups and the research were already known to the researcher. Furthermore, some of the participants who had taken part in previous research had been following the research project (Chapter 4), and were involved in the current research again, so were also known to each other. This made some aspects of running the groups less formalised, which helped with developing a rapport, especially with those who were new to the researcher as the participants within a focus group often already knew of each other. As a result, CB recognised they were gaining a more thorough knowledge of the topic of tics and how this impacts wellbeing, as well as the participants having more knowledge about this research area. This may mean that participants were coming to the research with a predefined idea of what they wanted in the intervention and similarly, CB's idea of the intervention was becoming more concrete and biases towards certain features could appear. To overcome this, CB aimed to remain open to hearing different opinions about features, and tried to use their rapport with the participants to allow for open and honest discussions about certain features and ideas. Additionally, the inclusion of ES in this project was another way to provide a different perspective on this, as researchers travelled to and from focus groups together and debriefed after the group. ES was not involved in the previous studies, and so hearing their thoughts on whether ideas were being pushed or not was helpful to CB for reflecting on this. The reflective diary was also used to notice any potential biases and be mindful of them if they were appearing.

Data Collection and Sampling

Focus groups involving YP aged 8-19, with a clinical diagnosis of TS or TD and their parents were conducted. Recruitment was through opportunistic sampling, as participants were invited to take part in a focus group held during or after support groups in Hull, York, Nottingham, and Manchester. Focus groups were completed over a period of 1 month, from the 27th October 2019 to 23rd November 2019. For an overview of focus groups as a method for research, please see Methods (Chapter 3).

Prior to attending support groups, a poster, animation video (https://www.youtube.com/watch?v=wvrH2GmwfXc&t=4s), and information on the research was shared online through the researcher's (CB) personal social media (Twitter, Facebook, LinkedIn) and through Tourette's Action social media pages. YP and their parents were each offered a £10 shopping voucher for taking part in the research.

Ethics permission for carrying out this study was granted from the University of Nottingham Division of Psychiatry and Applied Psychology Research Ethics Committee, School of Medicine [Ref: 043] (see Appendix 11 for ethics approval letter) , prior to recruitment. YP and parents were required to give their consent or assent to take part in the study, and parents had to give consent for children under 16 to take part. It was explained that participants could withdraw at any time from the study and at various time points. Prior to the recording of the focus group verbal consent was also taken. Please also see Data Storage and Protocols section of Methods (Chapter 3) for more information on ethical considerations taken during data collection.

Results

Participant Characteristics

There were 19 YP recruited to the study between 8 and 18 years old, (mean = 12, SD = 2.8) all male except for one female. Four participants had TS-only, one participant had chronic motor tic disorder and 15 participants had cooccurring conditions including anxiety (n=6), epilepsy (n=1), OCD (n=5), ASD (n=2), dyslexia (n=1), ADHD (n=2), sensory processing disorder (SPD, n=3), learning difficulties (LD, n=1), developmental coordination disorder (DCD=1). There were 19 parents recruited to the study, and in five of the six focus groups, parents were present for all YP involved.

In total six focus groups were run, which varied in length from 26 to 61 minutes, with an average time of 44 minutes. YP in the focus group ranged from one young person to five YP with tics. Due to having less than 30 minutes with some groups, the focus group guide was split into two halves for four of the groups, equating to two complete focus groups. Focus group 1 and 6 covered the ground rules and slides two to six, focus group 2 and 4 covered the ground rules and slides 7-10, and focus group 3 and 5 completed all the slides (1-10). All parents completed the post-group surveys and the majority of YP completed their post-group measurements (n=18). No participants withdrew from the study.

Parent-rated RCADS showed average total anxiety symptom scores of 74 (IQR=66-95) and total anxiety and depression scores of 76 (IQR=69-97), where children had average scores of 62.8 (SD=16.3-) and 61.5 (IQR=48-78) respectively. Two children self-reported scores over 70 and five parents rated their children over 70, indicating the clinical threshold for symptoms of anxiety and depression, and parents rated two children scoring above 65 indicating borderline clinical threshold for symptoms. The child-reported C&A-GTS-QoL showed an average rating of 89 (IQR=63-106) and the VAS scored a median of 65 (IQR=38-83). Parent ratings of the TODS gave a mean of 93.1 (SD=35.6), with all scores from each parents being above 60 indicating moderate to severe TS (Hollis, Pennant, et al., 2016). Families were asked to complete assessment measures within a week of completing the interview. On average it took participants 5 days to complete the surveys (Parents: IQR=2-11, YP: IQR=2-10).

Hybrid Thematic Analysis Results

From the focus groups, 16 themes were developed. These fit into three separate groups, ‘Desired Features of the App’, ‘Desired Functions of the App’ and ‘Mood and Stigma’. The first and second group related to features and functions of the app, with eight themes making up the former and five themes making up the latter. The final group related to other experiences around mood and stigma for YP with TDs, including three themes.

During the process of theming, some were combined for streamlining and some codes were removed or were not felt to constitute a theme. This included combining a theme on mindfulness that was previously independent, to a subtheme within calming strategies (Theme 6). Further, two themes initially existed on art and music, but these themes were relatable as both activities were found to mediate the same calming effect and were merged (Theme 2). Finally, the screen-time and monitoring of the app themes (Theme 12) had originally been separate, dedicated to a safety category however it was recognized these were also fitting for 'features of the app', and helped to streamline the categories. As noted earlier, some codes were not substantial enough to become themes and did not overlap to be merged with other themes. These codes comprised of topics around cooccurring symptoms, accepting TS, variation in symptoms over time, media and stigma, positive thinking, negative family experiences, communication with others.

The final category, 'Mood and Stigma' was not considered to be in direct relation to the main aim of this research; however, in light of its exploratory nature pertaining to the implication of the link between mood states and tics, it was deemed to be important and was included.

Desired Features of the App

Nine themes related to groups of codes that all identified aspects of the app they would like to see incorporated. These included entertaining activities such as games (Theme 1), music, art (Theme 2), videos (Theme 3), and activities that might improve their mood such as wellbeing strategies (Theme 4), diaries (Theme 5), calming (Theme 6) and confidence boosting (Theme 7) strategies. Finally, a feature relating to information about TS was also wanted on the app (Theme 8).

Themes	**Subthemes**
Theme 1 - YP currently use and find certain games to be calming and make them feel better, which parents agree with	
	Subtheme 1a - YP want puzzles and problem-solving games on the app
	Subtheme 1b - Parents recognise playing violent and competitive games is not helpful, supported by YP
Theme 2 - YP desire music and art features on the app	

	Subtheme 2a.- YP listen to music to keep calm and would be happy for the app to hold and suggest music, supported by parents
	Subtheme 2b - YP actively engage with music, such as through playing instruments and music games, which would be wanted on the app
	Subtheme 2c - Some YP find art relaxing and have suggested colouring in and drawing features for the app
Theme 3 - YP currently enjoy videos and find them relaxing, but only see their purpose on the app if videos can inform them on calming strategies or to convey information	
Theme 4 - Parents and YP feel that notifications would be useful to help remind YP and to prompt the use of well-being strategies	
Theme 5 - Diaries help YP with their worries	
	Subtheme 5a - Diary features including to-do lists and scheduling would help YP who are concerned about what's going on in their day
	Subtheme 5b - Mood diaries enable an opportunity for YP to reflect on their feelings
Theme 6 – Effective calming strategies that YP engage with would be desired on the app	
	Subtheme 6a - Relaxing strategies before bed help YP with sleep, as this can be a problem
	Subtheme 6b - Mindfulness was not reported as being positive by those who had used it
Theme 7 - Activities to improve confidence on the app would be useful	
Theme 8 - The app should contain an engaging information section about TS	
	Subtheme 8a - An alternative to just writing and reading information on the app would be preferred

Theme 1 - YP currently use and find certain games to be calming and make them feel better, which parents agree with.

YP talked about their current use of gameplay, especially puzzles which helped them to feel calm, ‘sometimes I'll play with my Lego and it calms me down (AY26)’. As noted in Subtheme 1a, it was puzzle and problem-solving games that YP thought would be useful on the app. Parents held more of a sceptical position on whether games were useful for YP’s wellbeing, as some games can be negative for mood (Subtheme 1b). This theme was supported by a priori themes also, with codes both in favour of and against previous findings that games foster a calm and relaxed mood.

Subtheme 1a - YP want puzzles and problem-solving games on the app

YP were explicit about wanting puzzles or problem-solving games on the app. The overall feeling was that puzzles and problem-solving games, such as ‘Rubik’s cubes’ (DD24) or ‘knowledge testing games’ (FD52) would be calming or improve mood in a positive way, where other genres may not.

> ‘GD74-F: What games do you play on your tablet?
> GD74: Problem-solving ones.
> Interviewer: Problem-solving games, yeah? ...what would that help you with?
> GD74: Just, like, to stop you thinking about it’

Subtheme 1b - Parents recognise playing violent and competitive games is not helpful, supported by YP

Parents were quick to identify that certain games would not be helpful on the app, including violent or competitive games. One parent explained, ‘yeah, I think that’s where you’ve got to be careful, ‘cos otherwise they do get too drawn into it’ (GD74-F), suggesting there is an optimum ‘level’ where a game can go from helpful to unhelpful. This was something YP agreed with after discussion, and recognised that some games may be fun, but not beneficial for an app such as this:

> ‘Interviewer: What games are not relaxing?
> AL17: Stuff like violence’

Theme 2 - YP desire music and art features on the app

Most YP wanted to see art and music features on the app, supported by both a priori and posteriori themes, and by parents. Music was felt to be a calming feature and desired as both something to listen to (Subtheme 2a) and engage with, such as through playing instruments and music-related games (Subtheme 2b). Similarly, art was thought of as a mechanism to destress and YP identified how they would like this to look on the app, with drawing and colouring in features (Subtheme 2c).

Subtheme 2a - YP listen to music to keep calm and would be happy for the app to hold and suggest music, supported by parents

Already being used as a mechanism for keeping calm, YP highlighted they would also be happy for the app to continue this by including music. In addition, YP explained that it would be useful if the app held the music on it, allowing the music to be easily accessible without need for going elsewhere to listen to it. Further, YP wanted the app to suggest types of music to listen to. This was heavily agreed upon by parents who also recognised that music acted as a calming strategy for children. Sounds, such as nature noises, were also included within music, although the preference was mostly for music.

> ‘Interviewer: Yeah, erm, so the next one is about music and sounds. So, YP that we've previously asked have said that music helps them to feel calm. So, have you guys found this?
> XC21: Yeah
> Interviewer: Yeah? It helps you to feel calm does it?
> XC21: It helps me like when I listen to it in my headphones and it calms me down
> Interviewer: Does it? OK, that's really good. What kind of music helps you feel calm?
> XC21: Any kind of music, anything
> Interviewer: DD24 and SB86, what do you think about music on the app?
> DD24: I’d like that’

Subtheme 2b - YP actively engage with music, such as through playing instruments and music games, which would be wanted on the app

Continuing the use of activities YP are already engaging with, YP requested that there be an option on the app to play music. This is different from the previous code, which included listening to music, as this theme required active engagement with the activity opposed to passive engagement.

> 'Interviewer: Does anyone else have ideas about, in general, how the app should look?
> GD74-F: Maybe not just listening to music, maybe give them a chance to be able to like play with like, I don't know, even like drums-
> Interviewer: Yeah-
> GD74-M: They do, there's that game-
> GD74-F Like press the things and record your own music'

Suggestions centred on the idea that you could play virtual instruments on the app, such as the 'keyboard' (VD96) and 'drums' (GJ23-M). Some parents also felt active engagement with music would be useful on the app, and in line with a priori findings, active engagement was recognised for reducing negative mood.

Subtheme 2c - Some YP find art relaxing and have suggested colouring in and drawing features for the app

Art was a desired feature on the app by those who currently use it and find it relaxing. These YP specified features on the app that would allow them to colour in or draw, as explained here: 'like different drawings and you have to do like colour by numbers' (AL17). For some YP who do not enjoy art, they explained that such an activity would not be helpful, 'if I'm colouring something in and I go out the lines, then I get angry and it like makes my tics bad' (XC21).

Theme 3 - YP currently enjoy videos and find them relaxing, but only see their purpose on the app if videos can inform them on calming strategies or to convey information

In general, YP and parents reacted positively to videos and said the use of videos can be relaxing, supported by both a priori and posteriori codes. On the other hand, in terms of its application to the app, posteriori codes also highlighted videos were only desired as a method for relaying information. In particular, YP wanted videos to tell them about calming strategies or to convey information about TS, opposed to using them as the calming strategy. This seemed to come about as a reaction to many YP accessing other platforms to watch videos, such as YouTube. One young person reported that YouTube is where they access calming videos: ‘but most people, say if they're trying to listen to like relaxing music to help calm them, they just go on YouTube to look for them’ (DD24). Another young person requested that the app have a ‘link to YouTube’ rather than playing videos directly on it.

Theme 4 - Parents and YP feel that calendars, notifications and to-do lists would be useful to help remind YP, and to prompt the use of well-being strategies

It was noted by both parents and YP that reminders would be needed to support YP in remembering their daily activities and to prompt the use of wellbeing strategies as YP often forget to complete activities. These are in line with previous findings, and so this theme was supported by both a priori and posteriori codes. Parents were especially aware that YP need to be reminded about their daily activities, likely due to this being a role parents take on, which the app could provide support for:

> ‘If we're going out it has to be we're going out on Sunday, and then on Sunday, were going [in] half an hour so you've got like an alarm kind of to know to try and remind him of that’ (SW21-M)

This was also a theme YP wanted, explaining they often forget things, ‘if I wanna know something, then I forget what I wanna know, it annoys me’ (VD96). This could include reminders for wellbeing strategies like sleep routines, ‘yeah it could say like go to bed within an hour’ (SI49), or activities such as taking medication:

> ‘XT46: You could use it for like your medications as well, if you need to take medications
> Interviewer: Oh, that's a good, yeah, yeah, yeah
> XT46: Yeah, like at mornings and nights and that
> Interviewer: So, as like is it a reminder? Is that a reminder to take the medication?

> XT46: Yeah, say like take some at night and take some in the morning and it'd remind you of each'.

The reminders could take the form of calendars such as schedules, which parents thought would be especially useful, or notifications, 'so that it sets something on your home-screen so like when you turn your phone on its on your home-screen saying that you need to do something' (GD74), or a to-do list:

> FD52: maybe a to do list
> Interviewer: a to do list?
> FD52: like remind you of stuff
> Interviewer: what stuff?
> FD52: so if you can do something

Theme 5 - Diaries help YP with their worries

Parents felt diaries would help emotionally support YP who were worried about the upcoming events in their day (Subtheme 5a) and both YP and parents felt a mood diary would allow YP to reflect how they are feeling (Subtheme 5b). This differs from the previous subtheme in that it's not about remembering to complete activities but is a source of relieving anxiety through understanding or reflecting on the activities. This theme was developed of a priori and posteriori codes.

Subtheme 5a - Diary features and scheduling would help YP who are concerned about what's going on in their day

Schedules as a mechanism to support wellbeing had been noted in the previous research and were again supported in this research, however the addition of posteriori codes identified that using a schedule in this instance helps to relieve YP of anxieties about the upcoming events in their day:

> 'I think more of a schedule would be useful, 'cos VD96 if he doesn't know what's coming or, or what's happening in advance, then it makes him quite anxious. So, if he had something on the app that would remind him today that he's doing this, this, this, he'd be able to look at that and think, yeah, this is what I'm doing and it would make him calmer' (VD96-M)

YP also recognised a desire to know what's going on throughout the day and felt it would be supportive to know this in advance, 'cos I'm always asking mum and dad, what we doing now what we doing now what we doing now' (BP64).

Subtheme 5b - Mood diaries enable an opportunity for YP to reflect on their feelings

> 'Interviewer: And what's in your diary now?
> KG93: Just how I'm feeling. I write down what's in my head.
> Interviewer: So you, erm, is it more like a mood diary?
> KG93: Yeah, depends on how I'm feeling that day. If there's too much stuff in my head, I'll write them down to make myself feel better.
> Interviewer: Sure. And would it be good to have that sort of thing in an app?
> KG93: Yeah, 'cos then you can see how you were feeling that day and make yourself write or feel better this day. But because of that add in and then you can find out the source of the problem'

This subtheme was made up of both a priori and posterori codes, and suggested that YP would use diaries to reflect on the days or activities they've had. This could support YP in learning how to recognise the impact certain activities have on their mood. Both YP and parents supported this feature.

Theme 6 - Effective calming strategies that YP engage with would be desired on the app

Across groups and confirmed by YP and parents, it was noted that calming strategies should be included on the app. Some YP highlighted ways they were already implementing effective calming strategies into their routines, 'but it's like I could relieve stress paying football and obviously you could listen to music' (SI49). A priori coding highlighted support in the previous and current research for calming strategies to support sleep (Subtheme 6a), and in rejection of previous coding for mindfulness (Subtheme 6b).

Subtheme 6a - Relaxing strategies before bed help YP with sleep, as this can be a problem

Without relaxing before bed, parents noted that YP struggle to get to sleep. For example, this parent and child had a conversation about nightmares before bed when they have not done something to distract them:

> ‘GJ23-M: Cos sometimes like you had bad dreams didn’t you, but you won't talk about them. So if you had something that made you think of something happy-
> GJ23: that would give other people nightmares
> GJ23-M: but it might, if you had something that made you happy, it might distract you a little bit’

Furthermore, good quality sleep was noted to have positive benefits the next day, ‘when he's had a really good sleep stuff [tics] is just really minimal’ (AL17-M). Whilst some YP highlighted that they had found calming strategies that supported their sleep, ‘[I] sit next to my dog and just with the alarm thing so it’s a bit of like watching tv for a bit and I use it just before bed at night’ (BP64), other YP reflected that the app could support them with this as they struggle to engage with sleep facilitating activities such as being away from screens, ‘yeah it could say like go to bed within an hour, then you’ve not looked at your phone then before you’ve gone to sleep’ (SI49). The need for relaxing strategies supported by the app was also acknowledged by a priori codes.

Subtheme 6b - Mindfulness was not reported as being a positive experience by those who had used it

Although not all YP had tried to use mindfulness as a relaxation method, those that had were not positive about their experiences of using it, ‘no I find them boring’ (GD74) and, ‘it’s like right yeah I'm sat in a chair but then I think about it too hard and it's like… yeah, basically, have an existential crisis’ (XT46).

One parent who has a diagnosis of TS explained that:

> ‘Self-meditation for Tourette’s I'm afraid is gonna be extremely difficult because your brain's going too quick, too fast, processing too much

> information, and to try and force that to slow down is near impossible'
> (GJ23-F)

This is in juxtaposition to the a priori codes which had promoted the use of mindfulness for YP with tics, therefore these were coded in rejection of the a priori codes for those with experience of mindfulness.

Theme 7 - Activities to improve confidence on the app would be useful

A theme developed around a desire for the app to hold activities aimed at improving confidence. Although supported by some a priori codes, this theme was mainly formed of posteriori codes and came from mostly YP. YP explained the importance of confidence, 'if you don't have confidence, then obviously you're missing something. It has to be there' (SI49). Further, another young person talked about the effect a lack of confidence had on them at school, highlighting self-esteem can be an issue for YP with tics and they wanted to learn how to manage it:

> 'like maths because like in my old school I didn't feel very confident because everyone was really good and I was more in the middle bit and I didn't and whenever I tried really hard and I didn't really get any really higher so I would like to get more confident at maths' (BP64)

Theme 8 - The app should contain an engaging information section about TS

For the app, YP and parents both felt that it requires a feature that contains information about TS, 'like it could describe exactly what it is' (XT46). Experiences of looking for information online were described, 'if you search it up and you search up like the side effects of a condition or anything like that, it always says like you're gonna [sic] die or something' (SI46), recounting how getting information on your condition can be overwhelming. YP had ideas about how this section should look, for example there was a desire for it to be made more interactive than usual webpages, 'it could be like either so if you don't like wanna read on the internet, like it can make it more fun on the app (AL17)'. Furthermore, YP made comments on a need for the section to be succinct, 'I don't think it should be too much information though' (IO98).

There were few a priori codes relating to this theme but the majority of these were made up by posteriori codes, however a general crossover was that psychoeducation was felt to be important for understanding and managing tics. These a priori codes were only coded to parent participants. Similarly, parents were dominant in Subtheme 8b with a desire for a parent part of the app, although YP did support this. On the other hand, it was mainly YP who requested that the information feature of the app contain variations to just reading and writing (Subtheme 8a).

Subtheme 8a - An alternative to just writing and reading information on the app would be preferred

Alongside the desire for the information part of the app to be interactive and engaging, YP requested this feature of the app to not be verbose. There were different reasons for this including YP finding reading difficult, so it works ‘for people that can't read very well’ (AL17-M). A suggestion made by a young person included, ‘you could like press a button and it reads it to you’ (AL17) which was supported by other YP who did not want the information section to be words, ‘…not just writing, I'm just thinking what would make it more fun’ (BP64). Furthermore, having lengthy information was described as difficult to comprehend, so the information needs to be engaging as well as easy to read:

> ‘to go on a website and have to read paragraph after paragraph after paragraph to answer questions it doesn’t sink in, it doesn’t stay in my brain so I don't know what I’m even reading’ (KG93)

Subtheme 8b - A parent section of the app would be useful

Parents highlighted a desire for a section of the app to be for parents only. The purpose of this would be to inform parents what it is like to live with a TD, as this parent highlights:

> ‘they [YP] just get on with it, because they have no choice and it's more us, as parents, that talk to others. Like we was doing it earlier, wasn’t we? And finding out, we was talking to someone with Tourette’s and you know, a grown up and asking him about like your teenage years and y'know, and it's more parents who want to find out more, whereas they just accept it and it's the norm to them [sic]’ (GD74-M).

Other reasons for a parent section included helping to disseminate potential techniques to parents:

> ‘a parent’s area or something so that you could include some of the things that wouldn’t be interesting to these, but it might be interesting to us, like the breathing techniques and the other things you can do’.

Or for alerting parents if the young person becomes unwell, as suggested by a young person:

> ‘it could like tell parents about like serious, say like if a kid starts having a tic fit and they’ve never had one before and the parents don’t know anything about Tourette’s, they could like look on the app and like figure out what it is, or if their legs go and they can't walk’ (XT46)

There were also many different ideas about how the parent section would look, including parents having access to the app through their own i.e., the parents’ phone, ‘I would say so, I don’t think they'd like the whole sharing their phone thing’ (GD74-F), or having two different sections on the app ‘there could be like a section, like a kid’s section and a parent’s section’ (AL17). Whilst this was a theme dominated by parent-coded responses, it appeared that YP either agreed or did not mind the idea, ‘I don’t mind’ (VD96).

Desired Functions of the App

This category was formed of themes that related to functions of the app. Functions are aspects of the intervention that run across the features and activities within the app. For example, the app being accessible was a theme within this category (Theme 9) and accessibility must then run across features of the app. Other functions of the app include being able to interact with others with TS (Theme 10), which was desired across many of the earlier features, monitoring to keep the app safe for children and from inappropriate users (Theme 11) and being flexible to different needs of YP (Theme 12). Finally, it was felt that the app should support YP in regulating screen time (Theme 12).

Theme 9 - Current resources for TS are not accessible, therefore the app must meet this criteria	
	Subtheme 8a - Professionals services don't provide enough understanding or support
Theme 10 - The overarching experience of interacting with others with TS is positive for families with tics, and would be desired as a feature on the app	

	Subtheme 10a - Interacting with others with TS normalises and reduces isolation for people with TS and helps to inform families about the condition
	Subtheme 10b - Communication and sharing information with others on the app would be useful
	Subtheme 10c - There are some difficulties when interacting with others with tics
	Subtheme 10d - Being able to share up-dates on your condition with parents, teachers and other necessary contacts would be helpful on the app
Theme 11 - Parents want the app to be monitored to ensure safeguarding against inappropriate app users	
Theme 12 - Parents feel screen time should be regulated, but both YP and parents think the app could help manage time on screens	
Theme 13 - The aesthetics and content should be flexible to YP's different needs whilst supporting them	
	Subtheme 13a - The look of the app needs to be personalised
	Subtheme 13b - The app should make appropriate suggestions for individual requirements

Theme 9 - Current resources for TS are not accessible, therefore the app must meet these criteria

There was a consensus among the posteriori codes from both YP and parents that the current available resources for TS are not accessible. This related to both self-help resources such as online websites and books, and professional support such as mental health services (Subtheme 9a). This is a result of resources not being available, ‘I got told I was going to CAMHS. Still waiting, two and a half years ago. It's like what the point. I had to cope with everything by myself’ (KG93), and those that are available, are expensive, ‘there is a book, I did have a look on google, but it's really expensive’ (FS35-M). Furthermore, the information that is available can be overwhelming, ‘there's like too much information on the websites’ (SI49).

Subtheme 9a - Professionals services don't provide enough understanding or support

This theme was agreed upon by both YP and parents, that professional services do not understand TS, and do not support YP with TS. Many YP expressed dissatisfaction with doctors not understanding their condition:

> ‘I didn’t know what it was and doctors don't know what it is, unless you get a doctor that's like designed for that person. So say you just go to the hospital and say I've got Tourette’s then they ask what that is and if you can't give a good enough description, then they search it up and find out a description of what it is. So, we go to the hospital knowing more than they do, so it makes it all just a pointless thing, so there's no point in trying to ask them for help when we can just do it better ourselves’ (SI49)

Additionally, it was felt that continuous care and support is not offered by professional services, and families were often left to seek their own information after an appointment or diagnosis:

> ‘GD74-M: They just give you a diagnosis and tell you that’s y'know, that’s more or less it. They don't tell you about all the other parts that come with that and how to deal with it. They don’t. You're left on your own. And you walk out of that room feeling like the worst parent in the world.
>
> FS35-M: You feel more scared walking out than you do walking in-
> GD74-M: And then you go to google, and YouTube and you look at your videos and you do your own research to get a better understanding because the professionals don’t give you that knowledge base’

Theme 10 - The overarching experience of interacting with others about TS is positive for families with tics, and would be desired as a feature on the app

Interacting with others with TS has been frequently reported to be a positive experience for families with tics, which can reduce isolation and give information on TDs (Subtheme 10a), although it was recognised that these interactions can lead to some difficulties for ticcing behaviour (Subtheme 10d). Overall, there was a desire for such interactions to be available on the app which would be useful (Subtheme 10b), but this was also expanded to people without TS, such as parents and teachers when in relation to their condition (Subtheme 10d).

Subtheme 10a - Interacting with others with TS normalises and reduces isolation for people with TS and helps to inform families about the condition

Supported by both a priori and posteriori codes, the notion that interaction with others with TS for YP with TS is helpful was maintained by both YP and parents. As found previously, these interactions have a normalising effect for YP with tics, ‘they are around other children with Tourette syndrome and it makes them feel more normal’ (GJ23-M) and,

> ‘you think you’re some weirdo with Tourette’s and then you come to a group and there's just like loads of people, you just feel normal don’t you, and then you got a weight off your shoulders that says I'm not the only one’ (SI49).

Interactions also enabled the opportunity for parents and YP to be supported and learn from others: ‘I wasn’t aware of the comorbids [sic] until I joined this group and then when I got a copy of that, I was like, oh yeah, he has that’ (FS35-M) and

> ‘It’s always good to find out what other people are going through and then you don’t feel alone. ‘Cos coming here you can speak to everyone and we're all on the same boat and we all know what's going on’ (KG93)

Subtheme 10b - Communication and sharing information with others with tics on the app would be useful

As a function of the app, it was requested that YP would be able to communicate and share information with others who have tics on the app, which parents agreed with as long as it was safe, ‘yeah, I'd want to approve who he's linking up with’ (GH97-M). YP had many different ideas about how this would look, ‘video, facetime’ (KG93), ‘emoji’ (FS35), ‘role models’ (XT46), ‘chatting’ (AL17), ‘typing’ (GH97) and the purpose of the communication was not always clear, ‘so you can get different strategies’ (SW21), ‘just talking about what day you’ve had with them’ (AL17-M), or to ‘hear other people's opinions on what's going on… so you know you’re not alone’ (KG93), however this was a theme that was desired to span across features.

Subtheme 10c - There are some difficulties when interacting with others with tics

A caveat of interacting with others with tics was highlighted that in turn, this can often result in an increase in tics as people ‘catch’ each other’s tics, ‘it’s good seeing everyone, but tics are through the roof and you’re bouncing off each other’ (KG93). This tic-echo effect has been previously noted in research and was therefore made up of both a priori and posteriori coding. It can also occur after seeing videos of other people with tics, ‘yeah, you picked up one of his [video blogger] tics’ (GJ23-M). Overall however, it was noted that despite the potential increase in tics from others, ‘it is far more valuable’ (GJ23-M) to have a friendship with someone with tics, than not.

Subtheme 10d - Being able to share updates on your condition with parents, teachers and other necessary contacts would be helpful on the app

Being able to contact others about their condition was also a function YP wanted from the intervention. This was a new theme and so was made up of entirely posteriori coding from both YP and parents. The type of sharing was varied, including parents wanting to communicate to teachers, for example:

> ‘you don't want to go into school everyday going, last night were really bad, ‘cos you'd be there like constantly [sic]. And, just simple things like we talked about the diary and we have issues of forgetting to bring things home, like spellings and things and so if there were just a bit of a communication thing where they [teachers] could have an overview… without us having to constantly contact school’ (BP64-M)

Or, YP wanting to reach their parent or emergency contact both asynchronously, ‘you have the choice to speak to your parents if you don’t want to go and tell them in person you can just like message them’ (BP64), or in real-time, ‘you could have like an emergency number sort of thing where you could just like press a button and it calls your mum or like’ (XT46) which would allow YP to tell significant others if something needs to be communicated.

Theme 11 - Parents want the app to be monitored to ensure safeguarding against inappropriate app users

Across all features of the app, parents wanted to ensure that it would be safe to use, especially for safeguarding. This theme consisted mainly of parents and was supported by a priori and posteriori coding. Many of the concerns centred around the idea of who may be accessing the app, ‘how do you know who's gonna [sic] download the app’ (FS35-M), which created alarms about who YP may be communicating with, ‘the aspect of who are my kids talking to online’ (GJ23-M). Suggestions around how to control who downloads the app included, ‘could it be like a code and then you have to type them in, so only you can get into it, so people that don’t have tics can't get into it’ (BP64), or parents being able to manage what’s happening on the app, ‘like block them’ (AL17-M). However, as this parent notes, there’s a fine line between parenting and policing the app, so that it doesn’t have a dysfunctional affect:

> ‘the under 18s as well, the app's got to be mirrored on the parents, so you both have an app and you can see exactly what's happening, but then there's that fine line of both policing it from a parental point of view and then it sort of loses it's the point of it all’ (BP64-F).

Theme 12 - Parents feel screen time should be regulated as it effects functioning, but both YP and parents think the app could help manage time on screens

From the a priori codes and across the focus groups, parents were coded to a need for the app to support in the regulation of screen time, ‘I can notice a big difference if BP64's been on, what I consider too long. He does change’ (BP64-F). Many parents reported different aspects of functioning they thought screen time affected, including social isolation, ‘cos the gaming and stuff can cause a lot of isolation’ (GD74-M), sleep, ‘it can have an impact on their ability to be able to fall asleep’ (BP64-M) and conditions, ‘too much time in front of the tv, his computer, his Xbox or the phone, it can send everything else, the ADHD and anything else, it just goes off the chart’ (SB86-F). This was not something YP were in support of as some reported that screen time didn’t affect functioning and therefore these codes were in opposition their parents. For example, one young person felt sleep was a form of break from screens, ‘it’s having another break when you go to sleep’ (FD52). Nonetheless, YP did come up with ways the app could help YP manage their screen time, ‘it shouldn't restrict you, but it should like give you, tell you to like, every now and then that you should take a break’ (GD74), or ‘you’ve got a notification that comes down and it starts beeping so like you know you should come off’ (BP64).

Theme 13 - The aesthetics and content should be flexible to YP's different needs whilst supporting them

Flexibility within the app was desired as a function, to allow the aesthetics and content to be changeable depending on the needs of the YP using it, whilst also having access to an intervention that makes individualised suggestions appropriate for them. This theme was developed from posteriori codes only, mainly from YP. One young person described this as, ‘you wanna [sic] have a little friend helping you along the way’ (KG93), emphasising the need for the app to be compatible to them but also offering them support. In terms of flexibility in personalising the app, YP suggested that you should be able to change the colours, ‘you should be able to set it to, like, your colours’ (SI49), brightness, ‘bright lights, certain lights’ (KG93), fonts, text, and other formatting of the app. These suggestions were often made in reference to cooccurring conditions YP had, for example, one parent requested a ‘colourblind setting’ (BC28-F) for their son, another YP felt curved edges opposed to squares would help them with their OCD ‘I look at that I see 4 edges, when I was younger with my OCD brain, I'd like count the edges before I'd walked past it, but if it's curved I wouldn't’ (SI49).

In addition, YP wanted the app to make appropriate suggestions for their individual requirements:

> ‘It should just have this thing where when you come on it, you should say how you feeling or summit [sic], and then like if you're feeling ok you might say listen, watch a video and if you're feeling sad then watch a movie or listen to music, you know what I mean’ (VD96)

> ‘Different children enjoy different things and if it's directing you to something that’s not particularly your strength or something that’s going to stress the child out, it’s not gonna [sic] do them any good. So, if it was personalised to what they found helps them, it'd work better for them’ (GD74-F)

This was to avoid the app suggesting activities or features that weren’t desired or appropriate for that young person. This could be through having many different features on the app that will help the young person to, ‘figure out what helps them themselves’ (GJ23-F), or it could be through telling the app initially what you like or don’t like, ‘then you can select what you like and what you don't like and that could be, so that things like that would come up' (KG93), so it makes recommendations based on those inputs.

Mood and public understanding

The three final themes are not related to features or functions of the app but help to bring understanding as to how the app could be useful to YP with tics. These included how distracting activities can be helpful to both mood and tics (Theme 14), how YP with tics often experience a lack of understanding from others (Theme 15) and the relationship between tics and mood, which can affect functioning (Theme 16).

Theme 14 - YP with tics enjoy engaging in distracting activities, which can help with mood and tics	
Theme 15 - Parents believe that more public awareness of TS is needed as YP with tics often experience stigma	
Theme 16 - Mental states can affect tics, and tics can affect day to day functioning, resulting in very negative moods	

Theme 14 - YP with tics enjoy engaging in distracting activities, which can help with mood and tics

Distractions have been found to be a way to improve mood and tics, through YP becoming engaged in an activity, enabling a change of focus from the negative mood or tic, 'normally, sometimes if I take my mind off it, it kind of goes away' (IO98). Previous findings highlighted how distractions enabled a change in focus from the YP being negative, and so this theme was made of both a priori and posteriori codes, but most frequently noted by YP. One parent with a diagnosis of TS talked about the importance of finding the 'thing' that supported tic reduction for them, 'you'll find something that works for you that you don't tic [sic]. For me it's like if I'm out on my mountain bike hurtling down the hillside; no tics whatsoever' (SB86-F). Some parents noted the potential benefit of the app in supporting this, 'so that any time that they feel anxious or y'know [sic] they need something to focus on, they've got the option of going in and choosing them games' (GD74-M).

Theme 15 - Parents believe that more public awareness of TS is needed as YP with tics often experience a lack of understanding from others

A lack of understanding around tics in society and within certain environments was previously reported, which was also matched in the current theme, thereby making it constitute of both a priori and posteriori codes. This was mainly developed from parent coding, where parents felt there is not enough awareness about TS, ‘it needs more awareness definitely’ (AL17-M). This was noted in various contexts, including within families, ‘our experience has been very close families totally dismissing it, it doesn’t exist’ (BP64-F), and often related to not knowing about tics at all, or misunderstanding that tics are about swearing only. For example, one parent said, ‘she didn’t want to bring her kids [to support groups], cos she didn’t want them round that kind of language and stuff and so I think there is a lot of misconception’ (GJ23-M). A YP explained how they have to educate their peers about their tics to prevent them asking what they’re doing, ‘but I don’t want them to be thinking why are you doing that’ (BP64), as the understanding isn’t already there.

Theme 16 – Mental states can affect tics, and tics can affect day to day functioning, resulting in very negative moods

The circular relationship between mental states and tics was noted by this group across both YP, parents, a priori and posteriori codes. Mental states, such as anger, excitement, anxiety and tiredness, all resulted in a negative impact on tics, ‘when I start getting a bit excited, but a bit nervous, my tics get really bad’ (BP64), ‘I get angry and it like makes my tics bad’ (XC21), and ‘tiredness, anxiety it all makes them worse don't [sic] it’ (AL17-M). On the other hand, some mental states such as being calm and not tired, were seen to reduce tics, ‘when he's had a really good sleep, stuff is just really minimal’ (AL17-M), ‘that relaxes him and he doesn’t tic’ (DD24-M. These codes matched a priori codes which had identified how calm or relaxed states led to minimal tics. On the other hand, the impact tics had on mood and day-to-day functioning was always negative. Participants SI49 explains how tics can get in the way of the simplest every day activities, ‘I'd say what was you talking about? And I'd have no clue, because I would have been ticcing for like 30 seconds like in between sentences’ which continues to impact on mood after the event, ‘even when its stopped it’s still bothering you’ (SI49). Finally, YP and parents sometimes talked about the very negative moods YP were experiencing, which could be a result of living with tics or having co-occurring mood conditions, ‘I go into very very very negative depressed states, like I don't wanna [sic] speak to anyone and sometimes it can just be brought on but other things kind of put me into this state’ (IO98).

Discussion

19 YP and 19 parents were recruited to focus groups to explore whether previously proposed features from interviews with YP and professionals were desired and supported in focus groups of YP with tics and their families. While there tends to be a dominant male to female ratio in TDs, there was a fairly low ratio of boys to girls, with most of the participants being male. As previously found, the age of the sample averaged early adolescence, although there was a wide range of ages from 8-18, spanning the age inclusion criteria. The average parent rated RCADS suggested YP in this sample had above average severity of anxiety and depression symptoms, whereas YP reported themselves as being just below the clinical threshold for borderline anxiety and depression symptoms. These were very similar findings to the previous study. YP rated themselves as having reduced QoL on the C&A-GTS-QOL scale, indicating poorer QoL on both the visual scale and measurements, compared to the previous sample. Nonetheless, a score of 65 on the VAS suggests they were on the upper end of satisfied with life. The parent-rated TODS scales indicated moderate to severe TS for the sample on average, with a fairly broad range suggesting the sample included YP on either end of the spectrum.

This discussion will be a brief overview of the findings, as Chapter 7 will consist of an interpretation of the results using sequential, multiple method design from the present and previous chapters (Chapter 4 and 5). Three categories of themes were developed from the 16 themes identified within the data. Eight of these themes fit the category ‘desired features of the intervention’, five of these themes were nested within ‘desired function of the intervention’ and three made up the category, ‘mood and public understanding’.

Of the broad variety of features explored by the focus group guide, the themes elaborated on how these features could be presented in an app that would support wellbeing from the perspectives of YP and their parents. From initial proposals of games and puzzles, these findings suggest that only the genres of puzzles and problem-solving games would be useful with the recognition that competitive and violent games would not fit the app’s objectives (Theme 1). This finding helps to clarify the previous discussion point from Chapter 4, where games were reported as a management strategy, but it was difficult to disentangle if YP were actively seeking games as a mood management strategy. It could be more likely that YP seek certain types of games, i.e. puzzles and problem-solving games, when wanting to calm down, but not other genres of game that were reported to be less helpful. In addition, music and art were also found to be activities YP in this group use to relax, in line with previous findings (Chapter 4) and there was a desire for these to exist as a feature of the app (Theme 2). The relationship between tics and music is documented, although mainly anecdotally and sparsely, in the academic literature; however, an association with tic reduction when performing and listening to music has been noted (Lees et al., 1984; Sacks, 2006). Albeit a small sample, one study investigated tic frequency whilst participants diagnosed with TS actively and passively participated in musical activity, and found a significant reduction in tics, most pronounced in the performance condition. A questionnaire surveyed the sample to explore other tic reducing factors and found creative activities such as drawing and crafting reduced tics. Furthermore, a self-report survey with a larger sample supported these findings, adding that for music to be tic-reducing it should be ‘soft, calming, familiar, pleasing, and preferred’ by the participant, for both passive and active involvement with music (Bodeck et al., 2015, pp. 44). Playing games, music and completing creative activities all require concentration, attention and fine motor skills, which have also been linked to tic reduction (Bodeck et al., 2015; Jankovic, 2001; Leckman et al., 2006) and similarly to Theme 14, distracting activities have been found to reduce tics. Whilst YP reported art, music and games were calming and not explicitly tic-reducing, the calming effect of these activities may also be tic-reducing, which could be associated with a positive impact on mood. This is also in line with Theme 16, where YP identified a circular relationship between tics and mental states. Thereby, making these activities especially useful to YP if employed by the intervention for both mood management and tic relief.

The desire for use of videos to convey information only (Theme 3) is interesting as it had been anticipated that videos would be used to relax based off previous findings. With YouTube being the most highly accessed social media platform, and 84-87% of YP aged 13-17 accessing the platform, it is likely YP have already found a way to access videos to relax. The use of videos to convey information mean they would likely function in the information section of the app, which YP also confirmed a desire for (Theme 8).

Specifically, YP requested alternative formats to reading and writing in this section, where videos could be useful (Subtheme 8a). Alternative formats also map onto other parts of the app that were requested, including increased accessibility (Theme 9), and being flexible to different needs (Theme 13). With the high rates of comorbidity with TS, increased accessibility and flexibility enables a greater variance of YP with TS to be able to access the intervention. As mentioned in the Introduction (Chapter 1) up to 90% of YP may have a cooccurring diagnosis, with the most common including OCD, ADHD and ASD, and other mood disorders being prevalent in around one third of people with TS (Eapen et al., 2016; O'Hare, Helmes, Eapen, et al., 2016; Robertson, 1989). Increased accessibility will enable the intervention to support YP who are likely to be experiencing a range of additional symptoms to tics.

The use of strategies that would improve mood had been proposed by professionals in prior research (Chapter 5), including a variety of suggestions, from planning, to mindfulness, self-esteem, CBT and dairies, but these were not suggested by YP in the interviews (Chapter 4). On the other hand, most of these features were endorsed by YP in this research, who felt diaries (Theme 5), confidence boosting activities (Theme 7) and reminders in the form of calendars, to-do lists, and notifications (Theme 4) would be useful. For YP who had previously used mindfulness, this was not reported to be wanted on the app, or something they found relaxing (Subtheme 6b). This was similarly noted by Reese et al. (2015) albeit who found a mindfulness-based stress reduction intervention to be effective in older adolescents and adults with tics, but qualitative feedback reported it was frustrating and uncomfortable to learn the skill. Nevertheless, other calming strategies such as relaxing before bed were still desired (Theme 6). YP in the previous sample (Chapter 6) had also suggested interacting with others as part of the app, which this group of YP upheld (Theme 10). This included being able to update others about their condition, such as parents or teachers (Subtheme 10d) and being able to communicate with others with tics (Subtheme 10c), which helps to reduce isolation and give support.

Finally, some themes were derived mainly of parent perspectives. The inclusion of caregivers can help to broaden understanding, as recommended in the PBA and is well-documented when developing interventions using co-design style approaches, especially when they may also be end-users (Bevan Jones et al., 2020; Yardley, Morrison, et al., 2015). Furthermore, parent input, which ranged from setting up the intervention to active participation, has been found to lead to increased effect sizes in a review of technology delivered interventions in YP with anxiety and depression (Grist et al., 2019). Whilst the relationship between parent input and efficacy is not well understood, it may be that parent acceptability could increase the benefits YP experience with the intervention. These themes included functions of the app such as safeguarding (Theme 11) and regulating screen-time (Theme 12), and as a comment on ‘mood and public understanding’, in parent’s recognition of a lack of awareness of TS (Theme 15). The foundations of these themes can also be seen in prior work with professionals, who indicated that YP with tics experience stigma, and requested that an intervention be developed in a safe manner with screen time regarded as an important aspect of safety. There is no known research to show the relationship between screen time and TDs, yet research investigating screen time and wellbeing in adolescents suggests a negative relationship, in particular in relation to sleep, as was found in YP with ADHD (Hong et al., 2020; Ogretmen, 2019; Twenge et al., 2018). Whilst all these studies imply screen time negatively effects wellbeing, they are correlational and cannot imply cause, so should be interpreted cautiously. Nonetheless, functions to support minimising screen time may make the intervention more acceptable to parents and professionals, whilst avoiding potential detrimental effects screen time may have on wellbeing.

Limitations and Strengths

Using support groups to collect data provided access to YP with tics, however it meant the researchers were somewhat restricted in the control they had over the set-up of the focus group. This resulted in one focus groups including only one family, as the only attendees of the support group (focus group 3), whereas other support groups had many families who were interested in taking part. This meant the focus group was fitting in around the activities of the support group and due to time and space limitations, there were only brief intervals to conduct the focus group, opposed to the planned 40 minutes to one hour session as suggested (Liamputtong, 2015; Vaughn et al., 1996). Therefore, for focus groups 1, 2, 4 and 6 the focus group guide was split into two halves (Slides 1-6 and slides 7-10) in order to be able to run through all the slides (Hennessy & Heary, 2005). This resulted in some participants not being able to comment on all the proposed features included in the focus group guide. Nevertheless, the equivalent of four focus groups were conducted and data adequacy was felt to be achieved, in that further data collection would not have resulted in different themes (JM Morse, 1995). This also enabled more YP to express their thoughts on the features and the principles of the application, which helps to ensure the research is ‘on track’ with the views of the community. It is acknowledged that this is not a typical way to conduct a focus group. In the future, being more aware of the structure of the support groups prior to developing a focus group guide may enable more realistic application to the focus group.

On the other hand, the use of focus groups within predefined ‘support groups’ has been argued to help with disclosure and talking about sensitive issues, that may not be discussed in a group of strangers, ‘familiarity rather than anonymity may be the key to free-flowing discussions’ (p9. Liamputtong, 2014). This could be especially relevant within a support group, where the format often leads to discussing the shared experiences and challenges of being diagnosed with or having a TD. Although, a drawback of this is that homogenous groups may be less likely to feedback different perspectives (Liamputtong, 2015), in the Nottingham group, which was made up of participants who had never previously met, the researchers did not note a difference between the flow of conversation between this group and previous groups that were run at pre-existing support groups. This could be the result of having a slightly more homogenous sample than previously, which consisted of a majority of males with only one female participant. This is a particularly low ratio of girls to boys, which is usually somewhere between 3:1 to 5:1 (Hirschtritt et al., 2015; Yang et al., 2016) and likely reflects the gender bias in TS. Gender differences in symptoms of TS have suggested females may have a later age of maximum severity for tics, that are more likely to get worse than better compared to males with tics (Lichter & Finnegan, 2015). As a result, females may be less likely to come to support groups as YP are usually accompanied by parents, where girls may not yet be presenting tics at all or as severely yet for a family to feel the need to attend. Therefore, these themes may be more representative of young males with TS.

Finally, as noted earlier, there are some design inconsistencies that may have led to different responses from different focus groups. Two of these were mentioned above, and include one of the focus groups being run at a newly developed support group where others were long-standing support groups, and the other included a focus group made up of only one young person with tics, and their family. Another inconsistency included the use of parent participants in some focus groups but not in others. This was a decision made between parents and YP themselves, and whilst the focus groups involving younger aged participants had their parents included, the focus group of older YP did not want parental involvement. This was also touched upon previously, with parents sometimes being involved in interviews with YP (Chapter 4). The reason for allowing parents to be present was two-fold, and included gaining parent perspectives on the intervention to ensure they also viewed it as acceptable and to make YP feel more comfortable (Adler et al., 2019), especially noted when the YP is disabled or unwell. However, some research argues that the presence of parents can inhibit YP's responses or make them feel obliged to give socially acceptable answers (Shaw et al., 2011). Furthermore, as parents influence children's opinions, their presence may lead to an enhanced influence (Chandler, 2011). Guidelines suggests that parents should be given specific clarification of their role in the focus group, which would hopefully dissuade parents from influencing YP's responses, however it was also noted that there are very few guidelines on running focus groups with parents and YP together (Adler et al., 2019). Although some effort was made to explain to parents in their role in the focus group, more emphasis on the expectations of parents could have been made. It is also worth questioning whether a separate parent-only focus group may have been useful for gaining parent perspectives, away from their children. This would have given parents the opportunity to voice their opinions and may have reduced their involvement in the focus groups with their children.

Conclusion

This study brings together findings from previous research of features that were formerly proposed based on explicit requests of desired features, and implicit features formed from a greater understanding of YP with tics. This has led to the presentation of a series of supported features that have been further explored with YP and their parents in focus groups. These focus groups have helped to increase the comprehension of the originally proposed features in order to gain more support for the claim that these are aspects of an intervention YP would find engaging, motivating, and useful whilst also being acceptable to parents, in line with PBA. Furthermore, the current evidence suggests the intervention is being developed on target of what YP and parents think would be important. Further iterative methods will help to further support the claim that other YP with different presentations of tics, who may not be part of any support groups, would also find such features acceptable should be conducted. Currently, the list of proposed features and functions of the intervention are variable and wide-ranging; to be able to move into the intervention design stage of the PBA, the research needs to be defined to develop the key objectives and distinctive features of the intervention.

Chapter 7 - Integration of Results and Online Focus Groups

Integration of results

To this point, three qualitative studies have been conducted to explore the behavioural issues, needs and challenges a young person with TS may experience. Understanding the experiences of YP with TS was crucial to help towards the development of an intervention aimed to improve their wellbeing in engaging and useful manner. The initial qualitative study (Chapter 4) consisted of interviews with YP which aimed to address YP's understanding of their own wellbeing, to explore what they currently do for their wellbeing, and to find out whether an intervention for wellbeing would be useful. The second study (Chapter 5) investigated professionals' experiences of working with YP with tics, to explore how professionals perceive and what they feel impacts on, or determines, wellbeing in this population, what strategies they believe would be useful for managing wellbeing and whether they think a tool to improve wellbeing would be acceptable, in relation to YP with tics. Finally, the most recent study (Chapter 6) used focus groups with YP with tics and parents to explore whether the previously proposed features were supported, and to gain further information on how such features could function. This chapter will present an integration of these findings in order to illustrate how the triangulation of findings raised the need for a focus group study, which also informed the nature and design of the intervention and will be presented at the latter section of this chapter. These findings have been used to develop an intervention that improves wellbeing, but one that is also useful and engaging for YP with tics, in line with the PBA (Yardley, Morrison, et al., 2015). With increased understanding of the needs of end-users, suitable features of the intervention can be identified.

The use of different qualitative methods helped to enhance the comprehensiveness of the research (Pope & Mays, 2008), alongside the use of different stakeholder groups which are reported to increase the richness of the data (Knowles et al., 2018). This approach resulted in the generation of a broad spectrum of themes relating to the proposed features of the intervention. In order to summarise the features that had been identified for the intervention, themes and subthemes which related to similar features were organised into categories based on the feature. This was conducted using a similar process to the focus group guide development in Chapter 6. When proposed themes across methods supported one another, the proposed feature was added to a category. When themes counteracted, this rejection was noted. An example of some of the themes that were in support of one another or rejected, across each of the categories developed during the process is displayed in Table 13. This process helped to ensure that each feature was supported by at least children and parents, children and professionals, or parents and professionals. In total there were 21 themes that validated a feature. These fit into nine categories; Schedules, Reminders, Socialising, Screen-time, Safeguarding, Accessibility, Coping, Calming, Psychoeducation. Two sets of themes invalidated one another, suggesting they should not be included in the intervention. Six of the nine features were felt to be activity related, and three of the features were functions, in that they would affect the way the app worked.

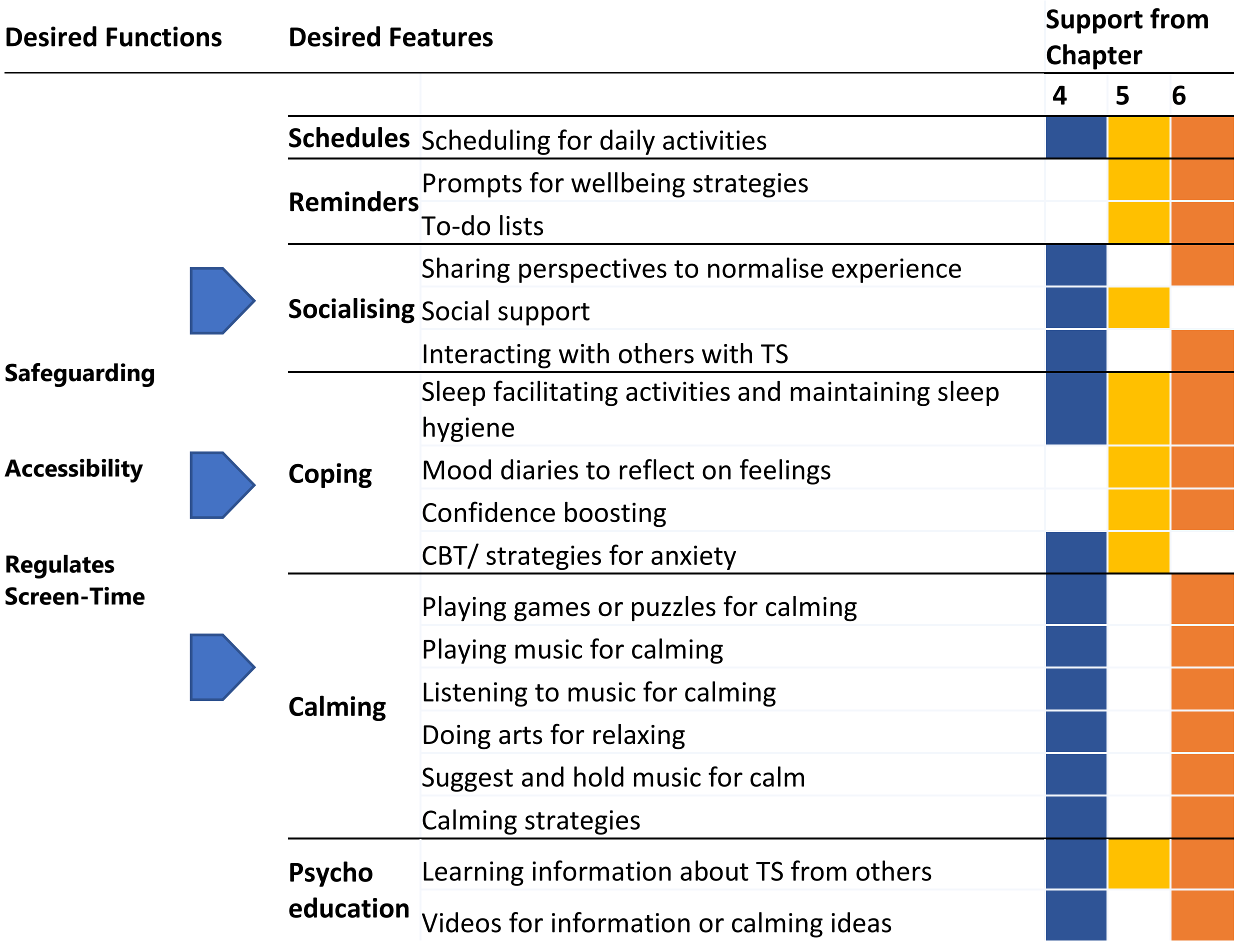
For an overview, a model was created which can be seen in Figure 4. The development of this model highlighted a need to streamline the 23 different features and functions in order for the intervention to remain focused and effective. In a meeting with MindTech, suggestions were made for how such methods of streamlining could be applied. It was decided that a final focus group study should be conducted with YP and parents, which would use design choices to force users into making a preference of one feature over the other, based on the model. This would provoke end-users into thinking about what they need from such an intervention to support them and would enable hierarchising of the importance of each feature to the end-user.

Together, this integration of findings using multiple research methods (Chapters 3-6) led to the development of a model of supported features from across the methods of study. The model, see Figure 4, brought together different proposed features and functions of a DHI that were felt to be supportive to the wellbeing of YP with tics. The model consists of six categories of features, including Schedules, Reminders, Socialising, Coping, Calming, Psychoeducation and three overarching functions which would pervade across features; Safeguarding, Accessibility and Screen-time. Overall, 23 features were proposed that were also supported by findings from at least two methods of data collection (Chapters 3-5), which all fit within one of the categories of features or functions. Each of these features were felt to be important to support the wellbeing of YP with tics, either directly through developing coping mechanisms, or indirectly such as through supporting one’s functioning, leading to an improvement in wellbeing. Nevertheless, the mass of features in the model highlighted a need to hierarchise the different components in order to keep the intervention focused and effective, as aimed to be achieved in the subsequent section of this paper.

	App-Relevant Themes			**Support across number of chapters**		
Proposed feature category	Interviews with YP (Chapter 4)	Interviews with Professionals (Chapter 5)	Focus Groups with YP and parents (Chapter 6)	Two	Three	Rejected
Schedules		Theme 12 - Planning helps YP better manage day to day life leading to improved mood	Theme 5 - Diaries help YP with their worries	✓		
Reminders	Theme 18 - Need for a function that acts as a reminder for the day's activities	Subtheme 12d - Timetabling helps YP implement routines and remember to-do's	Subtheme 5b - Diary features including to-do lists and scheduling would help YP who are concerned about what's going on in their day		✓	
Socialising	Subtheme 16b - Normalisation of experience is gained through sharing	Subtheme 2b: Knowing other YP with tics can reduce isolation and share advice although can increase tic symptoms	Subtheme 10a - Interacting with others with TS normalises and reduces isolation for people with TS and helps to inform families about the condition		✓	
Coping	Theme 13 - YP use strategies to avoid anticipated anxiety	Subtheme 13e: For anxious YP the intervention should include CBT approaches		✓		
Calming	Theme 17 - Being able to select music, sounds and games will help YP to be calm		Theme 6 - Effective calming strategies that YP engage with would be desired on the app	✓		
Psycho-education	Theme 16 - There is a need for psycho-education derived from interacting with others' lived experience of tics		Subtheme 10b - Communication and sharing information with others with tics on	✓		

			the app would be useful			
Screen-time		Subtheme 5a: Whilst screens are likely to be a desired feature by YP, they should be regulated	Theme 12 - Parents feel screen time should be regulated as it effects functioning, but both YP and parents think the app could help manage time on screens	✓		
Safe-guarding		Theme 5 - The intervention must be safe to use, which can be achieved through thorough research before publishing	Theme 11 - Parents want the app to be monitored to ensure safeguarding against inappropriate app users	✓		
Access-ibility		Theme 6 - The format of the intervention as a mobile phone application will engage YP and can be flexible to different needs	Theme 13 - The aesthetics and content should be flexible to YP's different needs whilst supporting them	✓		
Games	Subtheme 11a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress		Subtheme 1b - Parents recognise playing violent and competitive games is not helpful, supported by YP			×
Mind-fulness		Subtheme 13a: There are different forms of mindfulness that help YP to relax	Subtheme 6b - Mindfulness was not reported as being a positive experience by those who had used it			×

Table 10 An example of the process used to categorise themes related to features of the intervention. This was completed to understand which features were supported across samples, in order to be able to prioritise types of features for inclusion in the intervention. Themes were organised based on similarity and given a category name. For each proposed category, an example of the themes that supported that category are presented. The final two categories represent two features that were rejected by themes developed across methods.



Desired Functions

Safeguarding

Accessibility

Regulates Screen-Time

Desired Features		Support from Chapter 4	5	6
Schedules	Scheduling for daily activities	🟦	🟨	🟧
Reminders	Prompts for wellbeing strategies		🟨	🟧
	To-do lists		🟨	🟧
Socialising	Sharing perspectives to normalise experience	🟦		🟧
	Social support	🟦	🟨	
	Interacting with others with TS	🟦		🟧
Coping	Sleep facilitating activities and maintaining sleep hygiene	🟦	🟨	🟧
	Mood diaries to reflect on feelings		🟨	🟧
	Confidence boosting		🟨	🟧
	CBT/ strategies for anxiety	🟦	🟨	
Calming	Playing games or puzzles for calming	🟦		🟧
	Playing music for calming	🟦		🟧
	Listening to music for calming	🟦		🟧
	Doing arts for relaxing	🟦		🟧
	Suggest and hold music for calm	🟦		🟧
	Calming strategies	🟦		🟧
Psycho education	Learning information about TS from others	🟦	🟨	🟧
	Videos for information or calming ideas	🟦		🟧

Figure 4 Model of the all the desired features and functions of the intervention that were supported across at least two methods. Features included aspects of the intervention that would be available to use, and functions were part of the intervention that would work across all the features of the intervention. Chapter 4 is coded as blue and refers to interviews with YP, Chapter 5 is yellow and refers to interviews with professionals and Chapter 6 is orange, referring to focus groups with YP and parents.

Using online focus groups with YP with tics to hierarchise proposed features and functions in the intervention

Introduction

Prioritisation of features is necessary to ensure that the intervention is feasible for the development team (Bradbury et al., 2014), especially in light of time and cost restraints that need to be considered when implementing research into practice (Van Velsen et al., 2013). Furthermore, the PBA recommends deciding upon the key features felt to be crucial to address the objectives of the intervention (Yardley, Ainsworth, et al., 2015). Therefore, in line with the PBA and intervention development guidelines, selecting the features that are most relevant to the intervention objectives needs to be carried out to ensure feasibility and focus of the intervention (Bradbury et al., 2014; Yardley, Ainsworth, et al., 2015). Although there is little documentation of how prioritisation can be done simply when developing complex interventions whilst including stakeholders (Bevan Jones, Thapar, Rice, et al., 2018; Bradbury et al., 2019), a focus group with stakeholders on the prioritisation of features could allow for multiple viewpoints to be taken into account (Braun & Clarke, 2013). Once this information is collected, Bradbury et al. (2014) propose a balanced consensus can be reached in consideration of the stakeholders' needs as well as the technology team development capacities. Once features have been prioritised, the findings can be used to develop guiding principles and a logic model, which are the main outcomes after the completion of the initial two stages i.e. intervention planning and intervention design of the PBA. These guiding principles are then utilised in the development phase to ensure the intervention continues to meet its key objectives (Yardley, Morrison, et al., 2015) whilst the logic model explains how the intervention will achieve this (Baxter et al., 2014). As explained in Chapter 3, the guiding principles specify the objective of the intervention and what the intervention must do to address the needs of end users (Morrison et al., 2018). In parallel, following the COM-B models and BCW, a behavioural analysis can be developed. This comprises of the methods as outlined in Chapter 3 and includes using primary data to identify the problems YP with tics experience and to identify intervention functions based on what needs to change (Michie et al., 2014).

Behavioural change techniques can be used to help identify components of the intervention to support the change needed (Michie et al., 2013), which can then be integrated into the logic model to illustrate how the intervention will lead to short or long-term outcomes (Baxter et al., 2014).

The current study will employ a similar approach to evidence-, theory- and person-based approaches that has been used in the development of other DHIs. For instance, as in the case of Bradbury et al. (2018) a digital intervention for cancer survivors was developed using a rapid scoping review, and informed the guiding principles, behavioural analysis and logic model for a rigorous and systematic intervention plan. Likewise, in the intervention plan and development phase of a digital intervention for antidepressant discontinuation, Bowers et al. (2020) used theory, evidence and person-based approaches by conducting two systematic reviews, primary qualitative research, a behavioural analysis and then developed guiding principles and a logic model for their ADvisor intervention. This resulted in a comprehensive strategy integrating commonly used theory and methods with full understanding of the target users' perspectives and context. Prioritising the current features with groups of YP and their parents will help to ensure that the development team focuses on the most crucial aspects of the intervention to the end-users, whilst ensuring the intervention continues to meet its aims and objectives. The use of focus groups to conduct this research enables group discussion and multiple viewpoints to be heard. These methods will enable the identification of guiding principles and intervention functions in line with theory-based approaches.

Study Aims and Research Questions

The aim of this research was to ask YP and their parents to hierarchise, in terms of priority of importance or need, the currently proposed features of the intervention, both within and across the categories of previously proposed features. Further exploration of how or what the features would look like to be preferable to YP is also warranted.

1. What categories of features are felt to be the most important?
2. What features within the categories of proposed features are felt to be more important?
3. How and what should the desired features look like and function in order to be helpful?

It was explained to participants and parents that they could withdraw at any time from the study and at various time points. Prior to the recording of the focus group, verbal consent was taken. Please see ‘Data Storage and Protocols’ in Chapter 3 for more information on ethical considerations taken during data collection.

Methods

Procedure

As explained in the Methods Chapter (Chapter 3), parents or children responded to the recruitment call by completing online forms (information sheets for young people can be found in Appendix 19 and for parents in Appendix 20). After obtaining their contacts details, parents were contacted to check the online forms had been completed by themselves and their children, to give an overview of the research procedure and to begin to develop a rapport between the parent, child, and researcher.

Once all forms had been completed and checked, and availability confirmed, participants were added to a Teams meeting in Microsoft Teams one week prior to the focus group. Where possible, focus groups were grouped of YP who were of similar ages. Participants were also given a guide for how to use Teams. This allowed participants one week prior to the focus group to ensure they could access and familiarise themselves with the platform. The familiarisation video was also uploaded to the Team to encourage access to Teams. The aim of the familiarisation video was to introduce the participants to the researchers and give them an example of the questions they would be asked during the focus group, with an example slide from the focus group guide.

Microsoft Teams was used to conduct the online focus groups as it uses Office 365 security and compliance. This means that all the data is encrypted, and personal data remains with the tenant and the service they have signed up to. Further, Teams gives different abilities to Owners of the Team (the researchers) and Guest members (the participants), meaning only CB could record or download the focus group recording.

During the focus group, the first 15 minutes was allocated to technical issues and learning the functions of Teams (e.g. mute, screen on or off, hand raising), followed by establishing the ground rules and reaffirming that participants can withdraw at any time. The focus group was recorded both by using the ‘Record Meeting’ function on Microsoft Teams and using a dictaphone. All participants were informed that the focus group was being recorded both verbally by the researchers and via a notification at the top of their screens. CB asked questions listed on the focus group guide (see below) and the research assistant (MR) supported this through prompts, follow up questions and ensuring all questions had been covered.

After the focus group, parents received the RCADS-P and the TODS-PR and children received the RCADS and the GTS-QOL-CA (Chapter 3). In receipt of completing the surveys YP and parents would be emailed a £10 shopping voucher. An open response section at the end enabled feedback to be given about their experiences of the focus group and involvement in the research.

The RCADS scale was adapted in view of some questions potentially being redundant due to Covid-19. Participants were able to select 'Not Applicable' for all questions and a sentence was added to the questionnaire to highlight this, 'We recognise that due to the pandemic, some of these questions may not be applicable to your child and your current circumstances. If you feel unable to answer that question due to the pandemic, please select 'Not Applicable''. A similar sentence was added to the child RCADS questions. During coding, for the RCADS, N/A answers were coded as 'missing items' and prorated with the other items in the scale (Weiss & Chorpita, 2011). For other scales, missing items were given a mean average based on the items reported and a note was made to record this. For participants who did not have a parent or guardian, they were asked to complete the parent rated measures themselves.

Development of focus group guide

The focus group guide (Appendix 21) was based on the model developed at the beginning of this chapter in 'Integration of Features' and an example of slides relating to the category 'calming strategies' is depicted in Figure *5*. This was created on Microsoft PowerPoint and presented via screen-share during the focus group in order to provide structure and visual support.

There were six sections of the focus group guide, schedules, reminders, socialising, well-being strategies, calming strategies and learning about tics. Simple images and icons were used to portray the feature or category, placed on a 'phone-like' background to reference the platform of the intervention as a mobile phone application. Pictures around the outside were used to facilitate discussion and related to previous themes as much as possible. For each category with proposed features, YP were asked how they would like the feature to look (e.g. slides 1-4 in Figure *5*). Once each of the features had been presented, a priority question was asked to the YP to find out which of the features would be the most preferred within that category (e.g. slide 5, Figure *5*). The final slide of the focus group guide consisted of each category (e.g. slide 6, Figure *5*) and YP were asked which category they liked the most. When asking preferential questions, the researchers would prompt by asking what the favourites were and what the least favourites were. One pilot group was run and included in the final analysis as few changes were made to the final focus group guide. Minor changes included the addition of a contents page to the focus group slides, which acted as both a 'landing page' at the start of the focus group and a way to explain the structure of the focus group to participants, and the title of each category was added to every feature-based slide, as can be seen in the top left-hand corner of the slides in Figure *5*.

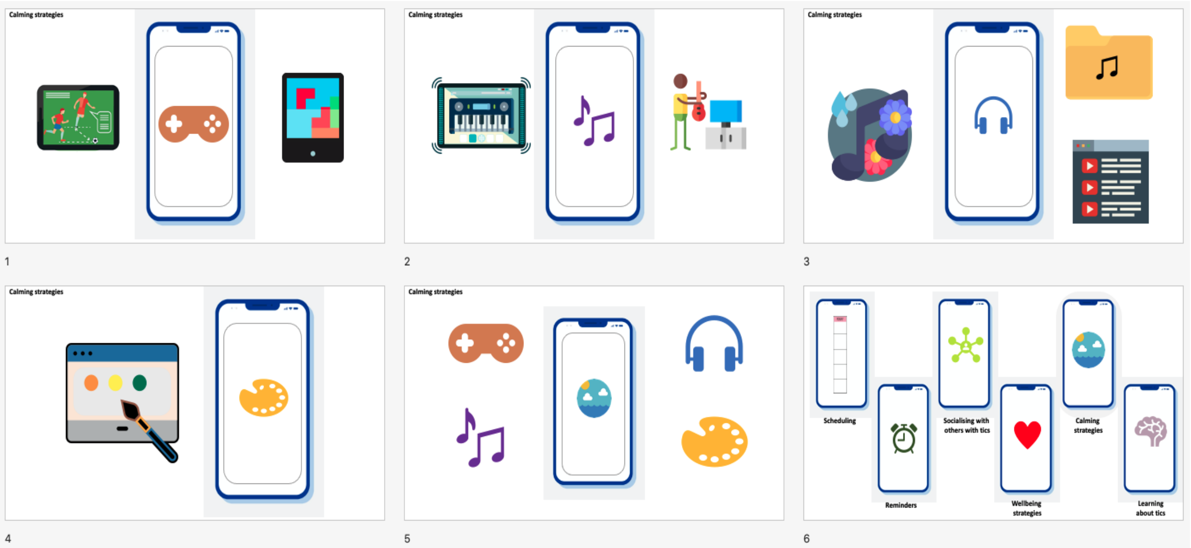


Figure 5 An example of the focus group guide presented to YP. This includes the section of features from the category 'Calming Strategies', with five features depicted in separate slides (1-4), a prioritisation of features slide (5) and finally the overall prioritisation of categories of features slide (6).

Setting of Data Collection

Focus groups took place on Microsoft Teams for all participants. Focus groups therefore took place in the participants desired location. Similarly, researchers (CB and MR) conducted the focus groups from their homes. Parents were involved in the conversations, and most parents could be seen or heard during the focus group. Whilst the researchers always aimed to direct questions to child participants, parents often supported YP in the conversation or helped to clarify what YP had said.

The post-group online survey including the other three quantitative measures were completed in the respondents' selected environment through a personal device within two weeks of completing the interview.

Data Analysis

As noted in Methods (Chapter 3) obtaining data saturation in focus groups can be challenging (Hancock et al., 2016). Furthermore, the fewer focus groups that are conducted, the more difficult it is to ascertain whether saturation has been reached. In light of the pandemic, conducting focus groups and obtaining research participants was challenging, while there are ethical dilemmas in recruiting participants during a pandemic (Townsend et al., 2020). These include adding burden to people during an anxiety-provoking time and the possibility that participants may not be able to access their usual support services. Therefore, a 'hard-push' for recruitment was felt to be inappropriate, so a shorter timespan (June 2020) was spent recruiting participants with an emphasis on recruiting those who would readily and promptly respond to the advert. When recruitment interest started to plateau, this was felt to be a reasonable time to stop recruiting. Further, in line with the debate outlined previously (Chapter 3), the researchers aimed to gather depth of information rather than breadth, to target a deeper analysis. It was also felt that the focus group guide was becoming more focused and less exploratory, so it was thought that sample sizes may not be required to be as large as in previous studies.

Nonetheless, both researchers noted in their field notes and discussions after focus groups that similar discussions were being held across groups. Whilst an additional focus group may have helped to confirm that data saturation was reached, it was also felt that further data collection would not have yielded any information different to what had been already gathered (Fusch & Ness, 2015).

Transcriptions were taken automatically from Microsoft Teams and checked against the video recording by MR, following the 'data storage and protocols' processes outlined in the Methods (Chapter 3), with edits made into a word processing software. CB checked the final transcripts were verbatim to the video recordings and made edits directly to the transcript. The qualitative analysis software, NVivo (QSR International, 2019) was used to analyse the qualitative data. Descriptive data was analysed using SPSS v24 for Mac (IBM Corp., 2016).

A hybrid thematic analysis approach was chosen for this study, to allow building on previous research findings and to explore new information (Boyatzis, 1998; Braun & Clarke, 2006). A priori codes were based on the supported themes from Table 9 which were used to develop the model depicted in Figure 4. A codebook of a priori codes was created which included notes about each of the themes the codes were developed on, to ensure codes accurately reflected the theme the code had been based on. These codes were inputted into NVivo prior to beginning the coding of the transcript. Posteriori codes were developed throughout the process of coding as outlined by inductive reflexive thematic methods (Boyatzis, 1998; Braun & Clarke, 2006) and relevant details were also coded to the codebook, in a separate sheet to the a priori codes (see Appendix 22). For more information on both these approaches, please see Methods: Analysis.

Coding of the a priori and posteriori codes happened in parallel, with the transcript being searched for anything relevant to the research question. On identification of relevant data, a priori codes were checked to see if previous themes fit the data and if no match was identified, they were coded to new posteriori codes. The development of themes followed a similar process to Chapter 6, in a continuous cycle of grouping and regrouping until stable themes were developed. A priori and posteriori codes and themes were kept separate in order to acknowledge what themes were formed on previous findings and which were developing themes. It was difficult to ascertain whether codes were coming from YP or parents, however where possible these distinctions were made. Preference questions were always aimed at YP and answered by them directly, and therefore can easily be identified as features YP desired.

Reflexive Statement

This was a new method of data collection for CB, so whilst CB had become quite comfortable with running focus groups from experiences gained in the previous study (Chapter 6) and had similar feelings regarding an increased knowledge and understanding of TS, the context of online focus groups was new to the researcher. Furthermore, the wider context of collecting data during a pandemic made CB very aware of the burden of taking part in research. From being involved in online support groups via social media, CB knew that many YP were not able to access their usual health care support and many YP were experiencing difficulties with highly stigmatising tics such as sniffing and coughing. The pressure of running focus groups online during a pandemic, and knowing it was the final research study added a lot of pressure to the data collection. CB felt it was important to be aware of this, and to recognise there were no ‘right’ or ‘wrong’ answers that could be gained from the focus group. As with the previous research, being open to differences of opinion and working with the research assistant to overcome potential biases from the previous research was helpful. MR was new to the research, which meant MR may have brought a more balanced view of the different themes that could be coming from the data. Debriefs at the end of each focus group also allowed time to consider the methods of the online focus group and ways to promote rapport building or to allow for greater exploration of a topic.

Data Collection and Sampling

This study recruited YP aged 8-19 years with a clinical diagnosis of TS or TD, and their parents or carers. Participants were recruited using snowball and opportunity sampling strategies, disseminating posters and a short-animation video shared online (https://www.youtube.com/watch?v=Aig6DPH5kAk&t=1s) through the researcher’s (CB) personal social media (Twitter, Facebook, LinkedIn). These were also distributed to previous participants on research registers. Both the YP and their parents were given a £10 shopping voucher as an inconvenience allowance for taking part.

Ethics permission for carrying out this study was granted from the University of Nottingham Division of Psychiatry and Applied Psychology Research Ethics Committee [Ref: 1570] (see Appendix 23 for ethics approval letter), prior to recruitment. YP and parents were required to give their consent to take part in the study, and parents had to give consent for children under 16. It was explained to participants and parents that they could withdraw at any time from the study and at various time points. Prior to the recording of the focus group, verbal consent was taken. Please see ‘Data Storage and Protocols’ in Chapter 3 for more information on ethical considerations taken during data collection.

Results

Participant Characteristics

In total, 17 YP and 15 parents were recruited to the study. Five YP and four parents withdrew, one child and parent couple due to illness and the others didn't attend the focus group. There was a very high 'anxiety' comorbidity in the YP, with four of the YP being diagnosed with anxiety and three also having OCD. Of the five, two also identified as non-binary gender. Overall, 12 YP completed the focus group and were between 8-19 years old, (mean=13, SD=2.7), two female and 10 males. Five participants had TS-only, one participant had chronic motor TD and six participants had cooccurring conditions including ASD (n=2) , OCD (n=1), ADHD (n=4), anxiety (n=2), dyslexia (n=1), SPD (n=1). All YP attended the focus group with a parent, except one YP who was above consenting age and lived away from their parents, giving a total of 11 parent participants. Four focus groups were run with the total duration of recordings lasting on average 1 hour 6 minutes (shortest: 00:54, longest 01:30).

All parents and YP completed the post-group surveys. Parent-rated RCADS showed average total anxiety symptom scores of 61 (IQR=51-79) and total anxiety and depression symptom scores of 65 (IQR=55-83), where children had average scores of 55 (SD=17.6) and 56 (IQR=46-62) respectively. Two YP's self-reported score reached above 70 indicating the clinical threshold for symptoms of anxiety and depression. Three parents also scored their children above 65, and four scored their children above 70 indicating the clinical threshold for symptoms of anxiety and depression. The child-reported C&A-GTS-QoL showed an average rating of 84 (SD=22.6) and the VAS scored a median of 65 (IQR=60-77). Parent ratings of the TODS gave a median of 85.5 (IQR=77-97).All parents scored their child above the cut-off on the TODS, suggesting moderate to severe TS symptoms (Hollis, Pennant, et al., 2016). On average, it took parents 4 days and YP 5 days to complete the surveys (IQR=1-9).

Across the RCADS scores, one YP indicated N/A on a question, and two parents indicated N/A, one for one question, and one on two questions across the measurement. These were handled as missing data and prorated (replacing the missing data with the mean average of the available items) across the scale (Weiss & Chorpita, 2011). On the C&A-GTS-

QOL, five parents indicated N/A on two questions, and one parent indicated N/A on three questions.

Hybrid Thematic Analysis Results

Five categories of features were developed from the data, which included ‘Calming Features’, ‘Wellbeing Strategies’, ‘Reminders and Schedules’, ‘Overall Preferences’ and ‘Operation’. Across these categories there were 13 themes.

Initially, codes relating to how the intervention should operate existed within separate themes for each feature of the intervention, for example within ‘Reminders and Schedules’ existed a subtheme that alarms should be personalised. This meant there were a lot of different themes, that had similar meaning, spread across feature themes specifying the elements that should be personalised. Therefore, it was felt that an ‘Operation’ category should be created, to better reflect how participants felt personalisation’s should span features, for example, and hence give deeper understanding. Two categories had been created to host themes relating to ‘Psychoeducation’ and ‘Socialising’, as they did not fit within other categories. Through discussion, it was noted that both these themes were also the most preferred features across the sample, and therefore a sub-group of ‘Overall Preferences’ was felt to be a shared topic amongst the two themes and was developed. For each feature, YP had been asked which was their favourite, leading to many codes that ranked or gave a preference index for features. These codes were felt to be important to answer the research question but did not give enough meaning to constitute themes, and therefore have been added as notes to each of the categories relevant to the preference.

Calming Features

Four themes related to calming features of the intervention, which included games (Theme 1), listening to music (Theme 2), art (Theme 3) and playing music (Theme 4). Of each of these features, YP had the greatest preference for playing games on the app, however listening to music was also very highly rated. Although not rated as highly, playing music and art strategies were still desired as calming features of the intervention. All the themes within this category were in line with previous findings, therefore were supported by a priori codes and both YP and parents showed similar feelings on themes.

Themes	Subthemes

Theme 1 – Simple puzzle and task-building simulation games were most preferred for being calming, whereas competitive games were not	
Theme 2 - Listening to music was felt to be calming	
	Subtheme 2a - The app should hold a selection of generalised calming music and link to other music platforms for specific preferences
Theme 3 – Engaging with art activities such as colouring and drawing were suggested for calming mood	
Theme 4 - User-appropriate features for playing music would be calming on the app	

Theme 1 – Simple puzzle and task-building simulation games were most preferred for being calming, whereas competitive games were not

Puzzles and task-building games were felt to be good for calming YP, supported by previous findings, as shown by a priori coding. These games included simple puzzle games such as Tetris or quizzes, 'just sort of any type of puzzle or game... for me if I'm honest. Sort of just takes my focus out of it… Just chills me out' (HFD7), or simulations revolving around task-building, such as Animal Crossing and Farmville. These types of games could be defined as 'casual games', which should be simple to play, easy to access and learn, referring to the gamers 'casual' investment or commitment to the game and the 'casual' development of the game with simple controls in the game (Kuittinen et al., 2007). Competitive games were not felt to be a good way to calm down however, supported by both YP: 'I think competitive games... as fun as they can be and as distracting as they can be, they don't calm you down. They just rile you up' (NPKN) and parents, 'it certainly triggers BZY4. It triggers him and he'll have um stronger tics… as a result… if it's competition based' (BYZ4-F).

Theme 2 - Listening to music was felt to be calming

In support of previous findings, listening to music was regarded as a calming activity. This included vocal music and non-vocal music, 'like the waves and stuff and like… trees or something; (Q3IK). Some YP explained that listening to music was one of the best ways to calm down, ‘I think for calming, I think sort of listening to music would be... um... the best way to sort of calm down’ (NPKN) and felt this should be accessible on the intervention, with further links provided if YP wanted more variation (Subtheme 2a). Both YP and parents agreed on this theme.

Subtheme 2a - The app should hold a selection of generalised calming music and link to other music platforms for specific preferences.

There was a consensus that the app should hold music, supported by a priori codes for the app holding and suggesting music, however it was also recognised that music can be accessed on other platforms. Therefore, it was felt that both, a selection of easily accessible calming music should be available, with the app suggesting the use of other platforms if more variety is warranted. A parent explains the need for easily accessible music on the app, so that a YP could access it quickly:

> Whether there could just be a uh like a bank or a handful of things… you know, rain on the- on the window, or the waves… without linking off elsewhere… If it- if we needed something very quick and you know at your fingertips quickly (G4BF-M)

Theme 3 - Engaging with art activities such as colouring and drawing were suggested for calming mood

As noted previously, art was felt to be helpful as a way to calm mood, and was already being used as a strategy by some YP; ‘I'm not sure if you heard of sandbox. It's like a drawing square game. It’s like you can do like different colourings and stuff and it quite calms me down’ (BZY4). It was also desired as a feature of the app, especially with the activities colouring and drawing, which were felt to be useful for relaxing and reducing anxiety, supported by parents also:

> FLDZ-Mum: It's either colouring in, you know, like paint by colours sort of thing, or um even just to have a paintbrush on there in black that they can just scribble on the screen… that probably would help when it comes to reducing anxiety with the kids that are arty

Theme 4 - User-appropriate features for playing music would be calming on the app

Playing music, i.e., playing an instrument such as a keyboard or the drums, and singing, was felt to be a calming feature that should be included in the intervention. This was deemed important by many YP who were interested in music or already using music to relax. However, a condition of such a feature added from codes found from exploratory data i.e., posteriori codes, was that it would not cause frustration, which could be determined by small screen size deeming the activity fiddley, or tics causing frustration during gameplay, 'so it might be quite frustrating if you can't play it as well as you could… uhm like… in real life situations.' (NPKN). This led to the inclusion that such a feature must be 'user-appropriate' within the theme.

Wellbeing Strategies

Themes	**Subtheme**
Theme 5 - Anxiety strategies albeit unspecified, were deemed to be a desired feature especially if presented interactively	
Theme 6 - Calming music was reported to be the most desired strategy for facilitating sleep	
Theme 7 - Positive affirmations and rewarding achievements could be used to improve self-esteem and confidence	
Theme 8 – Parents, but not YP, view trackers as important to monitor both mood and tics and share progress over time	
	Subtheme 8a - Trackers should have a variety of different methods to input emotions both visually and in verbatim

Across wellbeing strategies, these were all valued by participants in the focus groups, but sleep (Theme 6) and anxiety strategies (Theme 5) were especially favoured by YP. The other wellbeing strategies included self-esteem building (Theme 7) and the use of mood and tic trackers (Theme 8). In line with previous findings, the current findings all endorsed these features to be available on the intervention except for one (Theme 5).

Theme 5 - Anxiety strategies, albeit unspecified, were deemed to be a desired feature especially if presented interactively

Whilst all participants deemed the inclusion of anxiety strategies to be important on the intervention, the use of CBT strategies specifically was not supported by YP or parents in these focus groups and therefore the a-priori theme relating to anxiety strategies was not fully supported. Participants found it difficult to come up with anxiety strategies, 'but I don't know honestly, when it comes to anxiety strategies, I think it's quite tricky' (FLDZ-M) but did recognise their need in the intervention. As a result, the ideas that were discussed all tended toward interactive methods YP could engage with in the app to support their anxiety. These included activities where YP could, 'write down things that are bothering him at that time, and, uh, he can rip those up into shreds… and put that away' (BZY4-F)', or, 'I think we should put in like um a bubble with something [anxious thoughts] so when you get stressed you can just watch it float up and down' (G4BF) and finally, 'so you could have like your 5 to 1 strategy, where you have to type in… the five things you know you can see' (V5R3-M). All these ideas involved interacting with the anxious thought or calming strategies to alter mood.

Theme 6 - Calming music was reported to be the most desired strategy for facilitating sleep

As a therapeutic method to support YP getting to sleep, calming music was felt to be important by YP and parents. As reported previously and therefore supported by both a priori and posteriori coding, YP in these focus groups also found sleep to be a difficulty, and the use of relaxing strategies was reported to assist in sleep for YP with tics. Out of the strategies, music was agreed as being the most positively reported supportive strategy for assisting with sleep:

> I struggle with sleep quite a lot with it. So… I think anything like sort of helps. Like relaxing music or something like that or… anything that helps with that would be great (HFD7)

It was important that the music in this instance was calming. As music has already been identified as a theme to support relaxation (Theme 2), it is important to note that the genre of music in this is different as it must be calming to be relaxing, and not any genre desired by the young person, ‘maybe like calming nature sounds or something like that. Or like music, that's like soothing’ (BZY4).

Theme 7 - Positive affirmations and rewarding achievements could be used to improve self-esteem and confidence

YP and parents thought the app could help YP with tics to improve confidence and self-esteem through positive affirmations and logging achievements. Positive affirmations included the use of positive words or quotes, ‘like [a] quote every day, like a positive one’ (Q3I3), as there was a general feeling that YP with tics can have a negative outlook on life and themselves: ‘mine [my child] likes to read a positive affirmation ‘cos [sic] he doesn't necessarily… have them in his own head’ (FLDZ-M). Logging achievements and being able to reflect on those positively was another method participants thought would be useful to improve confidence or self-esteem:

> V5R3: The medal one.
> V5R3-M: The medal. Yeah. You can’t beat having a medal.
> Interviewer So if you like to see medals, how would that work?
> V5R3: Um gain them if you did certain things

Previously, themes had highlighted that strategies could be used to improve self-esteem by changing the way YP think about themselves, however this theme explored how the intervention could support this making it formed of both a priori and posteriori coding.

Theme 8 – Parents, but not YP, think trackers are important to monitor both mood and tics and share progress over time

Previous findings suggested the use of mood diaries would allow YP to notice emotions, which may help them to identify and control feelings, which parents in these focus groups felt was true for their children especially if they could use different methods to do so (Subtheme 8a), shown by this participant:

> They can then type in and add notes to that, say you know if they got all sad faces for a Wednesday, they can then type in, you know, lost my homework or something... the reason why… they felt like that (V5R3-M)

Furthermore, parents felt tracking could also apply to tics, expanding the current findings with posteriori findings:

> I think it would be good for us to keep track of how she feels… or if we can then track to say you are ticcing a lot and she can actually see it… (DPUU-M)

Nevertheless, few YP commented about such a feature, and mainly either agreed with parents or said little about it, suggesting that YP were less enthusiastic to monitor and track their moods and tics.

Subtheme 8a - Trackers should have a variety of different methods to input emotions both visually and in verbatim

Along with the desire for tracking features, parents also thought that if implemented they should include a variety of ways to convey emotion. This was especially relevant for YP with autism who may find talking about emotions hard, but also could support other YP who struggle with words, writing or comprehension. Different methods were suggested, varying from being able to input your own words, to selecting emoticons of mood, or using icons that symbolised mood. These parents explain how it would help their children with tics:

> Maybe even a thumbs up, as simple as a thumbs up sometimes. … You know 'cos [sic] he- he has Autism as well and struggles to- to identify that [moods] and related to his tics (G4BF-M)

> For example, my son … although we would see sad and happy… it may not be a word that he um, necessarily understood attached to those emotions. So um, if he had an option to be able to put the word that he wanted to put in um... he would then still understand his mood (FLDZ-M)

Reminders and Schedules

Themes	**Subthemes**
Theme 9 - Schedules support YP with their organisation but need to be simple and easy to use	
Theme 10 - Reminders are useful for attending to one's wellbeing and gaining independence through performing daily activities	
	Subtheme 10a -- In order for reminders to be effective, they need to be repeated or

	actively ticked off until the task is complete

Participants thought both reminders and schedules would be useful on the intervention, with schedules being something you use to plan your day (Theme 9) and reminders as prompts that the phone gives to attend to urgent matters (Theme 10). Reminders for daily activities and schedules were especially desired by YP, with reminders for well-being strategies specifically being something less desired. Some of these themes were in line with previous findings, and others were not supported by a priori findings.

Theme 9 - Schedules support YP with their organisation but need to be simple and easy to use

YP with tics reported that schedules would be very useful to help them be more organised, which YP explained they struggle with, for example forgetting their daily plans:

> G4BF: I would have a calendar.
> Interviewer: You'd have a calendar? OK. And why is that?
> G4BF: So- so I can get reminded to do certain things and not forget

Parents also agreed that schedules would support YP to be better prepared, with one parent talking from their own experiences of living with TD and cooccurring conditions:

> 2KY0-F: I think… the Tourette's brain, quite often, you know, you've got other things going on there like ADD and anything like that. I'm a terrible organiser … So a schedule, anything like a planner, would be good. And if it's all in one place on an app, then all the better

A caveat of the schedules was that they must be easy and simple to use, as YP explained they could easily get overwhelmed by the schedule, 'he likes the idea of focusing on one day at a time and he said, like with like little pictures of what he has to do would be good' (CN7S-M), and, 'I think a daily thing will probably be easier. Just a bit less overwhelming, I think' (HFD7). This theme was in line with some a priori codes, that schedules would support YP who are concerned about their day, however the mood-related a priori codes such as, 'planning helps better manage day to day life leading to improved mood' were not supported as the main idea of schedules was practical support opposed to managing mood. Further, this theme was also formed of posteriori codes with additions that features must function simply.

Theme 10 - Reminders are useful for attending to one's wellbeing and gaining independence through performing daily activities

YP supported the idea that the app could remind them to complete wellbeing activities and tasks within their day, with the latter generating the most support from YP. YP felt that daily activities such as taking medication reminders,

> So like maybe one for like medication or like… medical things so you have like the medical side of it … 'cos [sic] obviously if you have like a really long schedule with loads of things to do on that one day… then it might get quite overwhelming for some people (NPKN)

Or sleep routine reminders, '[a reminder] could like say it's time to go and read your book or to… get ready to go to bed or something like that' (XMT0), would be supported through the use of an app. This was also felt by parents who thought the intervention could give YP greater independence to do such activities themselves. For this reason, it was felt that reminders would be better if focused on activities necessary for daily functioning, opposed to reminders for other activities like hobbies or socialising. A further suggestion to make reminders more effective was that they would need to be ticked off (Subtheme 10a).

This theme was supported by a priori codes and developed with posteriori codes, as previous findings had proposed that reminders could help YP implement strategies that are supportive for their wellbeing whilst adding that it would support independence and be relevant for daily functioning. Furthermore, supporting sleep hygiene to support wellbeing was also supported by a priori codes.

Subtheme 10a - In order for reminders to be effective, they need to be repeated or actively ticked off until the task is complete

Noting that reminders would only be effective if there were continuous prompts for them to be completed, parents and YP suggested that the app would need to repeatedly remind YP to complete tasks. Without doing so, a YP could become distracted or ignore the prompt, leading to the task never being carried out, 'or she has to tick something to say, you've done it instead of just pressing OK?' (DPUU).

Overall Preferences

Themes	**Subthemes**

Theme 11 - Socialising with other YP with tics is felt to be supportive and should be featured on the app through different platforms	
	Subtheme 11a - If deemed necessary or for those new to socialising, interactions can be facilitated with ice breaking games.
Theme 12 - Psychoeducation on tics is desired on the app and should be clear, simple and easy to navigate	
	Subtheme 12a - Animation videos are a useful way to learn and reduce the likelihood of tics being passed on
	Subtheme - 12b - Learning from others' experience and perspectives allows opportunities to learn

Across all the categories of features, two categories were reported across participants that were the most important to YP: Socialising (Theme 11) and Psychoeducation (Theme 12). Of the two, socialising was deemed by YP to have the highest preference, although psychoeducation was still deemed very important. This theme is in support of a priori coding.

Theme 11 - Socialising with other YP with tics is felt to be supportive and should be featured on the app through different platforms

Socialising had previously been deemed an important part of the intervention, and again was supported by these participants with a priori and posteriori themes, by both YP and parents who saw the value in it. It was felt that this was a large part of support that was missing for many YP:

> That's the essential bit [socialising] that's missing. So yeah, I think um it would make everything better, if we, HFD7 could reach out more to people who might understand him more (HFD7-M)

Different forms of socialising were requested, from blogging 'I want I like the bloggie [sic] thing' (CN7S) to messaging, 'messages, I think' (XMT0), to interacting via games (Subtheme 11a). The support that socialising was felt to support in this instance did not relate to learning about tics but fit more with previous findings that it was a normalising experience.

Subtheme 11a - If deemed necessary or for those new to socialising, interactions can be facilitated with ice breaking games.

Many YP were concerned that it would be awkward to start socialising with a new person initially. As a result, across groups YP suggested that icebreakers through the form of games could help to support new interactions:

> It could like sort of break the ice in that sort of situation, 'cos [sic] obviously sometimes it can be quite awkward, just messaging some random person be like, hey, we both have Tourette’s, let’s talk (NPKN)

The types of ice-breakers all revolved around different games, such as playing a game with someone, ‘me and G4BF were just talking about this and we were saying about maybe playing hangman or anything like that just to break the ice’ (G4BF-M) or using leader boards to keep in contact, ‘then if we could link that with the friends that you've made on the social part of it, you can see you know who's… at the leader board of scoring’ (V5R3).

Theme 12 - Psychoeducation on tics is desired on the app and should be clear, simple and easy to navigate.

A psychoeducation section of the intervention to learn about tics was deemed one of the most important parts of the intervention, but necessitates being simple and easy to use. This is in line with a priori coding of previous themes that also recognised the importance of learning on the app, and of learning from others with tics (Subtheme 12b). All participants reflected that currently available psychoeducational resources on TS are overwhelming and can be incorrect, ‘cos [sic] sometimes looking on the Internet is quite like a minefield (DPUU-M), ‘it can be quite scary and actually quite- um there's a lot of misinformation out there’ (G4BF-M). Therefore, suggestions were made that explained how this feature could be made more enjoyable, which included the use of animation videos (Subtheme 2a), and small facts or snippets of information that did not require extensive reading from reliable sources. For example, ‘just quick bullet points would be really helpful’ (G4BF-M), or ‘a facts page on how it [TS] works and stuff’ (BYZ4), and:

> CN7S: Yeah, the little bubbles… like that have facts about it.
>
> CN7S-M: He didn't like the idea of having to watch a video of someone talking, he said no to that. But like, because he likes reading, like little

> facts that he could just click on and like a bubble would pop up with, you know, just a small bit of information

Subtheme 12a - Animation videos are a useful way to learn and reduce the likelihood of tics being passed on

Posteriori coding found that participants felt the use of animation videos to support learning about tics would be useful and engaging for YP. Some participants explained they had used animation videos for other conditions and had found them worthwhile:

> Like the autism animation, my son has… watched plenty of times and he really, it sort of is quite uplifting for him… But the animation thing with Tourette's and tics we are definitely lacking in (FLDZ-M).

Further, one parent reflected on their own experiences developing a tic-related animation video and found there was a positive reception to it:

> An animation of the information would be quite good as well. I recently made one on Tourette's... I've got so much feedback from it- from how kids could really kind of engage with it… It was the child telling the story of what Tourette's is. Um, so maybe something like that (V1PI)

One of the advantages of using an animation video was that YP would be less likely to pick up someone else's tics, which can be a problem when people with tics are interacting. This was especially noted by YP who were not as keen for face-to-face interaction:

> Q3IK-M: Yeah, I don't think you are keen on face… face to face, on camera, were you?
>
> Q3IK: No.
>
> Q3IK-M: Due to obviously making tics worse and things like that, but… I think he'd, he'd like the conversation

Subtheme - 12b - Learning from others' experience and perspectives allows opportunities to learn

Also coded by a priori codes, this subtheme found support for the need of the intervention to enable opportunities to learn through others with experiences of living with tics. Forums and chatrooms which allowed YP to ask questions or report how they manage and control tics were features YP thought would be useful, 'I think uhm, putting like questions out could be quite cool. Like, so you can get answers from other people if they've had the experience' (HFD7) or as explained by one YP, a search function could allow you to look up different ways to manage tics:

> Then it refers back to like the chat sort of section and it's like OK, today… I did X, Y, Z and it made my tics really bad so..., does anyone relate to that or how have you coped with that and things like that (NPKN)

Operation

Themes	Subthemes
Theme 13 – The way the intervention operates across its features can help to increase use	
	Subtheme 13a - Visuals such as emojis and pictures would improve the ease of use
	Subtheme 13b - The different features of the app would ideally link between one another
	Subtheme 13c - Personal preferences should be able to be applied across features of the app

The final category was made up of one theme (Theme 13) with three subthemes. This theme related to aspects of the intervention which would have an affect across all features of the intervention.

Theme 13 – The way the intervention operates across its features can help to increase use

Participants explained that the way the app will operate will have a great impact on how, and sometimes whether the intervention will be utilised. Different aspects of the intervention could support one's personal needs, such as supporting those who may help understanding parts of the app such as through visual support (Subtheme 13a) or ensuring relevant parts of the intervention are linked (Subtheme 13c), and finally ensuring the app is personalised so that features that are disliked are not presented to YP (Subtheme 13b). These themes were all formed posteriori.

Subtheme 13a - Visuals such as emojis and pictures would improve the ease of use

Across many of the different features, it was recommended that visuals be employed to help support YP when inputting into the app:

> But I also think that the faces is quite a good idea or like... To make it like more visually easy. So, it's not text that has to go in so much, but someone may be able to put in a like pics or something (FLDZ-M)

This was felt to be useful for a range of reasons including to help YP better understand features, or to help YP input to features more quickly, and to make the tool more engaging.

Subtheme 13b - The different features of the app would ideally link between one another

In order to increase usability of the intervention, a common theme included parts of the intervention linking between one another. This was noted earlier, with games and socialising being able to interact, ‘and then if we could link that with the friends that you've made on the social part of it, you can see you know who's… at the leader board of scoring’ (V5R3). If the app was set up to operate in this way, it could also mean other similar features could link, such as the reminders and schedules, as explained by this YP, ‘if you have reminders but no schedule, is like what's, what's it reminding you to do, and then if you have no reminders in a schedule, it just um doesn't like it doesn't remind you to do it’ (NPKN).

Subtheme 13c - Personal preferences should be able to be applied across features of the app

YP and parents explained that the app would be less desirable if it asked you to complete activities which would be detrimental to your wellbeing or disliked, therefore it was felt that the app would need to be personalised to the individual using it. As an example, a YP states, ‘I don’t... really like painting or doing art really ‘cos [sic] when I’m drawing or something, I get really annoyed’ (V5R3). If the app could be personalised, YP felt it would be suitable for a range of different YP, ‘uh, I think it's all like very good because… like everyone is gonna [sic] have their own opinion. And I don’t have to use everything’ (Q3IK).

Discussion

Overall, 12 YP and 11 parents were included across four focus groups to identify which of the currently proposed categories of features and which of the features within the categories were deemed to be the most important by YP with tics to support their wellbeing. Questions aimed to capture how and what these features should look like and function in order to be supportive. Across the participants, only two were female showing a sample bias of males to females, above that of the usual reported male-to-female bias in TS. This was also reported in the previous chapter (Chapter 6). The age range of this sample was broad and recruited YP who spanned the inclusion criteria, from 8-19. Wellbeing measures indicated YP in this sample who completed the focus group were less anxious than previously recruited samples, with average parent ratings of anxiety and depression just meeting borderline for clinical levels and being much more reduced in self-reported ratings. Despite this, YP in this sample scored similarly to the previous cohort on both the visual and total scales for QoL with the visual scale suggesting YP rated themselves on the upper end of quality of life, on average. Parent ratings of the TODS gives an indication of the impact their tic condition and comorbidities were having on their life, and this was also improved compared to previous samples; however, the score still indicates a moderate impact on life.

Five YP and their parents were withdrawn from the study due to not participating in the focus group. This group had highly cooccurring anxiety and OCD. It is expected that during the pandemic, YP with anxiety will likely be experiencing an exacerbation of symptoms (Jia et al., 2020; Young Minds, 2020). For people with OCD, who may experience excessive hand-washing and obsessive thoughts, government guidelines to increase hand washing and the frequent media reports of death will likely have resulted in a severe decrease in symptom management for people with OCD (Davide et al., 2020). Furthermore, anxieties are likely to be increased for the same reasons for YP with generalised anxiety. A further difficulty of tics is their tendency to increase in response to socially inappropriate behaviour. Anecdotally, patients with TS have reported an increase in coughing, touching, spitting and sneezing tics during the pandemic (Robertson et al., 2020), which is likely a cause of distress or anxiety for YP with tics. Therefore, it is possible the withdrawal group were different in that they could have raised anxieties during the pandemic, meaning this group felt unable to continue participation. It is also possible that participants may have developed symptoms of Covid-19, making them unable to take part.

13 themes were identified relating to different features or aspects of the intervention, categorised into five areas relating to either the type of feature (‘Calming Features’, ‘Wellbeing Strategies’, ‘Reminders and Schedules’) preference of the category of features (‘Overall Preferences’) or how the intervention would operate (‘Operation’). A rough ordering of importance was gathered for the type of, and categories of features alongside how they should look and function. The final category illustrated themes that were less representative of a priori theory and reflected data-driven themes. Therefore, these themes did not generate preference details but added detail to how the intervention should function or operate.

In terms of the most desired features, YP especially wanted the intervention to consist of casual games (Theme 1) and calming music that could be accessed within the app, with direction to other music preferences on external platforms (Theme 2). To support their wellbeing, YP felt interactive anxiety strategies would be the most useful (Theme 5), alongside calming music to support sleep (Theme 6) of which the need for these could be reflected by the borderline symptoms from the RCADS scores noted in the clinical assessments. Reminders and schedules for daily activities were given precedence (Theme 9 and 10) to support functioning. Finally, YP viewed the socialising with others with tics (Theme 11) and learning about TS through others with tics and via animation videos (Theme 12) were amongst the most important areas the app could focus on. Together, these findings have enabled a better focus of the objectives and components of the intervention, with these participants helping to narrow down which the most important features would be and how they would work. Furthermore, YP and their parents highlighted how aspects of the app should function to be useful, which included using visuals (Subtheme 13a), linking between sections of the intervention (Subtheme 13b) and being able to modify the intervention based on personal preferences and needs (Subtheme 13c).

In order to retain the crucial elements that address the interventions objectives, the components that are less desired should be removed (Yardley, Ainsworth, et al., 2015). Additionally, doing this will better support the feasibility of the tool’s development, reducing time and expertise needed for its creation (Bradbury et al., 2014). During the generation of themes, it was recognised that calming activities such as engaging with art activities (Theme 3) and playing music (Theme 4), whilst of interest to YP, were not rated as highly as other calming methods. This is likely as a result that not all participants would class themselves as artistic or musical. In the research with music and tics (Chapter 6), musical performance was more effective than listening to music for a tic-reducing effect. When investigating active versus passive participation in musical activity, all participants were non-professional musicians, therefore the findings can only be applied to musicians (Bodeck et al., 2015). For non-musicians, it is not known whether the same effect would be had on their tics. It has also been noted that frustration leads to increases in tics (Conelea & Woods, 2008b; K. P. O'Connor et al., 1994). Therefore, completing musical or art related activities when you are not practised in the skill could hamper achieving a calming state. Beyond the use of music with populations of YP with TS, music has been associated with unhealthy coping strategies such as rumination (Garrido & Schubert, 2013) and emotion-focused coping (Miranda et al., 2012) and may be related to an inability to select music that would improve mood (Hense et al., 2014). On the other hand, music can also be used to support mood regulation through methods such as self-reflection, identity formation and inspiration, therefore it could still provide positive coping strategies provided it is used in a way that maintains a healthy listening regimen, which the proposal of calming music only on the intervention could encourage and may help to achieve (Theme 2) (Miranda et al., 2012).

Other potential features of the intervention that were not as popular included positive affirmations (Theme 7) and mood trackers (Theme 8). The positive affirmations had been noted by participants as a technique to improve confidence and self-esteem. Issues with self-esteem have been noted for individuals with chronic conditions, and impacts effective self-management and coping, leading to further negative consequences of living with a condition (Bedrov & Bulaj, 2018). Therefore, previous interventions have integrated motivational quotes and affirmations (Bedrov & Bulaj, 2018). However, praise does not always result in positive outcomes; for example, one study found that when YP with low self-esteem were given inflated praise, it resulted in them being less likely to seek challenges. This result was attributed to a fear that the individual may have in performing well again in the future, so that inflated praise leads to avoidance strategies (Brummelman et al., 2014). It is possible that YP with tics may find positive affirmations do not always support their self-esteem. Another possibility is that YP may feel self-esteem boosting would be provided by other areas of the intervention, as one theory of self-esteem proposes it is a social construct, and can be remedied by relating to others, feeling understood or accepted (Leary & Baumeister, 2000), as the socialising aspect of the intervention would aim to do (Theme 11).

Finally, mood and tic trackers were a feature parents thought would be useful in the intervention, although YP were not as committed to this (Theme 10). Trackers were identified in the systematic review (Chapter 3) as a method to help YP monitor their mood with the intervention *Mobiletype*. Reid et al. (2011) found mood monitoring improved emotional self-awareness, had good retention rates and low risk of bias. Poor MHL, which includes an awareness of the emotions you are experiencing (previously discussed in Chapter 4; Jorm et al., 1997) could be a barrier to accessing support (Cheng et al., 2018) which may be improved by mood monitoring. Although findings from Chapter 4 indicated YP with tics have improved MHL comprehension compared to their peers, YP in this sample may not recognise the importance of identifying and tracking emotions, especially as boys tend to have lower MHL than girls and this sample was majority male (Coles et al., 2016). Whilst YP with tics may not show a desire for tracking, psychoeducation features which were requested (Theme 12) could fill this gap by helping YP with tics develop a greater understanding of emotions and subsequently their potential link with tic expression or management. A recent systematic review found interactive interventions or elements such as videos to enhance depression literacy in YP were helpful (Tay et al., 2018), with similar findings in another review with adults (Brijnath et al., 2016). Therefore, although the tracking was not as popular, psychoeducation components with videos and interactive activities may help YP improve their understanding, whilst retaining focus.

To capture the most preferred functions and focus of these functions, a new model has been developed based on the previous model, see Figure 6. Whilst the number of categories within the model has remained the same, there are fewer features per category and some of these have become more focused. The previous 'desired functions' of the intervention have been supplemented by other functions which were proposed in the current study. These functions are regarded as expectations by end-users, parents of end-users and stakeholders in order for the intervention to be acceptable, accessible and safe, therefore do not need prioritising as their inclusion is a must.

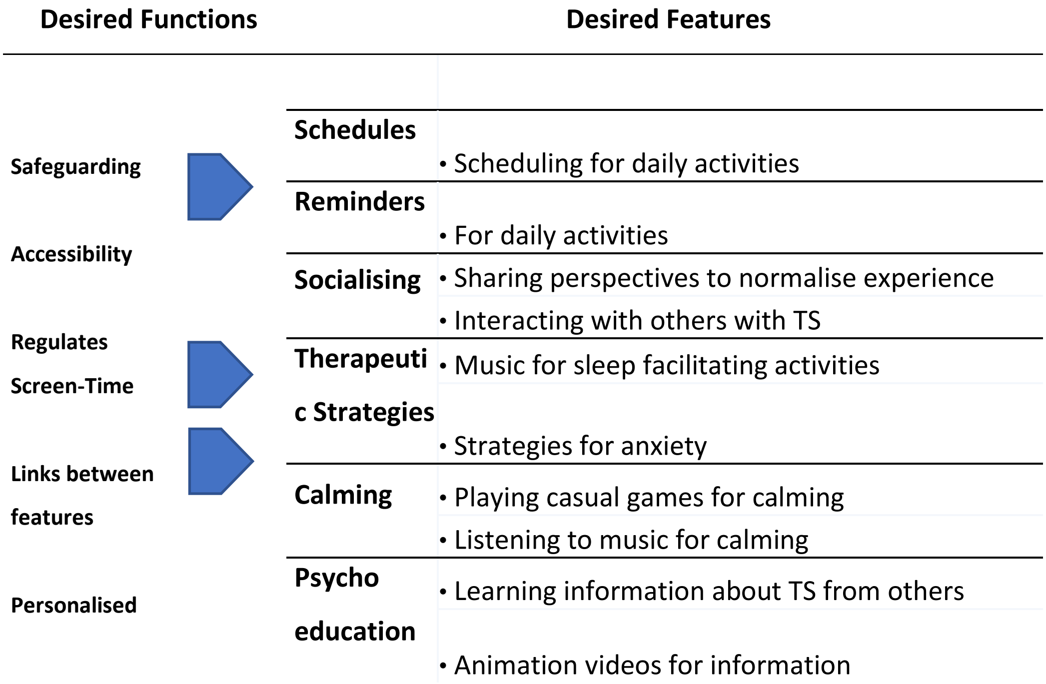


Figure 6 Refined model of the features of the intervention that were supported across at least two of the methods from Chapters 3-6, and identified as an important feature by preference in Chapter 7. Features include aspects of the intervention that would be available to use, and functions are part of the intervention that would work across all the features of the intervention.

Limitations and Strengths

The measures of wellbeing should be interpreted cautiously due to the impact of the pandemic. YP in this sample showed reduced anxiety and wellbeing compared to previous samples, but decreased QoL on the C&A-GTS-QOL. Considering the high levels of cooccurring anxiety in YP who did not complete the focus group, it could be interpreted that those YP who opted to take part in this trial are managing better with their tic condition during Covid-19 than similar aged peers (e.g., those who had previous taken part in the study). Reports indicate increased anxiety at a population level due to the pandemic, and across groups of YP, suggesting YP with anxiety during the pandemic would be especially negatively affected (Jia et al., 2020; Young Minds, 2020). Our measurements are not what was anticipated, as it had been expected that a rise in dysfunction would be seen across all scales. It is possible that the reason for this could be that YP with tics and cooccurring anxiety may be less likely to take part in this research than YP without cooccurring conditions. This is important to note because the aim of gathering measurements from YP was to ensure a diverse range of YP with tics was being accounted for in the qualitative findings (see Chapter 3). Nonetheless, the range and standard deviations suggest YP on lower and upper ends of the scales were included. Furthermore, parents in this sample still rated their children as borderline for anxiety and depression, and the TODS scale showed that YP felt their condition was having a moderate negative effect on wellbeing, suggesting these YP would potentially benefit from a self-help tool for wellbeing.

Another impact of the pandemic on the clinical assessments included missing items i.e., those scored with N/A due to some items in the scales being difficult to answer during non-normal times for participants. Deleting items from the scale would not have amended this problem due to varying circumstances between participants and this would make comparisons with previous study samples difficult. The RCADS user manual specified methods on how to prorate across their sample, and the number of items missing was within their recommended amount however, guidelines for prorating the other measurements, C&A-GTS-QOL or the TODS-PR, were not given. Given that the data had a low numbers of items missing (Graham, 2009), was only being used to describe the sample characteristics and not used in any further statistical analysis, proration by averaging and applying the average to missing scores was felt to be appropriate, but it is important to note that proration can lead to bias (Mazza et al., 2016).

Finally, there are some potential limitations of the focus group guide slides shown to participants. The slides were designed to help YP think about the different features and how they may look, and which they may prefer. This was in line with the aim of the research, to identify which features were preferred and to explore how they may look and function. The pictures selected on the slides aimed to represent different ways a proposed feature may look for example, slide 1 on Figure *5* aimed to identify what types of games YP would feel relaxing, e.g. puzzles or competitive games with an image of football and Tetris. However, the researchers noted that YP tended to select between Tetris and football, rather than seeing these pictures as representations of the types of games that could be included. Whilst the researchers would explain this throughout the focus groups, it was sometimes felt this presentation did not support the flow of conversation. The use of more ‘puzzle-like’ options, or better symbols of puzzles may have been better use of the slides, or potentially slides may not have been needed at all. This could have explained the resulting mass of themes that were mainly derived a priori, opposed to a more equal balance of both a priori and posteriori themes. Iterative methods present an advantage for such reasons, enabling rechecking with end-user groups about features, or using different methods of data collection to overcome any potential limitations of other methods.

Conclusion

In conclusion, the current research commenced with the development of a model of potential features and functions of the intervention. These components consisted of previously proposed features and functions, which were supported by at least two of the three previous studies (Chapters 4-6). This model was used to develop a focus group guide, which aimed to identify what YP and their parent's preferences were of the proposed features, and to explore whether these features should look or function in any desired manner. This was important to complete as prioritisation of features helps to ensure an intervention can be realistically developed, and that it remains focused to the aims and objectives of the intervention in line with the PBA. A hybrid thematic approach led to the development of themes which give an overview of which features were deemed to be most important and whether these were supported by previous findings or developed from new data. This was also applied to how such features and the intervention should operate. These features were merged with the initial model to develop a new model with the refined features based on YP's preferences, and both YP and parent's views. This refinement will enable the development of guiding principles which can be given to the development team to support the creation of the intervention.

Chapter 8 - Overall Discussion

Summary of Findings

Background

To recap, the aim of this study was to explore whether developing an intervention to support the wellbeing of YP with tics would be useful and to identify what features would be required to effectively support YP's wellbeing whilst keeping the intervention engaging and acceptable to YP and stakeholders. A review of the relevant literature identified YP with tics often experience reduced psychological wellbeing and deficits in QoL domains directly and indirectly related to their TD, also facing barriers in accessing mental healthcare. Currently, behavioural therapies available for tics are aimed at tic reduction and around half of YP do not respond to this therapy. Further, research into behavioural interventions aimed at wellbeing require more resources than currently available behavioural interventions, making them unlikely to be adopted. Self-help interventions for wellbeing outside of TDs have been found to be useful for improving management of wellbeing and access to care for YP with mental health disorders, therefore such interventions may provide a source of support for YP with tics. DHIs are regarded as 'low threshold' interventions, increasing people's access to care with their utilisation and as YP are avid internet-users and tend to have access to technology tools, DHIs were identified as an accessible method to disseminate a wellbeing tool to YP with tics. Limitations of DHI include low retention and take-up, which has been attributed to a lack of theory and evidence in the development of these tools. PBAs are believed to increase engagement with interventions due to high end-user and stakeholder involvement in the process; and the BCW integrates theory into the development process to increase the effectiveness of behaviour change interventions. Thus, the PBA and BCW has been followed during the intervention planning and design stages of intervention development, leading to the creation of guiding principles which specify the objectives and what the intervention must do to address the target needs of YP with tics, to support their wellbeing.

Overview of findings

The systematic review (Chapter Two) aimed to identify whether a wellbeing intervention existed for YP with tics, or for other mental or neurodevelopmental disorders, to better understand what features of interventions may be useful. The findings from the review gave support for the utility of digital self-help unguided interventions in populations of YP with tics, although no specific wellbeing intervention for this population or other populations of YP with neurodevelopmental disorders was identified. Whilst fantasy style games appeared the most effective for YP experiencing depression and anxiety, traditional linear-style interventions were still found to be beneficial, especially when they integrated CBT components. Furthermore, levels of retention for these interventions were reasonable.

In Chapters Three and Four, interviews were carried out with YP and professionals respectively to understand wellbeing in YP with TS, techniques YP currently engaged in or were proposed to YP for managing wellbeing, and to assess whether a DHI would be useful and acceptable to this group. Interviews with YP reflected a relatively proficient understanding of wellbeing from YP, indicating a level of MHL likely learnt from living with a neurodevelopmental disorder and cooccurring conditions. Further, YP highlighted the circular relationship between mental states and tics. Within their management strategy repertoire, YP often talked about the use of entertainment strategies for mood, which mirrored the activities YP used day-to-day, suggesting YP do not necessarily show active management of mental states. This was similar for tic-management, with strategies reflecting those used in everyday life. The intervention was something YP were interested in and suggested many features for, including games, puzzles, videos, music, art, interacting with others, schedules, support networks, relaxing activities and psychoeducation. Interviews with professionals highlighted that they saw a need for an intervention to support YP's wellbeing, which would also provide support to healthcare workers. Professionals advocated for the intervention as they recognised that tics were disabling, current support is not always accessible, cooccurring conditions reduce QoL and professionals do not receive training on how to deal with TDs. They felt the intervention should be on a mobile phone application, which would include features such as games and puzzles to distract from tics, psychoeducation via videos, music and sounds for mindfulness and distraction, social support and inspiration from others, therapeutic and self-regulation strategies, schedules for planning, sleep hygiene and managing daily life, but also encouraged considering the safety of using it.

The final two studies included focus groups. Chapter Six included in-person focus groups with YP and parents to determine whether the previously proposed features from YP and professionals were supported, and to gather any further detail on how the supported features should look. The focus group identified a series of desired features, including calming games, music and art, videos for information and to support calming states, notifications and diaries, calming and confidence boosting strategies and information on TS. Functions that would work across the features included accessible and flexible features, the ability to interact with others, safeguarding and screen time regulation. Themes also highlighted how distracting activities help mood and tics, and mental states affect tics and functioning and, finally, that there is a need for public awareness of TS. The final study, Chapter Seven, began with an integration of findings to identify which features had been supported by findings from another research chapter. Supported features from across the studies (Chapters 3-6) were integrated into the focus group guide in order to hierarchise the features in terms of importance and need. Focus groups included YP and parents and found socialising with others and learning about TS via videos and through socialising were the most important features of the intervention. Casual games and calming music were also desired in the intervention alongside therapeutic strategies for anxiety and calming music to support sleep. YP also highlighted a need for reminders and schedules to support functioning. Finally, the operation of the intervention was deemed to be important, with YP highlighting a need for visuals and emojis to help with accessibility, for the app to link between features such as socialising and gaming and that the intervention would be able to be personalised to the individual end-user.

Development of Guiding Principles

As highlighted in Methods (Chapter 3), the outputs of the planning and design stages of the PBA lead to the development of guiding principles which aim to summarise the key context-specific behavioural needs of the intervention (Band et al., 2017). Guiding principles are not intended to be exhaustive but aim to help developers easily recall the features that the planning stages have identified as being key to achieving the intervention objectives. As recommended, the first step in developing the guiding principles is to form the intervention design objectives, and for each intervention design objective, the key feature needed to achieve the objective should be outlined. Using a similar approach to Bradbury et al. (2019), where the previous literature findings were integrated within the guiding principles, a process was followed which enabled each design objective to be grounded in the primary research and literature review findings. The guiding principles can be seen in Table 15.

Literature Review or Research Findings	**Design Objectives**	**Key Intervention Features**
Current interventions for wellbeing in populations of YP with tics are resource-costly	A purely self-help approach will reduce resources required by professionals to guide the intervention	Use of engaging features to support self-help approaches Features must be clear and easy to use without support from professionals and/ or adults Use of virtual or automated coaches as a potential way to increase adherence
YP, especially males, show reduced help seeking behaviours	The use of DHIs are felt to increase feelings of autonomy, helping those reluctant to seek help	Ensure the intervention can be accessed independently on one's phone Features should be able to be used privately, without need for permission
YP with TS show reductions in QoL across domains including: Physical, Psychological, Social, Cognitive, Occupational Obsessional	Features of the intervention should effectively improve QoL in these domains	Where possible, the intervention should integrate CBT approaches to make it effective Aspects of the intervention should aim to reduce tic symptoms e.g. calming features Features of the intervention should support YP with mood and mental states e.g. wellbeing strategies and calming features The intervention should include means to support YP with school or occupational areas of life e.g. reminders and schedules The intervention should support YP with socialising
Qualitative review highlighted difficulties with: Socialising, Controlling tics and emotions, Acceptance, The impact tics have on one's life, School, Understanding TDs and stigma	The intervention should include features that are effective in helping YP with the highlighted difficulties	Features of the intervention should educate YP about their condition to help them with acceptance and understanding their TD The intervention should include mood management strategies which explain the relationship between tics and mood. These features should integrate CBT approaches to make them effective. The intervention should support YP with socialising and responding to stigma Features of the intervention could help YP with school e.g. reminders and schedules
YP with tics have low access to support and specialists for TDs	The intervention must be scalable	Features of the intervention need to work without therapist guidance and on technology that can be easily accessed by YP e.g. as a mobile app The intervention should be accessible and flexible to a variety of YP with varying severity or coexisting conditions in order for it to be scalable

Limitations of self-help interventions with YP include low adherence	The intervention must be engaging to YP to increase adherence and therefore must integrate features they desire, as proposed by the PBA	Socialising with others with tics and learning about tics through others, and via animation videos are the most important features of the intervention. For calming features, YP requested casual games and calming music, accessed on the intervention Interactive anxiety strategies and sleep-provoking strategies were desired to support YPs wellbeing The use of reminders and schedules in the intervention would help YP with daily functioning
Parents of and professionals who work with YP with tics can also be considered stakeholders and experts in the intervention design	The intervention must be viewed as acceptable by gatekeepers i.e. professionals and parents/ caregivers of YP with tics	The way the intervention functions can change how acceptable parents and professionals may view the intervention to be. Consideration must be given to the accessibility, safety and screen-time use of the intervention.

Table 11 Guiding principles based on previous literature reviews and primary research

Development of The Logic Model

Another output of the intervention planning and design stages of the PBA includes a logic model (Yardley, Morrison, et al., 2015). Prior to developing the logic model, a behavioural analysis needed to be completed. Using the COM-B model enabled behaviour change theory to be coded into the intervention features identified in the behavioural analysis (Band et al., 2017), which could then be integrated into the logic model, see Table 12.

The COM-B model was implemented as outlined in the Methods section (Chapter Two), first identifying the problem in behavioural terms to identify areas of needed behaviour change, then identifying these in terms of the intervention functions i.e., Education, Persuasion, Incentivisation, Coercion, Training, Restriction, Environmental Restructuring, Modelling and Enablement. Through this, the intervention function can be classified in terms of its model of behaviour, Capability, Motivation, Opportunity. This enabled identifying what the intervention aims to change in order to be effective (Michie et al., 2011). The feature content was developed using the refined feature and function's model of the intervention (Chapter 7, Figure 6) meaning this approach integrated evidence- and person-based findings. The taxonomy of behaviour change techniques can then identify the content of the features of the intervention, with techniques that have agreed definitions and distinct mechanisms, making them comparable across interventions (Michie et al., 2013). These behaviour change techniques are defined as 'observable, replicable, and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour' (Michie et al., 2013, pp. 82), which enabled the identification of 'key ingredients' in the intervention.

The logic model, presented in Figure 7, was constructed which captured the inputs, or design objectives, required to make the program successful, including the need for it to be delivered through a self-help platform, to be scalable, to overcome barriers to support, be engaging for YP and acceptable by gatekeepers to YP and ultimately to improve psychological wellbeing and QoL. The outputs of the model were developed from the behavioural analysis and consisted of platform and content-related mediators of change, for example increased motivation with progress monitoring and increased opportunity with a self-help platform for the former and socialising as a maintainer of behaviour change and improved knowledge of TDs through psychoeducation for the latter. The overall short and long-term outcomes are presented in the right-most column, highlighting how increased access to care, reduced therapist burden, an appropriate stepped care approach, reduced cost, increased knowledge of TDs, patient satisfaction, tic functioning and improved psychological wellbeing and QoL would be successful outcomes of the intervention (Americorps, 2011).

Future Applicability

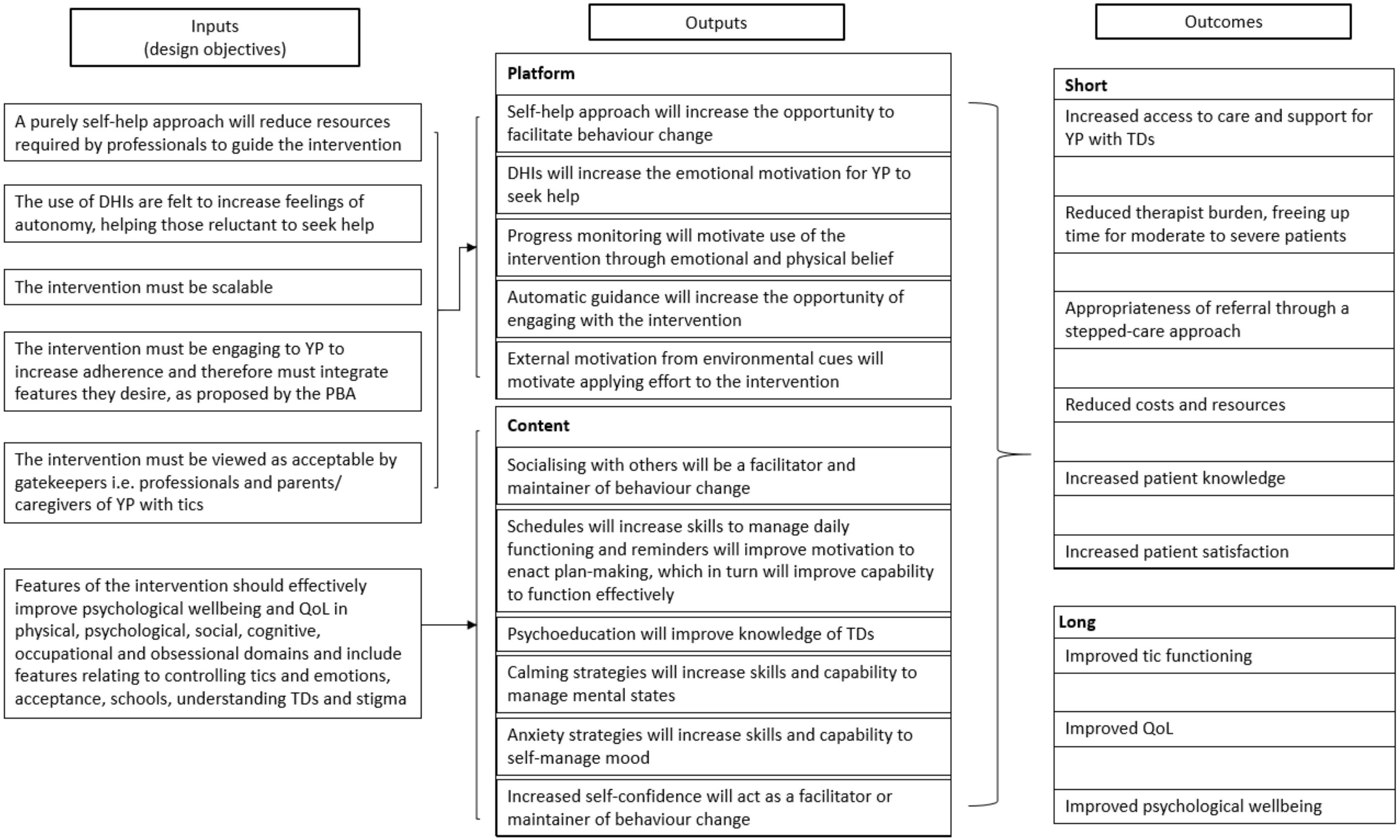
The steadfast dependency on technology for children and YP since the digital revolution, emphasized by Covid-19, makes a case for the utility of self-help DHIs. DHIs have the potential to enable huge barriers to care to be overcome, especially around coverage and cost. Regarding coverage, self-help interventions are highly scalable meaning they have the potential to improve mental health at a population level (Fleming et al., 2018). Additionally, self-help interventions reduce demand on professionals compared to other interventions, freeing up their time to support patients with more severe needs. Considering cost, one of the major barriers stems from a lack of investment, resulting in decreased service-user access and increased waiting times for child mental health services (British Medical Association, 2017; World Health Organization, 2019b). Reduced need for professionals delivering therapy reduces the cost of therapy and DHIs show minimal incremental costs as a result of being ubiquitously available and standardised. Further, initial reports of the cost-effectiveness of an online guided self-help intervention for behavioural therapy for tics have indicated it would be cost-effective (Andrén et al., 2019). An emerging body of literature proposes technology can also be used to foster social connection through social media, in a way that supports YP’s mental health, enabling access to support and advice (Pretorius et al., 2019). Online communities for TS offer valuable emotional support, reduce isolation and increase acceptance to those living with or alongside TDs (Perkins et al., 2020). All in all, the findings suggest that the use of technology as a platform to deliver support in the form of self-help DHI would be of value to YP with TDs and is a reasonable solution to the current barriers to care being faced by this population.

Target Behaviour	Feature Content	Barriers and facilitators	BCW construct	BCW function i.e. middle wheel	BCT Taxonomy
Improve mood management to improve psychological and obsessionality QoL	Therapeutic techniques e.g. CBT for anxiety management which are interactive. Calming strategies including casual games and music. Calming strategies should also help to facilitate sleep.	- Low MHL - Difficulties learning mood-management skills - Mood management practices not effective - Various co-occurring conditions	Psychological Capability	Education Training	- Self-monitoring of behaviour [2.3] - Instruction on how to perform a behaviour [4.1] - Behavioural rehearsal/practice [8.1] - Regulate negative emotions [11.2] - Distraction [12.4]
Reduce anxiety and stress through mood management to reduce tics	Application of mood and mental-state management skills. Information on the relationship between tics and mental states. Tic tracking and mood tracking to recognise change in tics despite tics waxing and waning.	- Not understanding the relationship between tics and mood - Not being able to see a difference in tics altering mood due to tics wax and waning - Poor MHL and understanding of TDs - Not motivated to learn about relationship	Psychological Capability Physical Capability	Education Training	- Self-monitoring of behaviour [2.3] - Behavioural rehearsal/practice [8.1]
Improve support for cognitive and occupational areas of	Inclusion of a schedule that is simple and easy to use with reminders related to the schedule to prompt for the	- Forgetting to apply reminders and input to schedules - Not being motivated to use reminders and schedules	Psychological Capability	Training Environmental Restructuring	- Prompts/ cues [7.1] - Action planning [1.4] - Goal Setting (outcome) [1.3]

life through reminders and schedules	activities required to be completed for the day.		Automatic Process		
Increase opportunity to socialise with others with TDs	Socialising with others as a feature to learn more about tics and to meet other people with TDs. Incorporation of ice-breakers to support socialising and different methods to communicate by to reduce difficulties.	- Safeguarding concerns - Modalities to communicate by - Lacking confidence to start conversations - Worries about picking up other people's tics	Social Opportunity	Modelling	- Social support (practical) [3.2] - Social support (general) [3.1] - Social support (emotional) [3.3]
Ensure adherence to the intervention	Methods to monitor progress and incorporate automatic guidance to remind and motivate one to use the intervention. External motivation from environmental cues i.e. parents, healthcare workers can help to increase motivation.	- Not logging onto the intervention - Forgetting to use the intervention - Reduced motivation with intervention - Lack of guidance - Not convinced it will work	Reflective Process Automatic Process Social Opportunity	Incentivisation Environmental Restructuring	- Health consequences [5.1] - Emotional consequences [5.6] - Social reward [10.4] - Comparative imagination of future outcomes [9.3]
Increased self-confidence and acceptance	Through features of socialising one may experience increased confidence by seeing other people living with TDs. Improved management of the	- Self-stigma - Low confidence	Social Opportunity	Persuasion Modelling	- Mental rehearsal of successful performance [15.2] - Verbal persuasion to boost self-efficacy [15.1] - Self-affirmation [13.4] - Identity associated with changed behaviour [13.5]

	condition may increase acceptance of the condition.				
Improve understanding of TDs	Psychoeducation through learning from others with TDs and via animation videos would support learning about TDs. Simple and clear information that is not too overwhelming and can be accessed in a variety of formats i.e. written, audio, videos could encourage interaction with the feature.	- Too much information - Not motivated to read - Difficulties reading	Psychological Capability	Education	- Health consequences [5.1] - Emotional consequences [5.6] - Social support (practical) [3.2] - Social support (general) [3.1] - Social support (emotional) [3.3]

Table 12 A behavioural analysis using the COM-B model to integrate behavioural theory into the features of intervention



Inputs
(design objectives)

A purely self-help approach will reduce resources required by professionals to guide the intervention

The use of DHIs are felt to increase feelings of autonomy, helping those reluctant to seek help

The intervention must be scalable

The intervention must be engaging to YP to increase adherence and therefore must integrate features they desire, as proposed by the PBA

The intervention must be viewed as acceptable by gatekeepers i.e. professionals and parents/ caregivers of YP with tics

Features of the intervention should effectively improve psychological wellbeing and QoL in physical, psychological, social, cognitive, occupational and obsessional domains and include features relating to controlling tics and emotions, acceptance, schools, understanding TDs and stigma

Outputs

Platform

Self-help approach will increase the opportunity to facilitate behaviour change

DHIs will increase the emotional motivation for YP to seek help

Progress monitoring will motivate use of the intervention through emotional and physical belief

Automatic guidance will increase the opportunity of engaging with the intervention

External motivation from environmental cues will motivate applying effort to the intervention

Content

Socialising with others will be a facilitator and maintainer of behaviour change

Schedules will increase skills to manage daily functioning and reminders will improve motivation to enact plan-making, which in turn will improve capability to function effectively

Psychoeducation will improve knowledge of TDs

Calming strategies will increase skills and capability to manage mental states

Anxiety strategies will increase skills and capability to self-manage mood

Increased self-confidence will act as a facilitator or maintainer of behaviour change

Outcomes

Short

Increased access to care and support for YP with TDs

Reduced therapist burden, freeing up time for moderate to severe patients

Appropriateness of referral through a stepped-care approach

Reduced costs and resources

Increased patient knowledge

Increased patient satisfaction

Long

Improved tic functioning

Improved QoL

Improved psychological wellbeing

Figure 7 Logic Model developed from the guiding principles and behavioural analysis to give an overview of the intervention, to summarise what and how the intervention intends to change the targeted problems and behaviours. This approach utilises a person, theory, and evidence-base

Strengths and limitations of the research

Inevitably, the current research has strengths and limitations, some of which have already been identified in the individual methods chapters. These have included the potential influences of parental involvement, delays in obtaining clinical assessments from participants, bias in the professional sample especially in relation to being educated about TS, a lack of consistency between focus groups settings, timings and the focus group guide, and the impact of the pandemic on data collection. There are wider strengths and limitations, nonetheless, pertaining to the methods and approaches that have been used to guide the current research, and in terms of the implications of the using DHIs with populations of YP. This research has focused mainly on the use of qualitative methods; however, the purpose of this research was exploratory and qualitative methods were deemed to be the most appropriate, enabling both an in-depth and broad understanding of the topic (Greenwell et al., 2018; M. Patton, 2002). As such, the aim was to capture heterogenous opinions from diverse perspectives (Braun & Clarke, 2013), achieved through the use of different recruitment strategies, ranging from YP being accessed via gatekeepers at support groups (Chapter Six) to the recruitment of YP from social media and charity research registers (Chapter Four and Seven). Furthermore, the variety in outcomes from clinical measures suggested YP on either ends of the spectrum for tic impairment, tic severity, anxiety and depression were recruited. However, a set of criteria was not made to specify who the intervention would support, and the wide ranges of inclusion criteria throughout the methods has not helped to identify a particular group that the intervention would be most suited to. This is especially relevant to the age groups, with the final study having an age criterion of 8-19 (Chapter Seven) spanning over ten years. Therefore, whilst the current research has aimed to recruit heterogenous groups to capture diversity, this could also be seen as a limitation of the current project and future work will be needed to identify who the intervention should be aimed at.

Whilst the PBA provides a method to develop a complex behavioural approach which is grounded in evidence and centres the end-user in its development, this approach requires significant time and resources. Over three years, the current project has only completed the initial stages of intervention design that were purported to take 6 months in method papers, and still much more research time and resources are required before the intervention would be ready to implement (Bradbury et al., 2019). There are many limitations of lengthy time-scales in DHI development, with major concerns that by the time they are developed and tested, they will have become obsolete (Blandford et al., 2018). Furthermore, the interventions with the best evidence base are not those available to the public and vice versa (Rickwood & Bradford, 2012). This was mirrored in the systematic review (Chapter Two) which found only two of the seven interventions were available. (Bradbury et al., 2019; Jake-Schoffman et al., 2017; Moore et al., 2015). Furthermore, a process evaluation was not completed for the current project, which risks a lack of host and resources for the continued development of the current intervention, potentially further decreasing the likelihood of further development (Moore et al., 2015). On the other hand, it is argued that whilst the PBA approach appears resource intensive, the process may waste less time and resources than other methods as it identifies any problems prior to implementation (Morrison et al., 2018) and despite its lengthy processes, the PBA can be seen as a very comprehensive approach to intervention development (Bowers et al., 2020).

A further limitation includes potential lack of consistency during qualitative analysis. The subjective nature of qualitative research means that the research is interpreted within a particular context, and this context has an influence on the methods, analysis and findings of the research (Braun & Clarke, 2013; Swain, 2013). Furthermore, one of the important methods of analysing qualitative data is consistency across the coding, so that you are treating the data equally across the findings. The inductive reflexive thematic approach aims to ensure that the analysis is grounded in the data, without pre-existing theory shaping this approach. The deductive approach, on the other hand, uses pre-existing theory to shape the data (Swain, 2013). As outlined in the Methods Chapter, these two approaches come from different epistemological stances, and therefore it is possible that the consistency between the coding could have become confused. It could also be argued that the inductive approach was less inductive as the researcher became more familiar with the topic. This could have led to unconscious researcher bias in preferencing specific features of the intervention, which would have been different to that prior to the identification of such features by YP. It is felt, however, that the involvement of the research assistants who were new to the topic area (Chapter 7, 8) and continuous researcher reflections throughout the methods will have identified any potential biases and supported some consistency of judgement for the analysis (Braun & Clarke, 2019).

Finally, potential harms from technology should always be considered. A review of online and mobile technologies concluded that personality factors, social factors and digital factors increase vulnerability to online harms (Livingstone & Smith, 2014). For example depression, behavioural problems and decreased self-esteem have been associated with cyberbullying and increased risky behaviours such as meeting people offline and pornography-use (Hinduja & Patchin, 2008; Olenik-Shemesh et al., 2012; Owens et al., 2012). Further, peer relations mediated adolescent's risky online behaviour (Baumgartner et al., 2010), whereas a sense of belonging to school, family or neighbourhoods reduced online risky behaviour (Willoughby et al., 2007). The realisation that YP vulnerable offline are likely to be those also vulnerable online means that YP with tics may be increasingly vulnerable to online harms (Odgers & Jensen, 2020). With this in mind, the intervention developers must pay particular attention to safeguarding functions of the intervention as YP with TS may be especially vulnerable to risky behaviours. Considering parents views is also important to ensure they are invested in an intervention that is felt to be safe for use (Odgers & Jensen, 2020).

Directions for Future Research

The next steps for the intervention, as outlined by the PBA, include intervention development and evaluation of acceptability and feasibility. These approaches require the development of a protocol intervention and mixed methods research to evaluate user reactions to the intervention elements, and to assess the acceptability and feasibility of the intervention, from the end-users, healthcare professionals and parent viewpoints (Yardley, Morrison, et al., 2015). Such research could include the use of think-aloud interviews, diary studies, usage analysis, questionnaire studies, focus groups, observation (Yardley, Ainsworth, et al., 2015). These methods should continue to be conducted iteratively to make refinements that optimise the prototype, ensuring the intervention remains or becomes more acceptable, engaging, easy to use and well-adhered to. Throughout these processes, the logic model and guiding principles should be adhered to, to ensure the changes are consistent with the principles of the core aims of the intervention (Yardley, Morrison, et al., 2015). Methods papers for guiding the process of modifying the prototype suggest the use of the MoSCoW criteria; Must have, should have, could have, would like (Bradbury et al., 2018) and a website has been developed to support researchers in developing and implementing interventions using the PBA (University of Southampton, 2020). The final stages of development will include trials of effectiveness, where it is recommended that the current research consider the use of high-quality controlled trials rather than RCTs to evaluate the intervention. Future research should aim to identify who the intervention is most effective for and continue to engage YP with participatory research when considering the content of the intervention to ensure it remains acceptable to that age group.

Considering the complexity of the current topic, in developing an intervention that was grounded in theory, person and evidence-based approaches, forthcoming research must also consider ways it can support researchers in using these approaches when developing interventions. Regardless of the methods papers available on applying the PBA, none of these related to YP and mental health, making it difficult to apply to this area. Further, although the COM-B model was developed to support applications of theory to interventions, the guidance was convoluted and challenging to understand. Likewise, for the development of the logic model, which had various instructions from different schools of thought, it was hard to gauge which logic model to use and how to develop a DHI-specific logic model. Much criticism exists towards intervention developers for not using theory, evidence, and PBAs to increase the effectiveness of interventions, but it stands to reason that such approaches are not being implemented when doing so requires so much time and effort. Further, without the transparency in reported outcomes from interventions, alongside provision of cost figures on intervention development and resources required, future intervention developers cannot make informed decisions about how effective or feasible their intervention may be to implement. Taking steps in increasing the comprehensiveness of the guidance for applying theory, person and evidence-based approaches to intervention development and in increased transparency of reporting for DHI outcomes, could reduce wasted resources and improve the quality of future DHIs.

Conclusions

Identifying a gap in the literature on psychological wellbeing support for YP with tics through a digital self-help platform, this project aimed to explore how an intervention could be developed that would be both engaging and effective to YP with tics, as well as supported by stakeholders and caregivers. Through a person, evidence and theory-based approach, guidelines have been followed to identify how the intervention will work to change behaviour, centred on the views of the end-users, resulting in suggested guiding principles and a logic model template. This information can be used to continue the development of a targeted intervention that would aim to promote and improve psychological wellbeing of YP with tics, which through its basis in theory and participatory approaches, will overcome limitations of previous interventions around adherence and engagement. Such a DHI could improve access to care for this group of YP, providing them with a stepped care approach which may help alleviate their commonly experienced mental health problems. By attending to these difficulties earlier on via the use of such interventions, long-lasting beneficial impacts on YP can be anticipated in terms of their psychological wellbeing and QoL more generally.

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Appendices

Appendix 1 - PICO table adapted for different databases

Population	Condition	Intervention Mode	Intervention Type
Adolescen*	Neurodevelopmental Disorders (MeSH)	E?health	Self?help
Teen*	Neurocognitive Disorders (MeSH)	Internet intervention*	Self?management
Youth*	Tic Disorders (MeSH)	Internet	Self?care
Minor*	Tics (MeSH)	Online intervention*	Self-help groups (MeSH)
Child*	Stereotyped behaviour (MeSH)	Mobile application*	Self-management (MESH)
Young pe*	Tourette Syndrome (MeSH)	Computer Intervention*	Self-care (MeSH)
Adolescent (MeSH)	Obsessive-Compulsive Disorder (MeSH)	Tablet intervention*	
Child (MeSH)	Obsessive Behavior [mh]	Electronic?Health	
	Compulsive Personality Disorder (MeSH)	Digital?health intervention*	
	Neurotic disorders (MeSH)	Digital Health	
	Autistic Disorder (MESH)	Digital intervention*	
	Autism Spectrum Disorder (MESH)	Electronic intervention*	
	Asperger Syndrome (MESH)	Telemedicine (MeSH)	
	Attention deficit disorder with hyperactivity (MESH)	Computer assisted instruction (MESH)	
	Impulsive behaviour (MESH)	Therapy, Computer-Assisted (MESH)	
	Attention deficit and disruptive behaviour disorders (MESH)	Medical Informatics Applications (MeSH)	
	Substance-related Disorders (MeSH)	Computer Systems (MeSH)	
	Anxiety (MeSH)	Telephone (MeSH)	
	Anxiety Disorders (MeSH)	Wireless Technology (MeSH)	
	Stress, psychological (MeSH)		
	Stress, Physiological (MESH)		
	Mood Disorders (MeSH)		
	Mental Disorders (MESH)		
	Affective symptoms (MESH)		
	Depression (MESH)		
	Depressive Disorder (MeSH)		
	Affect (MESH)		

Population	Condition	Intervention Mode	Intervention Type
	Child Behavior Disorders [mh]		
	Feeding and Eating Disorders [mh]		
	Attitude to health (MESH)		
	“Quality of Life” (MESH)		
	Sleep Wake Disorders (MeSH)		
	Self-Injurious Behavior (MeSH)		
	Fatigue (MeSH)		
	Rage (MeSH)		
	Involuntary Movement*		
	Coprolalia		
	Copropraxia		
	Echolalia		
	Echopraxia		
	Palilalia		
	Palipraxia		
	Premonitory Urge		
	Premonitory Urges		
	Coprophenomena		
	Echophenomena		
	Paliphenomena		
	“Chronic motor or vocal tic disorder*”		
	Impuls*		
	Compulsi*		
	Obsessive Behaviour		
	Obsessive Compulsive Symptom*		
	Hyperactiv*		
	Hyperkine*		

Population	Condition	Intervention Mode	Intervention Type
	Hyper?activ*		
	Conduct Disorder*		
	Anti?social behaviour*		
	Depression		
	Anxiety		
	Anxiety Disorder*		
	Stress		
	Affective Disorder*		
	Well-being		
	Mood		
	Coping		
	Distress		
	Sleep Disturbance*		
AND	**AND**	**AND**	**AND**

Appendix 2- Example search strategy for Medline

Name of the database	**Medline**
Platform	**OvidSP**
Date of Search	**28.08.20**
Database Coverage	**1946 present**
Search Strategy	

	Population	**Condition**	**Intervention Mode**	**Intervention Type**
OR	((Adolescen* or Teen* or Youth* or Minor* or Child* or Young pe*).ti. or (Adolescen* or Teen* or Youth* or Minor* or Child* or Young pe*).ab. or Adolescent.sh. or Child.sh.)	(Coprolalia or Copropraxia or Echolalia or Echopraxia or Palilalia or Palipraxia or Premonitory Urge* or Coprophenomena or Echophenomena or Paliphenomena or "Chronic motor or vocal tic Disorder*" or Impuls* or Compulsi* or Obsessive Compulsive Symptom* or Obsessive Behavio?r* or Hyperactiv* or Hyperkine* or Hyper?activ* or Conduct Disorder* or Anti?social behaviour* or Depression or Anxiety or Anxiety Disorder* or Stress or Affective Disorder* or Mood or Well?being or Coping or Distress or Sleep Disturbance* or Involuntary movement*).ti.	(E?health or Internet intervention* or Internet or Online intervention* or Mobile application* or Computer Intervention* or Tablet intervention* or Electronic?Health or Digital?intervention or Digital?health intervention* or Digital?Health or Electronic intervention*).ti or (E?health or Internet intervention* or Internet or Online intervention* or Mobile application* or mobile intervention* or Computer Intervention* or Tablet intervention* or Electronic?Health or Digital?intervention or Digital?health intervention* or Digital?Health or Electronic intervention*).ab or Telemedicine.sh. or Computer assisted instruction.sh. or Therapy, Computer-Assisted.sh. or Medical Informatics Applications.sh. or Computer Systems.sh. or Telephone.sh. or Wireless Technology.sh.	(Self?help or Self?management or Self?care).ti. or (Self?help or Self?management or Self?care).ab. or Self-help groups.sh. or Self-management.sh. or Self-care.sh.

	Population	Condition	Intervention Mode	Intervention Type
OR		(Coprolalia or Copropraxia or Echolalia or Echopraxia or Palilalia or Palipraxia or Premonitory Urge* or Coprophenomena or Echophenomena or Paliphenomena or "Chronic motor or vocal tic Disorder*" or Impuls* or Compulsi* or Obsessive Compulsive Symptom* or Obsessive Behavio?r* or Hyperactiv* or Hyperkine* or Hyper?activ* or Conduct Disorder* or Anti?social behaviour* or Depression or Anxiety or Anxiety Disorder* or Stress or Affective Disorder* or Mood or Well?being or Coping or Distress or Sleep Disturbance* or Involuntary movement*).ab.		

	Population	Condition	Intervention Mode	Intervention Type
OR		Neurodevelopmental Disorders.sh. or Neurocognitive Disorders.sh. or Tic Disorders.sh. or Tics.sh. or Stereotyped behaviour.sh. or Tourette Syndrome.sh. or Obsessive-Compulsive Disorder.sh. or Obsessive Behavior.sh. or Compulsive Personality Disorder.sh. or Neurotic Disorders.sh. or Autistic Disorder.sh. or Autism Spectrum Disorder.sh. or Asperger Syndrome.sh. or Attention deficit disorder with hyperactivity.sh. or Impulsive behaviour.sh. or Substance-related Disorders.sh. or Anxiety.sh. or Anxiety Disorders.sh. or Mood Disorders.sh. or Stress, psychological.sh. or Stress, Physiological.sh. or Mental Disorders.sh. or Affective symptoms.sh. or Depression.sh. or Depressive Disorder.sh. or Affect.sh. or Child Behavior Disorders.sh. or Attitude to health.sh. or Sleep Wake Disorders.sh. or Self-Injurious Behavior.sh. or Fatigue.sh. or Rage.sh.		

	Population	Condition	Intervention Mode	Intervention Type
OR		“Attention deficit and disruptive behavior disorders”.sh.	*NOTE must be added seperately into the search as MESH headings	
OR		“Feeding and Eating Disorders”.sh	*NOTE must be added seperately into the search as MESH headings	
OR		“Quality of life”.sh	*NOTE must be added seperately into the search as MESH headings	
OR			*NOTE must be added seperately into the search as MESH headings	
	AND	**AND**	**AND**	**AND**

Appendix 3- References searched and added to the review

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Appendix 4 - A detailed description of the contents of the interventions included in the systematic review

Title of intervention and authors employing intervention	**Description and contents of the intervention**
SPARX (Fleming et al., 2012; Merry et al., 2012)	A computerised CBT programme consisting of 7 modules in a game-world the user works through. The components of SPARX include CBT, psycho-education, relaxation skills, problem solving, activity scheduling, challenging and replacing negative thinking and social skills. An avatar guide talks about depression, mood and carries out safety checks and signposts the user to further help if they need it. At the start of each level the guide outlines the purpose of that level. The user inhabits a personalised character who must restore balance in the game world, using the skills that they develop against depression to do so. At the end of each level the guide enables the person to reflect on the skills from that level and how that can be applied to real life alongside homework challenges.
The Journey (Stasiak et al., 2014)	The Journey is a fantasy game delivered using a CD-ROM where the user selects an avatar to complete a quest through magical lands. There are 7 magical lands with different topics based on CBT. Prior to starting the topic a mood monitoring and recap of the previous topic are completed, along with a quiz to test that topic. Modules include agenda setting, interactive exercises, animations and videos and terminate with summaries and homework setting. The Journey is accompanied by a guidebook for the user to reflect on the module and to complete further challenges as part of the homework.
MoodGYM (Lillevoll et al., 2014; O'Kearney et al., 2006)	MoodGYM is an online programme with 5 main modules to work through based on CBT. The components of MoodGYM include information, relaxation, problem-solving, dysfunctional thoughts, negative thinking, self-esteem, cognitive restructuring, assertiveness and coping with relationships. MoodGYM is self-paced which allows the user to return to the module at the point they finished previously.
Mobiletype (Kauer et al., 2012; Reid et al., 2011)	Mobiletype (Mobile Tracking of Young People's Experiences) is a self-monitoring program used as an initial pathway to care. Mobiletype asks young people to monitor their mood, stress and daily activities on a mobile application four times a day. This information is accessible to both the young person and their GP to help GPs better understand the young person's mental health and to detect signs of depressive symptomatology and other mental health problems so that interventions can be implemented if needed. The activities that Mobiletype tracks include: current activities, location, companions, mood, recent stressful events, responses to stressful events, alcohol use, cannabis use, quality and quantity of sleep, quantity and type of exercise and diet.
Blogging (Boniel-Nissim & Barak, 2013)	Short for weblog, a blog is often written and saved onto a website and stored on a user's personal web space area. A blog can be of any nature ranging from hobbies, to professional to personal interests. As an intervention, blogging was required to be completed twice a week, with participants spending at least 20 minutes per blog and

	writing at least 200 words for each blog. Blogs may be visible to the public or closed, where open blogs can be commented on by other people, acting as a social aspect to a blog.
Cognitive Bias Modification Training (Sportel et al., 2013)	Cognitive Bias Modification Training consists of 20 sessions delivered through the internet and reminders that are delivered via email. The reasoning of these sessions are explained to participants before starting them. The components consist of 9 sessions of interpretive bias tasks and 8 sessions of attention bias tasks which both aims to modify negative interpretations and 3 further sessions to strengthen the association between social-evaluative situations and positive outcomes including word sorting and enhancing self-esteem.

Appendix 5 – Familiarisation Video Script

Hello…[name]

Thank you so much for taking part in this research, I'm just going to explain the process of the research we're going to do be doing to allow you some time to think of any questions you may have. This may also give you a chance to think about what you'd like to talk to me about on the day of our chat and also if you're not really keen on taking part any more, then you have a chance to let me know that you'd like to stop getting involved now. I'm really excited to hear what you have to say and think your views are really important and this is going to make a big difference to the research I am doing.

During the chat, there will be three 3 areas I will ask you about, but if you feel uncomfortable at any time then I really want you to let me know. This can include not wanting to talk about something personal to you, or if your tics are getting bad and you want a break. We can skip questions, talk about something else or stop the chat at any point. When we have that conversation, before I ask you any questions we will work out the best way for you to let me know that you may need a break or would lie to stop.

So, the first of the three areas will be around your day-to-day life and what it's like for you if you're having a good day, like feeling happy and sociable, or a bad day, such as feeling stressed or worried. I'll ask you how often you feel good or bad, what leads you toward or away from these feelings and how you feel about feeling this way. The second part of the conversation will be around what you do when you're feeling bad to feel better, or what you do that helps you to feel and stay feeling good. Lastly, I'm going to ask you some questions on what sort of technology you've used to help you when it comes to how you're feeling, whether this is talking to people, looking up some things or maybe you have an app or program/ website that you use. I'd like to know what sort of things you use and how it makes you feel or why it makes you feel better, or worse. It would also be good to hear ways you could use technology to help you day-to-day - especially things that would help you feel better in yourself and your mood, and how that would improve your day-to-day life, particularly around the good days/ bad days you described to me earlier.

There are no right or wrong answers, the right answers really are your opinions and experiences! It is whatever you think it is. I'm hoping that by understanding what leads you to have better days rather than bad days, and what is important to you, we can create a tool, like an app or website, that can be used by young people like yourself, based on what you think is important.

After we've finished our chat, I just have a few more questions to ask you about your tics. There will be a few other questions that I will send you to complete online in your own time.

So now, you should know what sort of thing to expect when we talk, and the kind of questions you will be asked during the conversation. If you have any questions, I hope that you know that you can get in touch with me to talk about those and if you have decided that you don't want to take part any more, that's more than fine and please just let me know, you don't need to explain why.

I'm really looking forward to talking to you on [date] via [mode] at [time]. Bye and speak soon!

Appendix 6 – RCADS-SR

Revised Child Anxiety and Depression Scale – To be completed online by the child after interview/ focus group

Your name
Date

Please put a circle around the word that shows how often each of these things happens to you.
There are no right or wrong answers.

1	I worry about things	Never	Sometimes	Often	Always
2	I feel sad or empty	Never	Sometimes	Often	Always
3	When I have a problem, I get a funny feeling in my stomach	Never	Sometimes	Often	Always
4	I worry when I think I have done poorly at something	Never	Sometimes	Often	Always
5	I would feel afraid of being on my own at home	Never	Sometimes	Often	Always
6	Nothing is much fun anymore	Never	Sometimes	Often	Always
7	I feel scared when I have to take a test	Never	Sometimes	Often	Always
8	I feel worried when I think someone is angry with me	Never	Sometimes	Often	Always
9	I worry about being away from my parent	Never	Sometimes	Often	Always
10	I am bothered by bad or silly thoughts or pictures in my mind	Never	Sometimes	Often	Always
11	I have trouble sleeping	Never	Sometimes	Often	Always
12	I worry that I will do badly at my school work	Never	Sometimes	Often	Always
13	I worry that something awful will happen to someone in my family	Never	Sometimes	Often	Always
14	I suddenly feel as if I can't breathe when there is no reason for this	Never	Sometimes	Often	Always
15	I have problems with my appetite	Never	Sometimes	Often	Always
16	I have to keep checking that I have done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
17	I feel scared if I have to sleep on my own	Never	Sometimes	Often	Always

18	I have trouble going to school in the mornings because I feel nervous or afraid	Never	Sometimes	Often	Always
19	I have no energy for things	Never	Sometimes	Often	Always
20	I worry I might look foolish	Never	Sometimes	Often	Always

Appendix 7 – RCADS-P

Revised Child Anxiety and Depression Scale – To be completed online by the parent after interview/ focus group

Your name & relationship to child
Child's name
Date

Please put a circle around the word that shows how often each of these things happens to your child.
There are no right or wrong answers.

1	My child worries about things	Never	Sometimes	Often	Always
2	My child feels sad or empty	Never	Sometimes	Often	Always
3	When my child has a problem, he/she gets a funny feeling in his/her stomach	Never	Sometimes	Often	Always
4	My child worries when he/she thinks he/she has done poorly at something	Never	Sometimes	Often	Always
5	My child feels afraid of being alone at home	Never	Sometimes	Often	Always
6	Nothing is much fun for my child anymore	Never	Sometimes	Often	Always
7	My child feels scared when taking a test	Never	Sometimes	Often	Always
8	My child worries when he/she thinks someone is angry with him/her	Never	Sometimes	Often	Always
9	My child worries about being away from me	Never	Sometimes	Often	Always
10	My child is bothered by bad or silly thoughts or pictures in his/her mind	Never	Sometimes	Often	Always
11	My child has trouble sleeping	Never	Sometimes	Often	Always
12	My child worries about doing badly at school work	Never	Sometimes	Often	Always
13	My child worries that something awful will happen to someone in the family	Never	Sometimes	Often	Always
14	My child suddenly feels as if he/she can't breathe when there is no reason for this	Never	Sometimes	Often	Always

15	My child has problems with his/her appetite	Never	Sometimes	Often	Always
16	My child has to keep checking that he/she has done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
17	My child feels scared to sleep on his/her own	Never	Sometimes	Often	Always
18	My child has trouble going to school in the mornings because of feeling nervous or afraid	Never	Sometimes	Often	Always
19	My child has no energy for things	Never	Sometimes	Often	Always
20	My child worries about looking foolish	Never	Sometimes	Often	Always

Appendix 8 – TODS-PR

Tic-Related Information – To be completed online by the parent/carer up to two weeks post-interview/focus group

To be completed by parent/carer who gave assent for their child to participate in this study
Tourette’s Disorder Scale (TODS)
Rated by: Parent/Carer
IN THE PAST WEEK, how much has the young person been bothered by the following symptoms?

Not at all A little Moderately Markedly Extremely

1. Irritable
0 1 2 3 4 5 6 7 8 9 10
2. Motor Tics
0 1 2 3 4 5 6 7 8 9 10
3. Argumentative
0 1 2 3 4 5 6 7 8 9 10
4. Sudden Mood Changes
0 1 2 3 4 5 6 7 8 9 10
5. Demands Attention
0 1 2 3 4 5 6 7 8 9 10
6. Hot Temper
0 1 2 3 4 5 6 7 8 9 10
7. Vocal Tics
0 1 2 3 4 5 6 7 8 9 10
8. Obsessions*
0 1 2 3 4 5 6 7 8 9 10
9. Inattention
0 1 2 3 4 5 6 7 8 9 10
10. Loud/talkative
0 1 2 3 4 5 6 7 8 9 10
11. Restless
0 1 2 3 4 5 6 7 8 9 10
12. Compulsions*
0 1 2 3 4 5 6 7 8 9 10
13. Tense, Anxious, Nervous
0 1 2 3 4 5 6 7 8 9 10
14. Depressed or uninterested in most things
0 1 2 3 4 5 6 7 8 9 10
15. Impulsive
0 1 2 3 4 5 6 7 8 9 10

Additional Information

Obsessions*

In the past week, has the young person been bothered by recurrent unwanted thoughts that kept coming into his/her mind that they couldn’t get rid of: like bad thoughts or urges; or nasty pictures? For example, did they think about hurting somebody even though they knew they didn’t want to?Were they afraid they or someone would get hurt because of some little thing they did or didn’t do? Were they afraid that they would do something really shocking? Do they feel that things need to be “just right.”

Note: Do not include simple excessive worries about real life problems. Do not include obsessions directly related to eating disorders, sexual behaviour or acohol or drug abuse because they may derive pleasure the activity and may want to resist only because of its negative consequences.

Compulsions*

In the past week, has the young person performed tasks or certain acts over and over without being able to stop doing it, like checking, counting, touching, washing, or organizing things over and over; or saying or doing something over and over until it feels “just right.”

Appendix 9 - C&A-GTS-QOL

To be taken two weeks post-interview/ focus group

To be the child who consented to participate in this study

1. How old are you? [open response]

If aged 12 or below:
Having a health problem can affect a person's quality of life in many different ways. This questionnaire addresses the issue of how your illness affects your well-being. Please put one cross in the box corresponding to the answer that fits your feelings best.
Note that this list includes many problems that you may never experience.

In the last 4 weeks have you…

NEVER RARELY SOMETIMES OFTEN ALWAYS

1. Been unable to control all your movements?
2. Had difficulty with school or sport activities?
3. Suffered pain or injuries as a result of your tics?
4. Been upset by noises you could not stop making?
5. Been worried about using bad words you did not mean to say?
6. Been worried about making rude gestures you did not mean to make?
7. Had to repeat words over and over?
8. Had to repeat things that other people did or said that you did not mean to do or say?
9. Had to do things over and over again, in a certain way (e.g. checking, touching...)?
10. Experienced unpleasant thoughts or pictures going through your mind?
11. Had difficulty concentrating?
12. Had problems with your memory?
13. Lost or misplaced important things (e.g. books, keys, toys)?
14. Had difficulty finishing your tasks once you started them?
15. Felt generally in poor health?
16. Felt sad?
17. Felt suddenly sad or suddenly happy without an apparent reason?
18. Given up doing something because you thought you could not do it?
19. Felt unhappy?
20. Felt fidgety?
21. Had difficulty controlling your anger?
22. Felt you were not in control of what you were doing?
23. Felt angry, when you did not manage to do something?
24. Felt you needed more help or support from other people?
25. Had difficulty spending time with a friend or friends?
26. Had difficulty going out with other people (e.g. cinema, parties)?
27. Felt lonely or isolated?

Please indicate how satisfied you feel overall with your life at the moment by putting a cross on the line between 0 and 100.
0 10 20 30 40 50 60 70 80 90 100

Extremely dissatisfied Extremely satisfied

Thank you very much for completing this questionnaire!

If aged 13 or above:
Having a health problem can affect a person's quality of life in many different ways. This questionnaire addresses the issue of how your illness affects your well-being. Please put one cross in the box corresponding to the answer that fits your feelings best.
Note that this list includes many problems that you may never experience.

In the last 4 weeks have you…

NEVER RARELY SOMETIMES OFTEN ALWAYS

1. Been unable to control all your movements?
2. Had difficulty with your daily activities or hobbies (e.g. cooking, writing)?
3. Suffered from pain or physical injuries as a result of your tics?
4. Felt troubled by noises you could not stop making?
5. Been worried about using swear words you did not mean to say?
6. Been worried about making embarrassing gestures (e.g. rude gestures)?
7. Had to repeat words over and over?
8. Had to repeat things that other people said or did (e.g. copying people)?
9. Had to repeat actions over and over again, in a certain way (e.g. checking, touching)?
10. Experienced unpleasant thoughts or pictures going through your mind?
11. Had difficulty concentrating?
12. Had problems with your memory?
13. You lost or misplaced important things (e.g. keys, mobile)?
14. Had difficulty finishing your tasks once you have started them?
15. Felt generally in poor health?
16. Felt sad of depressed?
17. Experienced sudden mood changes?
18. Experienced lack of self-confidence?
19. Felt anxious or worried?
20. Felt restless or fidgety?
21. Had difficulty to control your anger?
22. Felt you were not in control of your life?
23. Felt frustrated?
24. Felt you needed more help or support from other people?
25. Had difficulty seeing your friend?
26. Had difficulty taking part in social activities (e.g. going out for a meal or going to the cinema)?
27. Felt on your own or isolated?

Please indicate how satisfied you feel overall with your life at the moment by putting a cross on the line between 0 and 100.
0 10 20 30 40 50 60 70 80 90 100

Extremely dissatisfied Extremely satisfied

Thank you very much for completing this questionnaire!

Appendix 10 – Participant Information (Chapter 4)

Wellbeing in young people with tics: development of a self-management tool

Participant Information for Young People

Division of Psychiatry & Applied Psychology
School of Medicine, Faculty of Medicine & Health Sciences

Researcher: Camilla Babbage	Camilla.Babbage1@nottingham.ac.uk
Supervisor: Georgina Jackson	Georgina.Jackson@nottingham.ac.uk
2nd Supervisor: Elena Nixon	Elena.Nixon@nottingham.ac.uk
Ethics Reference Number:	

Thank you for responding to the recruitment advertisement!
We are inviting you to take part in a research study looking into creating a tool to help make the day-to-day lives of young people with Tourette Syndrome or Tic Disorders feel better! Before you begin, we would like you to understand why the research is being done and what it involves for you.

If you want to take part in the study it is your choice, you do not have to take part or continue the study if you do not want to. If you change your mind or if you don't feel comfortable at any point, you can stop taking part without having to explain, just let us know you want to stop.

This study has 2 parts, so you may only want to complete part 1 or 2, this is fine as well.

If at any point you would like your data to be removed, you must tell me within 24 hours so I can remove your data. Your data will always be kept confidential, and any information from you will not be traceable back to you.

What is the project about?

We're researching the areas of life young people who have Tourette Syndrome (TS) or Tic Disorders would like to manage better, particularly relating to those things that would make the day-to-day lives of young people with TS feel better! Knowing this will help us to understand what sort of things young people with TS may need to help them feel better. This 'thing' will be referred to as a 'tool', which could be something like an app or a website.

Part one of the project aims to understand what young people with tics find is important in their life for making them feel good or not. We want to know if young people like you use any techniques to help you feel good, and if you think these ideas could be incorporated into such a tool.

Part two is looking at the design of such a tool, to get your thoughts on it and any ways we could make it better. This will be with a small group of other young people who also have tics, talking about what parts you like or don't like in such a tool. Your parent will also come along as we want to hear what they think too, but they won't be part of the group work.

Who is being asked to take part, and why?

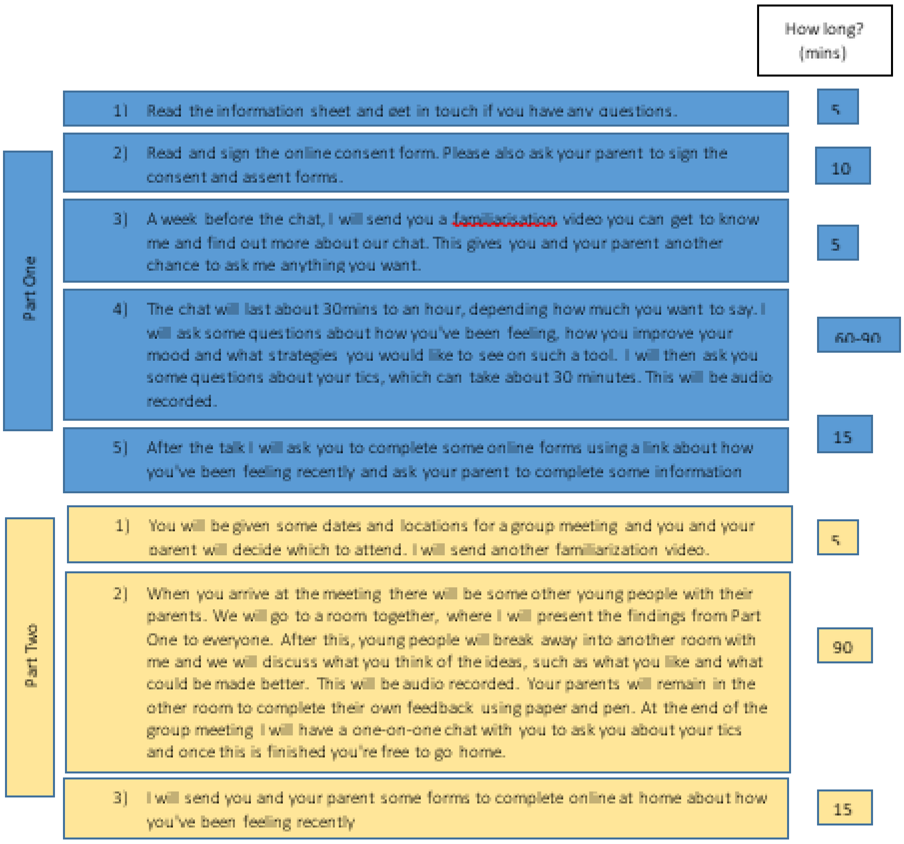
We're asking young people aged 9-17 years old, male or female, who live in the UK and who are diagnosed with Tourette Syndrome or a tic disorder. These young people need to have access to and use technology, such as using apps, accessing the internet or using a tablet. We feel young people with these experiences will have the best knowledge about how such technology could work to make them feel better. We're also asking their parents to take part in this study. Some of you may be signed up to the Tourettes Action Research Participatory Registry and this may also explain why and how you have been contacted.

Will the research be of any personal benefit to me?

It is unlikely that the research will be of any personal benefit to you and we cannot guarantee that the tool we plan to develop will be developed. However, we are hoping this research will help to further understanding of what sort of support young people with TS may need.

Any research findings can be sent on to you and we'd also be keen to involve you in the research along the way!

What will I be asked to do?



Part	Step	How long? (mins)
Part One	1) Read the information sheet and get in touch if you have any questions.	5
	2) Read and sign the online consent form. Please also ask your parent to sign the consent and assent forms.	10
	3) A week before the chat, I will send you a familiarisation video you can get to know me and find out more about our chat. This gives you and your parent another chance to ask me anything you want.	5
	4) The chat will last about 30mins to an hour, depending how much you want to say. I will ask some questions about how you've been feeling, how you improve your mood and what strategies you would like to see on such a tool. I will then ask you some questions about your tics, which can take about 30 minutes. This will be audio recorded.	60-90
	5) After the talk I will ask you to complete some online forms using a link about how you've been feeling recently and ask your parent to complete some information	15
Part Two	1) You will be given some dates and locations for a group meeting and you and your parent will decide which to attend. I will send another familiarization video.	5
	2) When you arrive at the meeting there will be some other young people with their parents. We will go to a room together, where I will present the findings from Part One to everyone. After this, young people will break away into another room with me and we will discuss what you think of the ideas, such as what you like and what could be made better. This will be audio recorded. Your parents will remain in the other room to complete their own feedback using paper and pen. At the end of the group meeting I will have a one-on-one chat with you to ask you about your tics and once this is finished you're free to go home.	90
	3) I will send you and your parent some forms to complete online at home about how you've been feeling recently	15

Any information you give during our chat will not be shared with your parent, and any information your parent gives will not be shared with you. If you are having a face-to-face interview, an adult your parent has nominated will be present and therefore will hear what you say.

A £10 shopping voucher will be given to you for completing Part One as an inconvenience allowance. After completing Part Two, both you and your parent will receive a £15 shopping voucher each as an inconvenience allowance. Any travel expenses will be paid for you and your parent to come to Nottingham (up to £30 per family).

What will happen to the information I provide?

The recorded data will be stored on a coded database on a password-protected computer.

When I write about what you said during the recording, all personal data that identifies you will be removed. If the research gets published, we may use your quotes but these will be confidential and will not identify you. If at any stage you wish to withdraw, all information about you will be removed from analysis but you must let me know within 24 hours after the date of the interview.

We have to follow laws regarding data and this means the University is responsible for the data including looking after your information and using it properly. This can make it difficult to change, move and access your information so we ensure as little as possible personally identifiable information is used.

If you reveal any information that makes me worry about your welfare I must pass this information on to my supervisor who will follow the Children and Vulnerable Adult Protection guidance given by the University.

What will you do with the data?

The findings from this research will be used in my work as part of my doctoral thesis (PhD). If possible, the research may also be published later research papers and results/ blogs may be posted on the Tourettes Action page. We can provide a copy of the papers so that you can read the results.

At the end of the project, all raw data will be kept securely by the University under the terms of the Data Protection Act. The raw data will not be kept elsewhere however anonymized transcripts may be uploaded to a data service program so that other researchers can use the data. This data would not hold any personal information and recordings would not be uploaded to such a site.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the above address.

I want to take part, what do I do now?

That's great! Please press 'Next' and you will be taken to the first set of forms to complete, the consent forms. Make sure your parent is happy for you to take part too as they have to give permission for you to get involved.

I don't want to take part, what do I do now?

That's absolutely fine! You don't need to do anything more unless you want to contact me to hear more about the study. If you have any questions, please email Camilla.Babbage1@nottingham.ac.uk.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

We believe there are no known risks associated with this research study however due to the potential use of video call for the interviews, a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

Services for young people with Tourette Syndrome or Tic Disorder

Service	Who and what is it for?	Contact details
Tourettes Action Helpdesk	The Tourettes Action Helpdesk provides confidential and impartial support to adults and children living with Tourette Syndrome (TS)	https://www.tourettes-action.org.uk/9-helpdesk.html 0300 777 8427 Contact form: https://www.tourettes-action.org.uk/65-contact-us.html https://www.facebook.com/TourettesAction
Base51	A counselling and psychotherapy service for 12-25 year olds experiencing a range of symtoms and diagnoses such as anxiety, depression and personality disorders.	www.base51.org.uk 01159525040 counselling@base51.org.uk
Kooth	Online and face-to-face counselling for children between 10-24 years who are experiencing emotional or mental health difficulties including self-harm, suicide, abuse, anxiety, bullying, stress, depression and low mood, anger, LGBT+, family relationships, relationships and bereavement.	Info@xenzone.com 07715906131 www.KOOTH.com
Childline	A service for children to call about anything via phone, online chat and email.	0800 1111 www.childline.org.uk
TouretteCanada Forum	A community bulletin board or forum for support, share ideas and a variety of	https://www.tourettesyndrome.ca/

	other topics for anyone who wants to talk about Tourette Syndrome.	

Appendix 11 – Parent Information (Chapter 4)

Wellbeing in young people with tics: development of a self-management tool

Participant Information for Parents

Division of Psychiatry & Applied Psychology
School of Medicine, Faculty of Medicine & Health Sciences

Researcher: Camilla Babbage	Camilla.Babbage1@nottingham.ac.uk
Supervisor: Georgina Jackson	Georgina.Jackson@nottingham.ac.uk
2nd Supervisor: Elena Nixon	Elena.Nixon@nottingham.ac.uk
Ethics Reference Number:	

Thank you for responding to the recruitment advertisement!
We are inviting you and your child to take part in a research study looking at how wellbeing in young people with Tourette Syndrome or a Tic Disorder can be improved.

If you want to take part in the study it is completely yours and your child's choice, you do not have to take part or continue the study if you do not want to. **If only one of you would like to take part or take part in one section only, that is completely fine!** We do not expect you to give reasons for why you do not want to take part.

If at any point you would like yours or your child's data to be removed, you must tell me within 24 hours so I can remove your data. All data will always be kept confidential, and any information from you will not be traceable back to either of you.

What is the project about?

We're researching the areas of life young people who have Tourette Syndrome (TS) or Tic Disorders would like to manage better, particularly relating to how they feel, also referred to as their wellbeing. This sort of understanding will help to identify what may be needed to help young people with TS for their wellbeing, such as an app or a website which we will refer to as a 'tool'.

Part one of the project aims to understand what is important to young people for their wellbeing, what affects wellbeing and to find out if there are any techniques to improve wellbeing that could be incorporated into such a tool. This will be understood through individual interviews with your child.

Part two is looking at the design of such a tool, to get both your thoughts and any ways we could make it better. For the young person, this will be a discussion within a group of other young people. For the parents this will be with other parents and will involve completing a feedback form during the group discussion.

Who is being asked to take part, and why?

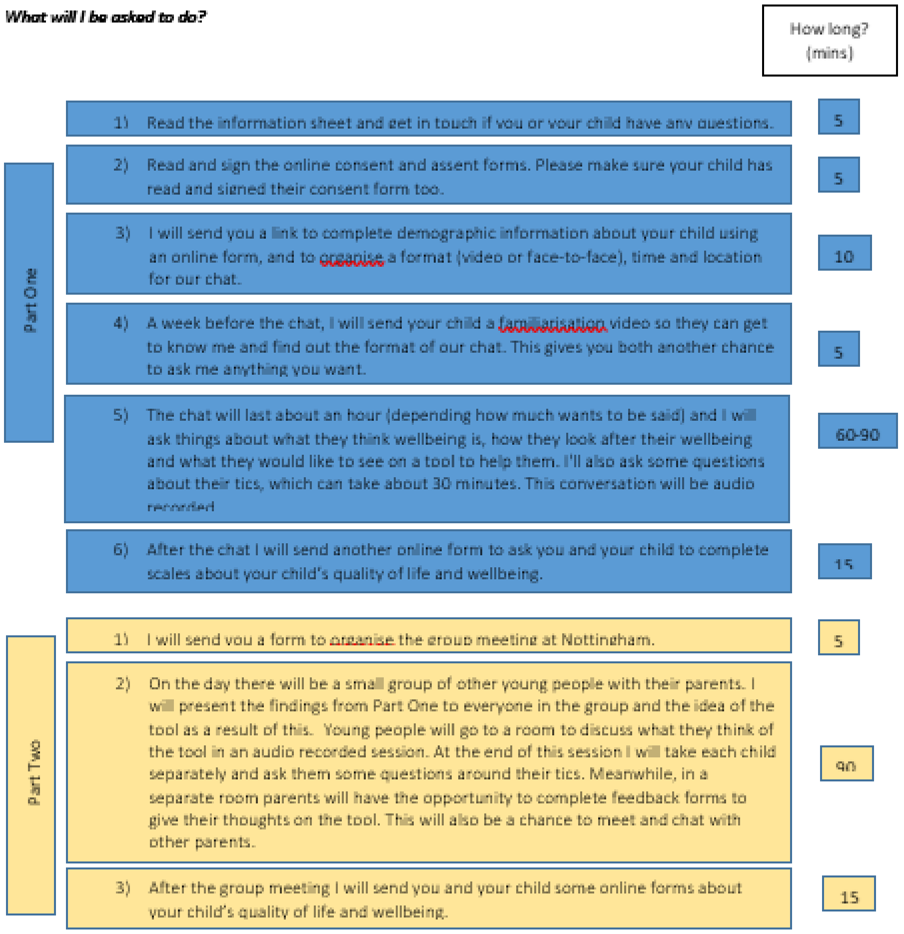
We're asking young people aged 9-17 years old, male or female, who live in the UK and who are diagnosed with Tourette Syndrome or a tic disorder. These young people need to have access to and use technology, such as using apps, accessing the internet or using a tablet. We're also asking their parents to take part in this study. In particular, we want to know what young people feel would be beneficial for their wellbeing and how this could be implemented into such a tool. If you would like to see the format of these studies, please just let me know and I can send them through to you before signing up to take part. You may have been contacted because you are signed up to the Tourettes Action Research Participatory Registry.

Will the research be of any personal benefit to us?

It is unlikely that the research will be of any personal benefit to you or your child and we cannot guarantee that the tool we plan to develop will be developed. However, we are hoping this research will help to further understanding of what sort of support young people with TS may need.

Any research findings can be sent on to you and we'd also be keen to involve you in the research along the way!

What will I be asked to do?



What will I be asked to do?

		How long? (mins)
Part One	1) Read the information sheet and get in touch if you or your child have any questions.	5
	2) Read and sign the online consent and assent forms. Please make sure your child has read and signed their consent form too.	5
	3) I will send you a link to complete demographic information about your child using an online form, and to organise a format (video or face-to-face), time and location for our chat.	10
	4) A week before the chat, I will send your child a familiarisation video so they can get to know me and find out the format of our chat. This gives you both another chance to ask me anything you want.	5
	5) The chat will last about an hour (depending how much wants to be said) and I will ask things about what they think wellbeing is, how they look after their wellbeing and what they would like to see on a tool to help them. I'll also ask some questions about their tics, which can take about 30 minutes. This conversation will be audio recorded	60-90
	6) After the chat I will send another online form to ask you and your child to complete scales about your child's quality of life and wellbeing.	15
Part Two	1) I will send you a form to organise the group meeting at Nottingham.	5
	2) On the day there will be a small group of other young people with their parents. I will present the findings from Part One to everyone in the group and the idea of the tool as a result of this. Young people will go to a room to discuss what they think of the tool in an audio recorded session. At the end of this session I will take each child separately and ask them some questions around their tics. Meanwhile, in a separate room parents will have the opportunity to complete feedback forms to give their thoughts on the tool. This will also be a chance to meet and chat with other parents.	90
	3) After the group meeting I will send you and your child some online forms about your child's quality of life and wellbeing.	15

Please note, the information you give will not be shared with your child, and the information given by your child will not be shared with you.

A £10 shopping voucher will be given to your child for completing Part One as an inconvenience allowance. After completing Part Two, both you and your child will receive a £15 shopping voucher each as an inconvenience allowance. Any travel expenses will be paid for you and your child to come to Nottingham (up to £30 per family).

What will happen to the information I provide?

The recorded data will be stored on a coded database on a password-protected computer. When I write up any data all identifiable data will be removed so it becomes anonymous. If the research gets published, we may use quotes from you, but these will be completely confidential and will not identify either of you in any way. If at any stage you or your child wish to withdraw, all information will be removed from analysis but you must let me know within 24 hours after the date of the interview.

We follow ethical and legal practice regarding data, and under UK Data Protection laws the University is legally responsible for the data security including looking after your information and using it properly. This means accessing, changing or moving your information is limited as we must comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more here: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you or child reveal any information that makes me worry about your child's welfare I must pass this information on to my supervisor who will follow the Children and Vulnerable Adult Protection guidance given by the University of Nottingham.

What will you do with the data?

The findings from this research will be used in my work as part of my doctoral thesis (PhD). If possible, the research may also be published later research papers and results/ blogs may be posted on the Tourettes Action page. We can provide a copy of the papers so that you can read the results.

At the end of the project, all raw data will be kept securely by the University under the terms of the Data Protection Act. The raw data will not be kept elsewhere however anonymized transcripts may be uploaded to a data service program so that other researchers can use the data. This data would not hold any personal information and recordings would not be uploaded to such a site.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the above address.

I want to take part, what do I do now?

That's great! Please press 'Next' and you will be taken to the first set of forms to complete, the consent forms. Once completed this will take you to the assent form and the participant demographic and details forms. You can complete these all now, or return and complete them later.

My child wants to take part, but I don't. What do I do now?

That's absolutely fine. Your child can take part in Part One without your involvement, as long as you are happy for them to get involved. Please complete this link to sign the assent forms (https://nottingham.onlinesurveys.ac.uk/parent-assent-part-one-and-two) and ask your child to sign their consent form (https://nottingham.onlinesurveys.ac.uk/young-persons-consent-part-one-and-two).

I don't want to take part, what do I do now?

That's absolutely fine! You don't need to do anything more unless you want to contact me to hear more about the study. If you have any questions, please email Camilla.Babbage1@nottingham.ac.uk.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

We believe there are no known risks associated with this research study however due to the potential use of video call for the interviews, a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

Services for young people with Tourette Syndrome or Tic Disorder

Service	Who and what is it for?	Contact details
Tourettes Action Helpdesk	The Tourettes Action Helpdesk provides confidential and impartial support to adults and children living with Tourette Syndrome (TS)	https://www.tourettes-action.org.uk/9-helpdesk.html 0300 777 8427 Contact form: https://www.tourettes-action.org.uk/65-contact-us.html https://www.facebook.com/TourettesAction
Base51	A counselling and psychotherapy service for 12-25 year olds experiencing a range of symtoms and diagnoses such as anxiety, depression and personality disorders.	www.base51.org.uk 01159525040 counselling@base51.org.uk

Kooth	Online and face-to-face counselling for children between 10-24 years who are experiencing emotional or mental health difficulties including self-harm, suicide, abuse, anxiety, bullying, stress, depression and low mood, anger, LGBT+, family relationships, relationships and bereavement.	Foxhall Lodge Foxhall Road Nottingham NG7 6LH Info@xenzone.com 07715906131 www.KOOTH.com
Childline	A service for children to call about anything via phone, online chat and email.	0800 1111 www.childline.org.uk
TouretteCanada Forum	A community bulletin board or forum for support, share ideas and a variety of other topics for anyone who wants to talk about Tourette Syndrome.	https://www.tourettesyndrome.ca/

Appendix 12 – YGTSS

YGTSS – To be completed with researcher immediately post-interview or focus group

Name of Child:
Rater:

1. Motor Tic Symptom Checklist

Age of first motor tic:
Describe **first** motor tic:
Was tic onset sudden or gradual?
Age of **worst** motor tics?

*In the boxes on the left below, please check with a mark (**x**) the tics the patient*
*1) has **EVER** experienced*
*2) is **CURRENTLY** experiencing (during the past week)*
*State **AGE OF ONSET** (in years) if patient has had that behavior.*
*Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).*

The patient has experienced, or others have noticed, involuntary and apparently purposeless bouts of:

- **eye movements**.

eye blinking, squinting, a quick turning of the eyes, rolling of the eyes to one side, or opening eyes wide very briefly. eye gestures such as looking surprised or quizzical, or looking to one
side for a brief period of time, as if s/he heard a noise.

- **nose, mouth, tongue movements, or facial grimacing**.

nose twitching, biting the tongue, chewing on the lip or licking the lip, lip pouting, teeth baring, or teeth grinding. broadening the nostrils as if smelling something, smiling, or other gestures involving the mouth, holding funny expressions, or sticking out the tongue.

- **head jerks/movements**.

touching the shoulder with the chin or lifting the chin up. throwing the head back, as if to get hair out of the eyes.

- **shoulder jerks/movements**.

jerking a shoulder. shrugging the shoulder as if to say "I don't know."

- **arm or hand movements**.

quickly flexing the arms or extending them, nail biting, poking with fingers, or popping knuckles.
passing hand through the hair in a combing like fashion, or touching objects or others, pinching, or counting with fingers for no purpose, or writing tics, such as writing over and over the same letter or word, or pulling back on the pencil while writing.

- **leg, foot or toe movements**.

kicking, skipping, knee-bending, flexing or extension of the ankles; shaking, stomping or tapping the foot. taking a step forward and two steps backward, squatting, or deep knee-bending.

- **abdominal/trunk/pelvis movements**.

tensing the abdomen, tensing the buttocks.

- **other simple motor tics.**

Please write example(s):
[open respose]

- **other complex motor tics**.

touching
tapping
picking
evening-up
reckless behaviors
stimulus-dependent tics (a tic which follows, for example, hearing a particular word or phrase, seeing a specific object, smelling a particular odor).

Please write example(s):
[open respose]

rude/obscene gestures; obscene finger/hand gestures.
unusual postures.
bending or gyrating, such as bending over.
rotating or spinning on one foot.
copying the action of another (echopraxia)
sudden tic-like impulsive behaviors.

Please describe:
[open respose]

tic-like behaviors that could injure/mutilate others.
Please describe:
[open respose]
self-injurious tic-like behavior(s).

Please describe:
[open respose]

- **other involuntary and apparently purposeless motor tics** (that do not fit in

any previous categories).

Please describe any other patterns or sequences of motor tic behaviors:
[open respose]

2. Phonic Tic Symptom Checklist

Age of first phonic tic:
Describe **first phonic** tic:
Was tic onset sudden or gradual?
Age of **worst phonic** tics?

*In the boxes on the left below, please check with a mark (**x**) the tics the patient*
*1) has **EVER** experienced*
*2) is **CURRENTLY** experiencing (during the past week)*
*State **AGE OF ONSET** (in years) if patient has had that behavior.*
*Also, in the tic descriptions below, please **circle** or **underline** the specific tics that the patient has experienced (circle or underline the words that apply).*

The patient has experienced, or others have noticed, bouts of involuntary and apparently purposeless utterance of:

- **coughing.**
- **throat clearing.**
- **sniffing.**
- **whistling.**
- **animal or bird noises.**
- **Other simple phonic tics**.

  Please list:
  [open response]
- **syllables**.

  Please list:
  [open response]
- -**words**.

  Please list:
  [open response]
- **rude or obscene words or phrases**.

  Please list:

[open response]

- **repeating what someone else said**, either sounds, single words or sentences. Perhaps repeating what's said on TV (echolalia).
- **repeating something the patient said** over and over again (palilalia).
- -**other tic-like speech problems**, such as sudden changes in volume or pitch.

  Please describe:
  [open response]
- Describe any other patterns or sequences of phonic tic behaviors:

  [open response]

3. SEVERITY RATINGS

Number

	Motor	Phonic
None		
Single tic		

Multiple discrete tics (2-5)		
Multiple discrete tics (>5)		
Multiple discrete tics plus as least one orchestrated pattern of multiple simultaneous or sequential tics where it is difficult to distinguish discrete tics		
Multiple discrete tics plus several (>2) orchestrated paroxysms of multiple simultaneous or sequential tics that where it is difficult to distinguish discrete tics		

Frequency

	Motor	Phonic
None No evidence of specific tic behaviors		
RARELY Specific tic behaviors have been present during previous week. These behaviors occur infrequently, often not on a daily basis. If bouts of tics occur, they are brief and uncommon.		
OCCASIONALLY Specific tic behaviors are usually present on a daily basis, but there are long tic-free intervals during the day. Bouts of tics may occur on occasion and are not sustained for more than a few minutes at a time.		
FREQUENTLY Specific tic behaviors are present on a daily basis. tic free intervals as long as 3 hours are not uncommon. Bouts of tics occur regularly but may be limited to a single setting.		
ALMOST ALWAYS Specific tic behaviors are present virtually every waking hour of every day, and periods of sustained tic behaviors occur regularly. Bouts of tics are common and are not limited to a single setting.		
ALWAYS Specific tic behaviors are present virtually all the time. Tic free intervals are difficult to identify and do not last more than 5 to 10 minutes at most.		

Intensity

	Motor	Phonic
ABSENT		
MINIMAL INTENSITY Tics not visible or audible (based solely on patient's private experience) or tics are less forceful than comparable voluntary actions and are typically not noticed because of their intensity.		
MODERATE INTENSITY Tics are more forceful than comparable voluntary actions but are not outside the range of normal expression for comparable voluntary actions or utterances. They may call attention to the individual because of their forceful character.		
MARKED INTENSITY Tics are more forceful than comparable voluntary actions or utterances and typically have an "exaggerated" character. Such tics frequently call attention to the individual because of their forceful and exaggerated character.		
SEVERE INTENSITY Tics are extremely forceful and exaggerated in expression. These tics call attention to the individual and may result in risk of physical injury (accidental, provoked, or self-inflicted) because of their forceful expression..		

Complexity

	Motor	Phonic

NONE If present, all tics are clearly "simple" (sudden, brief, purposeless) in character		
BORDERLINE Some tics are not clearly "simple" in character.		
MILD Some tics are clearly "complex" (purposive in appearance) and mimic brief "automatic" behaviors, such as grooming, syllables, or brief meaningful utterances such as "ah huh," "hi" that could be readily camouflaged..		
MODERATE Some tics are more "complex" (more purposive and sustained in appearance) and may occur in orchestrated bouts that would be difficult to camouflage but could be rationalized or "explained" as normal behavior or speech (picking, tapping, saying "you bet" or "honey", brief echolalia)..		
MARKED Some tics are very "complex" in character and tend to occur in sustained orchestrated bouts that would be difficult to camouflage and could not be easily rationalized as normal behavior or speech because of their duration and/or their unusual, inappropriate, bizarre or obscene character (a lengthy facial contortion, touching genitals, echolalia, speech atypicalities, longer bouts of saying "what do you mean" repeatedly, or saying "fu" or "sh").		
SEVERE Some tics involve lengthy bouts of orchestrated behavior or speech that would be impossible to camouflage or successfully rationalize as normal because of their duration and/or extremely unusual, inappropriate, bizarre or obscene character (lengthy displays or utterances often involving copropraxia, self-abusive behavior, or coprolalia).		

Interference

	Motor	Phonic
NONE		
MINIMAL When tics are present, they do not interrupt the flow of behavior or speech.		
MILD When tics are present, they occasionally interrupt the flow of behavior or speech.		
MODERATE When tics are present, they frequently interrupt the flow of behavior or speech.		
MARKED When tics are present, they frequently interrupt the flow of behavior or speech, and they occasionally disrupt intended action or communication.		
SEVERE When tics are present, they frequently disrupt intended action or communication.		

Impairment

	Motor	Phonic
NONE		
MINIMAL Tics associated with subtle difficulties in self-esteem, family life, social acceptance, or school or job functioning (infrequent upset or concern about tics vis a vis the future, periodic, slight increase in family tensions because of tics, friends or acquaintances may occasionally notice or comment about tics in an upsetting way).		
MILD Tics associated with minor difficulties in self-esteem, family life, social acceptance, or school or job functioning.		
MODERATE Tics associated with some clear problems in self-esteem family life, social acceptance, or school or job functioning (episodes of dysphoria,		

periodic distress and upheaval in the family, frequent teasing by peers or episodic social avoidance, periodic interference in school or job performance because of tics)..		
MARKED Tics associated with major difficulties in self-esteem, family life, social acceptance, or school or job functioning.		
SEVERE Tics associated with extreme difficulties in self-esteem, family life, social acceptance, or school or job functioning (severe depression with suicidal ideation, disruption of the family (separation/divorce, residential placement), disruption of social tics - severely restricted life because of social stigma and social avoidance, removal from school or loss of job).		

Appendix 13 - Interview guide for interviews with YP (Chapter 4)

Consent to record
Withdraw
Parents
Thank you

Understanding mood	**Good Days/ Ups**		**Bad Days/ Downs**
		Feelings - how do you feel? Examples (recent examples of ups/downs) What led you to feeling this way? What do you think you did/ was happening that made you feel that way?	
Relationship to tics		Good days with lots of tics? Times when tics are managed well? Examples (Days (birthdays) Times (holidays))	
Control over how they feel and tics		Feel able to have a good day regardless of tics? How easy do find it is to do these things to help yourself feel better?	
	What about your behaviour makes you feel better?		What about the tic can stop you feeling good?
Actions/ strategies to feel better	**Mood OR Stress**		**Tics**
		Strategies that make you feel better? What do you do? (e.g. hobbies, family, friends, social)	
	Can changing your mood/ behaviour to help how you feel? Examples	What is it that makes you feel better? How does it change how you're feeling?	Do your tics have to change to make you feel better? Examples
		How does it make you feel differently? Do other people suggest any techniques/ strategies to help you feel better? What are they, do they work?	
We want to know what helps you feel good to help us make a technology tool, like an app or website that can be used by young people like yourself			
Technology helpful?		What technology do you use, that you think impacts on how you feel? Would you use technology for how you were feeling? Would you use technology designed for people with TS? Would it be open to other people?	
	Mood	What would be helpful for you?	**Tics**
		What would be important to make you feel better on a bad day? What functions would be useful to you on a tool? (e.g. learning, mood monitoring, activities, socialising)	
YALE - Parents want to rejoin? Online forms - voucher *Quote and Picture about being involved in research!*	Can do at a later point		

Appendix 14 – Ethics Approval Letter (Ref: 043)

University of
Nottingham
UK | CHINA | MALAYSIA

DPAP Committee

29/10/2018

Supervisor: Georgina Jackson

Applicant: Camilla Babbage

Project: Project Id Wellbeing in young people with Tourette Syndrome: development of a self-management tool

A favourable opinion is given to the above-named study on the understanding that the applicants conduct their research as described in the above-numbered application. Applicants need to adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved. If any amendments to the study are required, an amendment should be submitted to the committee for approval. An end of study form will be required once the study is complete.

As a reflective point, if re-submitting an application in future, can you upload a summary of where changes have been made (e.g., point by point response to reviewers comments). This would greatly help with the re-review process.

Yours

David Daley

Professor David Daley

Co-Chair of DPAP Ethics Subcommittee

Amanda Griffiths

Professor Amanda Griffiths

Co-Chair of DPAP Ethics Subcommittee

Appendix 15 – Interview guide (Chapter 5)

We're interested in young people with TS specifically, preferably around the moderate-severe severity cases.
The purpose of this talk is to gain an idea from experts about what strategies or activities (e.g. psychoeducation, mood monitoring, hobbies) could be implemented onto a technology resource, such as an app or a website, for the daily self-management of mood for young people with Tourette Syndrome. It is not an online therapy for tics, but for the more general wellbeing of that young person.

Interview Guide TS Professional

Gain general background of profession

1) Would you be able to describe what you perceive wellbeing to be in young people?
   What would your end-goal be?

Case Studies? More severe cases?		
Socially	*Academically*	*Relationships*

2) Do you have experience with young people with TS who are managing well/ day-to-day?
   How do they manage well?
   What do they do to manage well?
   What about these children helps?

Case Studies? More severe cases?		
Socially	*Academically*	*Relationships*

3) Does having a co-occurring conditions/ comorbidity mean you have to deal with TS differently/ separately?
   What role do co-occurring conditions play?

4) In practice, do you find there are any useful self-help strategies/ techniques/ activities that you suggest to improve wellbeing/ mental health management in young people with TS?
   What sort of strategies are these?
   Do you think they could be completed through technology?
   What role do comorbidities play in this?

Case Studies? More severe cases?	*Strategies/ techniques*	*Activities*
Aim	*Delivery mode*	

5) Where would you signpost young people with TS to if they were having difficulties in managing their wellbeing?
   Is any of this digital/ technological? Self-help?
   What is the aim of this signposting support? Where do young people with TS go to get support?

Aim	*Delivery mode*	

6) Would you see such a tool aiding you in your role and supporting young people with TS?

   How would you feel about signposting a young person with TS to a self-help tool such as an app for their wellbeing?
   How would you, or other clinicians feel about this?
   What functions would be necessary on such a tool?

Appendix 16 – Codebook example during theming (Chapter 4)

RQ1 - Understanding Mental States	**Mental states are about the feelings associated, with and the causes. The impact those feelings had wasn't really explored by young people and so wasn't included in 'understanding' although this may be a part of understanding**	
T1 - Young people understand general negative mood in terms of feelings and causes	Negative mood could include: Low Mood, Negative mood, Bad Days, Down, Lonely, Tired, Grumpy	
T1a - School is a major factor that leads to "bad days"	Bad days' taken as this is how young people describe it	Negative - when the YP talks about overcoming a negative mood
T1b - Tiredness is a determinant of negative mood		
T2 - Young people feel a good day enables them to engage in activities they enjoy	Good, Happy, Good Days, Not bad	
T2a - Being energetic and not tired makes young people feel happy		
T2b - When in a positive mood young people engage in mood congruent activities such as arts and crafts	Mood congruent means activities YP feel match their mood	Positive - when the person talks about what they do that makes them/ keeps them happy or content, not if they are in a bad mood trying to get to a good mood (this would be under negative)
T3 - Having a difficult school day is understood to be a cause of stress	(purposefully not included 'cause' in overall Theme as young people do not give much time to the cause of stressors or relaxers)	
T3a - Peers within the school context constitute a source of stress	Peers, they are people at school.	
	Opposite of stress is: Calm, Relaxed, Chilled	
T4 - Anxiety is experienced physiologically and psychologically in the anticipation of negative situations	Anxiety is: Worry, Anxiety-related - Obsessive, Paranoid, Excesssive worry	
T5 - Anger is both understood in how it feels and what causes it	Irritation, Frustration, Competitive, Annoyed	

T5a - Anger is experienced as annoyance or irritations		
T5b - Losing in competitive games can be a cause of anger		
T6 - Tics disturb sleep leading to tiredness	Tiredness is a determinant of mood - see T1	
RQ2 - Managing Mental States	Always coded when the person talks about a strategy that they currently use or have used. For strategies that they think would be useful on the app, this goes to features of the app, but if you ask them about a feature of the app and they tell you a strategy they use to helpthemselves now, that goes to managing unless you are referring back to something you spoke about earlier and it's applicability to the app. The mood e.g. stress over relaxing is chosen when the YP refers to that in the question or answer. The YP does not have to be aware that the strategy they are using is beneficial for their emotional state, only that they are using a strategy/ doing something and are able to talk about how it affects their mood when prompted/ retrospectively etc.	
T7 - Interaction with others helps deal with bad days	Actively used as an interaction	
T8 - Videos, films and music is a way of relaxing when having a bad day or to improve negative mood in general	General mood - spreads over the whole day, specific moods -more time specific. Placed in relaxing if YP suggests they listen to music to clam down/ chill out/ in the background. More upbeat dancy music might go in the engaging section rather than relax section if this hasn't been made explicit. For example, if listening to music and lying down, walking/ not doing much this is relaxing. If listening to music and singing, dancing, this is engaging.	

T9 - Engaging in Games and Music helps relieve negative mood	Always in engaging when the pts talked about playing the instrument as this is assumed to be engaging. If in background, it's not really engaging, but it in foreground it is active and therefore engaging.	If YP talks about dancing/ singing and listening to music, assumed to be engaging. Sometimes this requires scanning further back in the text to work out what their music listening to relates to
	Originally had a subtheme coded as T3b - Music is a facilitator of positive mood , but this suggests there is no change in mood so now goes under negative mood only where it is coded as a change from negative to positive mood	
T10 - Having a support network helps maintain positive mood	Support network, not interaction strategy, as the young person is passive in the support they receive	
T11 - Engaging strategies help relieve stress	Engaging is whenever it completely distracts or requires attention	
T11a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress		
T11b - Engaging with des-stressing activities reduces physiological symptoms associated with stress		
T12 - Pastimes maintain a soothing state	If little is said then assume the simplest explanation	
T12a - Passively listening to sounds and watching videos sustains a calm and relaxed mood		
T12b - Actively engaging with arts and games fosters a calm and relaxed mood		

T13 - Young people use strategies to avoid anticipated anxiety	Anxiety is long term mood, and so these yp can predict and plan what to do in these situations to make them feel better. Young people with anxiety and comorbidities are the ones who have been quoted here, may be worth bearing this in mind. Avoidance is where someone else deals with it for them or they remove themselves from it, stop thinking about it rather than dealing with it	
T13a - Being accompanied reduces anxiety	Being accompanied reduces anxiety in anxieyy-provoking situations	
T13b - When possible young people add comforts to their anxious contexts, otherwise they remove themselves from it	Comforts include people, dogs, stars etc	
T14 - When experiencing anger young people engage in activities which shift their focus		
T15 - Engaging in relaxing activities to facilitate sleep helps avoid negative mood caused by sleep	To increase energy levels/ when feeling tired	
RQ3 - Features Desired for Tool	Any time someone talked about a feature they desired to be part of the app, but wasn't a management strategy they were currently using, unless they had already spoken about this and it had been coded under management strategies earlier	
T16 - There is a need for psychoeducation derived from interacting with others' lived experience of Tourettes		
T16a - Interaction with others enables learning more about Tourette Syndrome		
T16b - Normalisation of experience is gained through sharing		
T17 - Being able to select music, sounds and games will help young people to be calm		
T18 - Need for a function that acts as a reminder for the day's activities	Not to plan, but to remind them of what has already been planned	

RQ4 - Mental states and tics	When young people talk about moods and tics, this goes to managing tics. Mental states to include tiredness/ relaxed etc	
T19 - Anticipation or experience of tics is associated with negative mental states		
T19a - Excessive tics make it a bad day		
T19b - Minimal tics are associated with a calm or relaxed state		
T19c - Anticipation of tics causes anxiety		
T19d - Ticcing, or anticipating tics is associated with stress	Includes suppressing tics, urge to tic, ticcing	
RQ5 - Strategies and tics	Any time someone talked about a feature they desired to be part of the app, but wasn't a management strategy they were currently using, unless they had already spoken about this and it had been coded under management strategies earlier, it was coded here	
T20 - Engaging in pastimes can increase an awareness of a reduction in, or shift focus away from tics	Yp didn't say that pastimes increased tics, it was always a decrease or reduced bothered by. Pastimes can be active or passive, knowing how engaged the yp is is hard to guess. A focus away from is the suggestion that they are not monitoring their tics, it could be concentration toward or away from tics, or physical movements that do this.	
T21 - A 'tic-friendly' environment provides a private space for the free expression of tics	Away from people who judge, environments where you are allowed to tic/ do not have to suppress	
T22 - Physical Activity is a distraction from tic monitoring	Physical activity includes school sport, walking, hobbies etc. Monitoring is the self-consciousness of tics. Physical activity overides all, so if they say they do the activity and it makes them feel relaxed, still goes under physical activity	

Appendix 17 – Participant Information (Chapter 5)

Wellbeing in young people with tics: Development of a self-management tool

Participant Information for Professionals

Division of Psychiatry & Applied Psychology
School of Medicine, Faculty of Medicine & Health Sciences

Researcher: Camilla Babbage Camilla.Babbage1@nottingham.ac.uk
Supervisor: Georgina Jackson Georgina.Jackson@nottingham.ac.uk
2nd Supervisor: Elena Nixon Elena.Nixon@nottingham.ac.uk
Ethics Reference Number:

Thank you for responding to the recruitment advertisement.
We are inviting you to take part in a research study looking at how wellbeing in young people with Tourette Syndrome or a Tic Disorder can be improved.

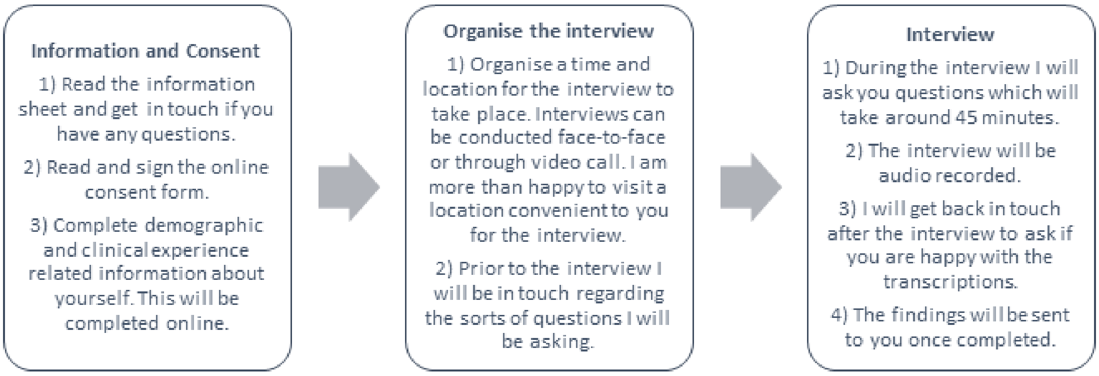
If you want to take part in the study it is completely your choice, you do not have to take part or continue the study if you do not want to. If at any point you would like your data to be removed, you must tell me within 24 hours. All data will always be kept confidential, and any information from you will not be traceable back you.

What is the project about?
We're looking at developing a digital tool such as an app to help improve wellbeing for young people with Tourette Syndrome (TS) or Tic Disorders. The tool would aim to help manage symptoms young people with Tourette Syndrome often experience as well as their tics such as stress and anxiety. This tool would be aimed at young people who are experiencing mild-moderate tics and would be a tool they could use alongside or before they have access to clinical treatment.
In order to understand what is important to young people with TS for their wellbeing, what affects their wellbeing and to explore such techniques to improve wellbeing we are interviewing young people with TS and TS professionals.

Who is being asked to take part, and why?
We are inviting TS professionals with experience of care for young people with Tourette Syndrome or Tic Disorders to take part in this study. We want to know how TS professionals deal with cases of young people who are having difficulties managing their wellbeing, what strategies and information TS professionals may suggest to young people to use and what sort of functions they would envisage as being useful in a self-help tool.
You may have been contacted because you are signed up to the Tourettes Action Research Participatory Registry.

Will the research be of any personal benefit to us?
It is unlikely that the research will be of any personal benefit to you, however we are hoping this research will help to further understanding of what sort of support young people with TS may need. Such a tool should help to improve the wellbeing of young people with TS and would help them to manage their day-to-day life. Any research findings can be sent on to you and we'd also be keen to involve you in the research along the way!

What will I be asked to do?



Information and Consent

1) Read the information sheet and get in touch if you have any questions.

2) Read and sign the online consent form.

3) Complete demographic and clinical experience related information about yourself. This will be completed online.

Organise the interview

1) Organise a time and location for the interview to take place. Interviews can be conducted face-to-face or through video call. I am more than happy to visit a location convenient to you for the interview.

2) Prior to the interview I will be in touch regarding the sorts of questions I will be asking.

Interview

1) During the interview I will ask you questions which will take around 45 minutes.

2) The interview will be audio recorded.

3) I will get back in touch after the interview to ask if you are happy with the transcriptions.

4) The findings will be sent to you once completed.

What will happen to the information I provide?
The recorded data will be stored on a coded database on a password-protected computer. During write up, all identifiable data will be removed so it becomes anonymous. If the research gets published, we may use quotes from you, but these will be completely confidential and will not identify you in any way. If at any stage you wish to withdraw, all information will be removed from analysis but you must let me know within 24 hours after the date of the interview.

We follow ethical and legal practice regarding data, and under UK Data Protection laws the University is legally responsible for the data security including looking after your information and using it properly. This means accessing, changing or moving your information is limited as we must comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more here: https://www.nottingham.ac.uk/utilities/privacy.aspx.

What will you do with the data?
The findings from this research will be used in CBs work as part of her doctoral thesis (PhD). If possible, the research may also be published later research papers and results/ blogs may be posted on the Tourettes Action page. We can provide a copy of the papers so that you can read the results.

At the end of the project, all raw data will be kept securely by the University under the terms of the Data Protection Act. The raw data will not be kept elsewhere however anonymized transcripts may be uploaded to a data service program so that other researchers can use the data. This data would not hold any personal information and recordings would not be uploaded to such a site.

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the above address.

I want to take part, what do I do now?
That's great! Please press 'Next' and you will be taken to the Consent form. Once you have completed your Consent form, you can also complete the Participant Details sheet which takes your demographic and clinical information and details for the interview. In total, these both should take around 15 minutes to complete.

I don't want to take part, what do I do now?
That's absolutely fine. You don't need to do anything more unless you want to contact me to hear more about the study. If you have any questions, please email Camilla.Babbage1@nottingham.ac.uk.

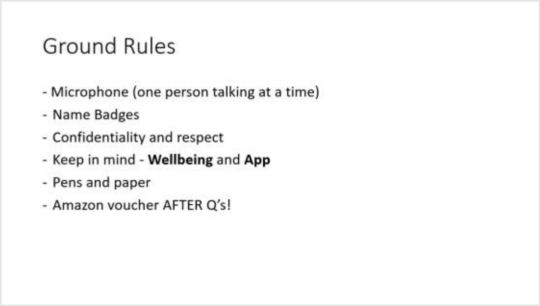
What if there is a problem?
If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of

Psychiatry & Applied Psychology’s Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

We believe there are no known risks associated with this research study however due to the potential use of video call for the interviews, a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

Appendix 18 – Focus group guide (Chapter 6)

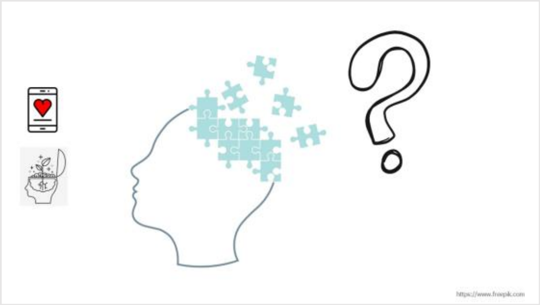
Ground Rules



Ground Rules

- Microphone (one person talking at a time)
- Name Badges
- Confidentiality and respect
- Keep in mind - **Wellbeing** and **App**
- Pens and paper
- Amazon voucher AFTER Q’s!

Psychoeducation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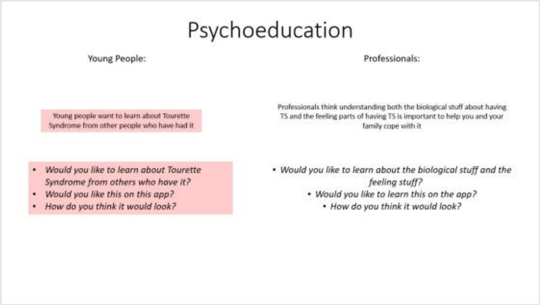

Psychoeducation

Young People:

Young people want to learn about Tourette Syndrome from other people who have had it

- *Would you like to learn about Tourette Syndrome from others who have it?*
- *Would you like this on this app?*
- *How do you think it would look?*

Professionals:

Professionals think understanding both the biological stuff about having TS and the feeling parts of having TS is important to help you and your family cope with it

- *Would you like to learn about the biological stuff and the feeling stuff?*
- *Would you like to learn this on the app?*
- *How do you think it would look?*

Interaction with others


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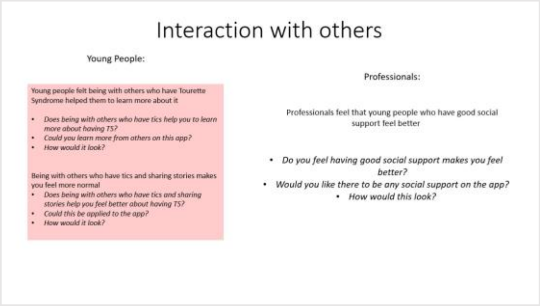

Interaction with others

Young People:

Young people felt being with others who have Tourette Syndrome helped them to learn more about it

- *Does being with others who have tics help you to learn more about having TS?*
- *Could you learn more from others on this app?*
- *How would it look?*

Being with others who have tics and sharing stories makes you feel more normal

- *Does being with others who have tics and sharing stories help you feel better about having TS?*
- *Could this be applied to the app?*
- *How would it look?*

Professionals:

Professionals feel that young people who have good social support feel better

- *Do you feel having good social support makes you feel better?*
- *Would you like there to be any social support on the app?*
- *How would this look?*

Games and puzzles

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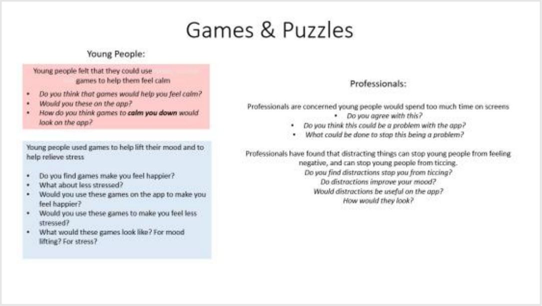

Games & Puzzles

Young People:

Young people felt that they could use games to help them feel calm

- *Do you think that games would help you feel calm?*
- *Would you these on the app?*
- *How do you think games to **calm you down** would look on the app?*

Young people used games to help lift their mood and to help relieve stress

- Do you find games make you feel happier?
- What about less stressed?
- Would you use these games on the app to make you feel happier?
- Would you use these games to make you feel less stressed?
- What would these games look like? For mood lifting? For stress?

Professionals:

Professionals are concerned young people would spend too much time on screens

- *Do you agree with this?*
- *Do you think this could be a problem with the app?*
- *What could be done to stop this being a problem?*

Professionals have found that distracting things can stop young people from feeling negative, and can stop young people from ticcing.
Do you find distractions stop you from ticcing?
Do distractions improve your mood?
Would distractions be useful on the app?
How would they look?

Support Network

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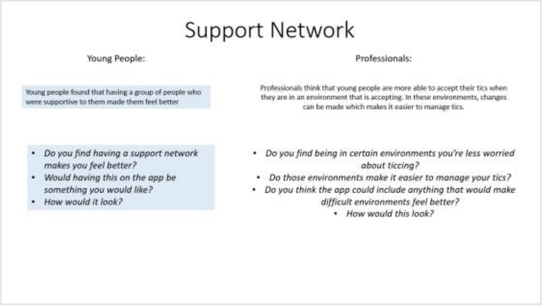

Support Network

Young People:

Young people found that having a group of people who were supportive to them made them feel better

- *Do you find having a support network makes you feel better?*
- *Would having this on the app be something you would like?*
- *How would it look?*

Professionals:

Professionals think that young people are more able to accept their tics when they are in an environment that is accepting. In these environments, changes can be made which makes it easier to manage tics.

- *Do you find being in certain environments you're less worried about ticcing?*
- *Do those environments make it easier to manage your tics?*
- *Do you think the app could include anything that would make difficult environments feel better?*
- *How would this look?*

Videos

https://www.freepik.com

Videos

Young People:

Professionals:

Young people said videos and films help them to relax, especially when feeling down or low

- *Do you think videos help you to relax?*
- *What about if you're already feeling down?*
- *Would videos on the app help you to feel this way?*
- *What would these videos look like?*

Music and Sounds

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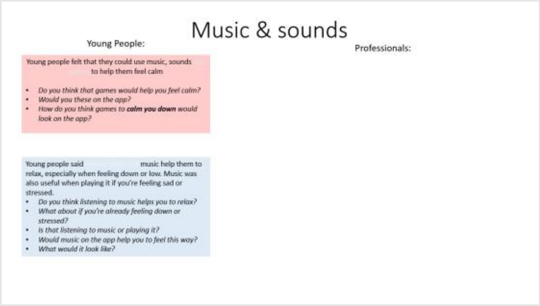

Music & sounds

Young People:

Professionals:

Young people felt that they could use music, sounds to help them feel calm

- *Do you think that games would help you feel calm?*
- *Would you these on the app?*
- *How do you think games to* ***calm you down*** *would look on the app?*

Young people said music help them to relax, especially when feeling down or low. Music was also useful when playing it if you're feeling sad or stressed.

- *Do you think listening to music helps you to relax?*
- *What about if you're already feeling down or stressed?*
- *Is that listening to music or playing it?*
- *Would music on the app help you to feel this way?*
- *What would it look like?*

Art

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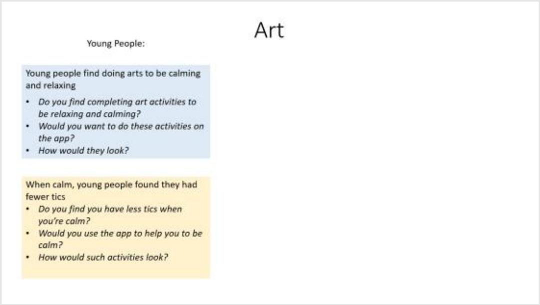

Art

Young People:

Young people find doing arts to be calming and relaxing

- *Do you find completing art activities to be relaxing and calming?*
- *Would you want to do these activities on the app?*
- *How would they look?*

When calm, young people found they had fewer tics

- *Do you find you have less tics when you're calm?*
- *Would you use the app to help you to be calm?*
- *How would such activities look?*

Schedules

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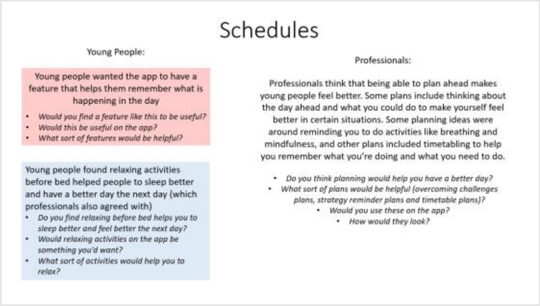


Schedules

Young People:

Young people wanted the app to have a feature that helps them remember what is happening in the day

- *Would you find a feature like this to be useful?*
- *Would this be useful on the app?*
- *What sort of features would be helpful?*

Young people found relaxing activities before bed helped people to sleep better and have a better day the next day (which professionals also agreed with)

- *Do you find relaxing before bed helps you to sleep better and feel better the next day?*
- *Would relaxing activities on the app be something you'd want?*
- *What sort of activities would help you to relax?*

Professionals:

Professionals think that being able to plan ahead makes young people feel better. Some plans include thinking about the day ahead and what you could do to make yourself feel better in certain situations. Some planning ideas were around reminding you to do activities like breathing and mindfulness, and other plans included timetabling to help you remember what you're doing and what you need to do.

- *Do you think planning would help you have a better day?*
- *What sort of plans would be helpful (overcoming challenges plans, strategy reminder plans and timetable plans)?*
- *Would you use these on the app?*
- *How would they look?*

Appendix 19 – Participant Information for young people (Chapter 7)

PARTICIPANT INFORMATION FOR YOUNG PEOPLE

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title: Wellbeing in young people with Tourette Syndrome: development of a self-management tool

Researcher/Student:

Camilla Babbage	Camilla.Babbage1@nottingham.ac.uk
Madeleine Roche	lpymr2@nottingham.ac.uk

Supervisor/Chief Investigator:

Georgina Jackson	Georgina.Jackson@nottingham.ac.uk
Elena Nixon	Elena.Nixon@nottingham.ac.uk

Ethics Reference Number:

Thank you for responding to the recruitment advertisement!

We are inviting you to take part in some research looking into creating an app to help make the day-to-day lives of young people with Tourette Syndrome or Tic Disorders feel better! If you're interested in taking part, we would like you to understand why the research is being done and what it involves for you.

What is the project about?

We're researching the areas of life young people who have Tourette Syndrome (TS) or Tic Disorders would like to manage better so we can understand what sort of things young people with TS may need to help them feel well. We've already spoken to young people who experience tics to find out what is important to them and how they manage how they feel, and they have identified an app would be useful. We've also talked to professionals like doctors and therapists about ways they suggest young people can manage their wellbeing.

We’re now looking at designing this app, and we’re asking you your thoughts on what has been said so far to find out what parts you like or not, and any ways we could make the app better. We will do this in an online video meeting with your parents and other young people who have tics.

Why have I been invited?

We are asking young people aged 8-19 years who experience tics to take part in this study as we feel young people with these experiences will have the best knowledge about how an app could make them feel better. We also understand that young people may feel more comfortable with their parents being present who may also have ideas about the app, so parents are also invited to get involved.

Do I have to take part?

If you want to take part in the study it is completely your choice, you do not have to take part or continue the study if you do not want to. Also, if you change your mind or if you don’t feel comfortable at any point, you can stop taking part without having to explain, just let us know you want to stop. If at any point you would like your data to be removed, you must tell me within 24 hours so I can remove your data. Your data will always be kept confidential, and any information from you will not be traceable back to you.

Will the research be helpful to me?

It is unlikely that the research will be of any personal benefit to you and we cannot guarantee that the tool we plan to develop will be developed. However, we are hoping this research will help to further understanding of what sort of support young people with TS may need.

An overview of what we find in the research can be sent to you and we’d also be keen to involve you in the research along the way!

What will I be asked to do?

1) You will recieve a link to a survey for you and your parent to complete.

2) One week before the group video meeting, you will be sent a document helping you to set up a Microsoft Teams account.

3) On the Microsoft Teams account you can watch a video introducing the researchers and giving you some information about how the video meeting will work.

4) During the group video meeting we will be on a video call together. We will present some of the ideas we have on the app so far and will then ask everyone what they like, dislike or other ideas you may have about the app. This will be recorded.

5) After the video meeting, we will send your parent some online forms and ask you both to complete these within 1-2 weeks about how you've been feeling recently.

After completing the tasks above, both you and your parent will receive a £10 shopping voucher as an inconvenience allowance.

I want to take part, what do I do now?

That's great! You will receive information on how to make a Microsoft Teams account soon, and then log in and join the call at the scheduled time. We are looking forward to seeing you there!

I don't want to take part, what do I do now?

That's absolutely fine! You don't need to do anything more unless you want to contact me to hear more about the study. If you have any questions, please email Camilla.Babbage1@nottingham.ac.uk.

What will happen to the information I provide?

Microsoft Teams uses Office 365 security and compliance which means that all your data will be encrypted to keep it safe. Microsoft say personal data remains with the tenant and the service you have signed up to. Teams gives different abilities to Owners of the Team vs Guest members, meaning you are protected as, for example, guests cannot record and are not able to download the video, but will be able to view it from the Teams account. After two weeks, the owner of the Team will delete the team and the data within it.

The recorded data will be stored on a coded database on a password-protected computer. When we write up any data all identifiable data will be removed so it becomes anonymous. If the research gets published, we may use quotes from you, but these will be completely confidential and will not identify either of you in any way. If at any stage you wish to withdraw, all information will be removed from analysis but you must let me know within 24 hours after the date of the interview.

We follow ethical and legal practice regarding data, and under UK Data Protection Laws the University is legally responsible for the data security including looking after your information and using it properly. This means accessing, changing or moving your information is limited as we must comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more here: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you reveal any information that makes me worry about your welfare we must pass this information on to the supervisors who will follow the Children and Vulnerable Adult Protection guidance given by the University of Nottingham.

What will you do with the data?

The findings from this research will be used work as part of Camilla Babbage's Doctoral Thesis and Madeleine Roche's Master's Dissertation. If possible, the research may also be published later research papers and results/ blogs may be posted on the Tourette's Action page. We can provide a copy of the papers so that you can read the results.

Data Protection

We will follow ethical and legal practice and all information will be handled in confidence.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

At the end of the project, all raw data will be kept securely by the University under the terms of its data protection policy after which it will be disposed of securely. The data will not be kept elsewhere

If you have any questions or concerns, please don't hesitate to ask. We can be contacted before and after your participation at the email addresses above.

Are there any possible disadvantages or risks in taking part?

We don't expect there to be any disadvantages or risks to taking part. We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Services for young people with Tourette Syndrome or Tic Disorder

Service	Who and what is it for?	Contact details
Tourettes Action Helpdesk	The Tourettes Action Helpdesk provides confidential and impartial support to adults and children living with Tourette Syndrome (TS)	https://www.tourettes-action.org.uk/9-helpdesk.html 0300 777 8427 Contact form: https://www.tourettes-action.org.uk/65-contact-us.html https://www.facebook.com/TourettesAction
Base51	A counselling and psychotherapy service for 12-25 year olds experiencing a range of symtoms and diagnoses such as anxiety, depression and personality disorders.	www.base51.org.uk 01159525040 counselling@base51.org.uk
Kooth	Online and face-to-face counselling for children between 10-24 years who are	Foxhall Lodge Foxhall Road Nottingham

	experiencing emotional or mental health difficulties including self-harm, suicide, abuse, anxiety, bullying, stress, depression and low mood, anger, LGBT+, family relationships, relationships and bereavement.	NG7 6LH Info@xenzone.com 07715906131 www.KOOTH.com
Childline	A service for children to call about anything via phone, online chat and email.	0800 1111 www.childline.org.uk
TouretteCanada Forum	A community bulletin board or forum for support, share ideas and a variety of other topics for anyone who wants to talk about Tourette Syndrome.	https://www.tourettesyndrome.ca/

Appendix 20 – Participant Information for Parents (Chapter 7)

Participant Information For Parents/Carers

Student Research Project Ethics Review

Division of Psychiatry & Applied Psychology

Project Title: Wellbeing in young people with Tourette Syndrome: development of a self-management tool

Researcher:

Camilla Babbage	Camilla.Babbage1@nottingham.ac.uk
Madeleine Roche	lpymr2@nottingham.ac.uk

Supervisor:

Georgina Jackson	Georgina.Jackson@nottingham.ac.uk
Elena Nixon	Elena.Nixon@nottingham.ac.uk

Ethics Reference Number:

Thank you for responding to the recruitment advertisement!

We are inviting you and your child to take part in research on creating an app to help make the day-to-day lives of young people with Tourette Syndrome (TS) or Tic Disorders feel better. If you're interested in taking part, we would like you to understand why the research is being done and what it involves for you and your child.

What is the purpose of this study?

We want to understand what areas of life young people who have TS would like to manage better, and to understand what could help young people with TS improve their wellbeing. We've already spoken to young people with tics to find out what is important to them and how they manage how they feel, and they identified an app would be useful. We've also talked to professionals like doctors and therapists about ways they suggest young people manage their wellbeing.

This part of the study is looking at the design of the app, to get yours and your child's thoughts on what we have so far and any ways we could improve it. This will be completed through an online group meeting on Microsoft Teams (an online platform for video calls) with other young people with tics and their parents/carers. Afterwards, you and your child will be asked to complete some online questionnaires.

Why have I been invited?

We are asking young people aged 8-19 years who experience tics to take part in this study, as we feel young people with these experiences will have the best knowledge about how an app could make them feel better. We also understand that young people may feel more comfortable with their parents/carers being present, who may also have ideas about the app, so parents/carers are also invited to get involved.

Do I have to take part?

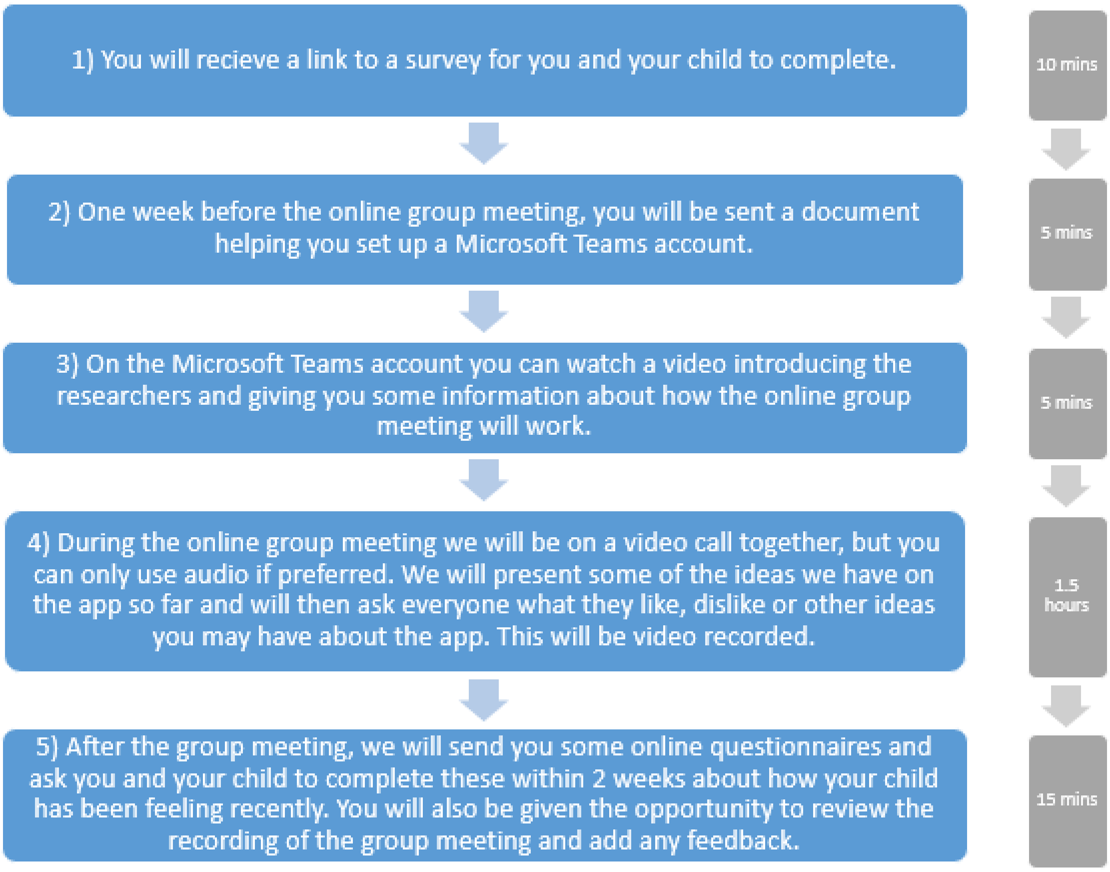
Taking part in the study is your and your child's choice. You do not have to take part if you do not want to and we do not expect you to give reasons for why you do not want to take part. Also, if you or your child changes their mind or if you/they don't feel comfortable at any point, you can stop taking part without having to explain, just let us know you want to stop and you can exit the survey or focus group at any time. If you would prefer it, you can choose to participate in the focus group via audio only (with the camera turned off).

The other participants will be able to see your email address and name but no other personal details will be visible to others. Microsoft Teams creates an automatic transcript of the focus group, which will be edited by the researchers as the software is not always accurate. This means that we can edit yours or your child's data out if you would like yours or your child's data to be removed at any point. Please tell us if you would like your data removed within 24 hours of the focus group. All data will always be kept confidential, and any information will not be traceable back to either of you.

Will the research be of any personal benefit to us?

It is unlikely the research will be of any personal benefit to you or your child and we cannot guarantee that the tool we plan to develop will be developed. However, we are hoping this research will help to further understanding of what support young people with tics may need. A brief overview of the research findings can be sent to you and we'd be keen to involve you in the research along the way! If you would like a summary of the research once it is completed, there will be a space for you to indicate this on the consent form.

What will I be asked to do?



1) You will recieve a link to a survey for you and your child to complete.

2) One week before the online group meeting, you will be sent a document helping you set up a Microsoft Teams account.

3) On the Microsoft Teams account you can watch a video introducing the researchers and giving you some information about how the online group meeting will work.

4) During the online group meeting we will be on a video call together, but you can only use audio if preferred. We will present some of the ideas we have on the app so far and will then ask everyone what they like, dislike or other ideas you may have about the app. This will be video recorded.

5) After the group meeting, we will send you some online questionnaires and ask you and your child to complete these within 2 weeks about how your child has been feeling recently. You will also be given the opportunity to review the recording of the group meeting and add any feedback.

The questionnaires you will be asked to complete are the Revised Child Anxiety and Depression Scale (RCADS) which asks how your child has been feeling recently and the Tourette's Disorder Scale (TODS) which measures how much your child has been bothered by TS symptoms in the past week. Your child will also be asked to complete the Gilles de la Tourette syndrome-quality of life scale (GTS-QOL) which measures how their TS affects their well-being and the Revised Child Anxiety and Depression Scale (RCADS) which asks how they've been feeling recently. You can help your child when completing the questionnaires.

In total, all of the steps should take around 2 hours to complete. After completing the tasks above, you and your child will receive a £10 shopping voucher each as an inconvenience allowance.

I want to take part, what do I do now?

That's great! Please email the researchers and let them know you are interested, they will then send you a link to complete an online survey which asks for you and your child's consent.

My child wants to take part, but I don't. What do I do now?

That's absolutely fine. Your child can take part in the group discussion without your involvement. However, we do ask you to supervise your child whilst they complete the online group meeting, to sign your child's assent forms beforehand and complete the online forms at the end of the study.

I don't want to take part, what do I do now?

That's absolutely fine! You don't need to do anything more.

What will happen to the information I provide?

Microsoft Teams uses Office 365 security and compliance which means that all your data will be encrypted to keep it safe. Microsoft expect personal data to remain with the tenant and within the service you have signed up to. Teams gives different abilities to Owners of the Team vs Guest members, meaning you are protected as, for example, guests cannot record and are not able to download the video, but will be able to view it from the Teams account. After two weeks, the owner of the Team will delete the team and the data within it.

The recorded data will be stored on a coded database on a password-protected computer. When we write up any data, all identifiable data will be removed so it becomes anonymous. If the research gets published, we may use quotes from you, but these will be completely confidential and will not identify either of you in any way. If at any stage you or your child wish to withdraw, all information will be removed from analysis but you must let us know within 24 hours after the date of the interview. If you or child reveal any information that makes us worry about your child's welfare I must pass this information on to my supervisor who will follow the Children and Vulnerable Adult Protection guidance given by the University of Nottingham.

What will you do with the data?

The findings from this research will be used work as part of Camilla Babbage's Doctoral Thesis and Madeleine Roche's Master's Dissertation. If possible, the research may also be published in later research papers with other researchers in other Universities and organisations both inside and outside the European Union. These results/blogs may be posted on the Tourette's Action page. We can provide a copy of the papers so that you can read the results. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

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We will follow ethical and legal practice and all information will be handled in confidence. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we use the minimum personally – identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx

Are there any possible disadvantages or risks in taking part?

We don't expect there to be any disadvantages or risks to taking part. We believe there are no known risks associated with this research study; however, as with any online activity the risk of a breach is always possible. We will do everything possible to ensure your answers in this study will remain anonymous. If you have any general questions or concerns about your child's Tourette Syndrome or Tic Disorder then there is a list of services for young people with Tourette Syndrome or Tic Disorders at the end of this document.

What if there is a problem?

If you have any queries or complaints, please contact the student's supervisor/chief investigator in the first instance. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee. adrian.pantry1@nottingam.ac.uk who will pass your query to the Chair of the Committee. If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Services for young people with Tourette Syndrome or Tic Disorder

Service	Who and what is it for?	Contact details
Tourettes Action Helpdesk	The Tourettes Action Helpdesk provides confidential and impartial support to adults and children living with Tourette Syndrome (TS)	https://www.tourettes-action.org.uk/9-helpdesk.html 0300 777 8427 Contact form: https://www.tourettes-action.org.uk/65-contact-us.html https://www.facebook.com/TourettesAction
Base51	A counselling and psychotherapy service for 12-25 year olds experiencing a range of symptoms and diagnoses such as anxiety, depression and personality disorders.	www.base51.org.uk 01159525040 counselling@base51.org.uk
Kooth	Online and face-to-face counselling for children between	Foxhall Lodge Foxhall Road

	10-24 years who are experiencing emotional or mental health difficulties including self-harm, suicide, abuse, anxiety, bullying, stress, depression and low mood, anger, LGBT+, family relationships, relationships and bereavement.	Nottingham NG7 6LH Info@xenzone.com 07715906131 www.KOOTH.com
Childline	A service for children to call about anything via phone, online chat and email.	0800 1111 www.childline.org.uk
TouretteCanada Forum	A community bulletin board or forum for support, share ideas and a variety of other topics for anyone who wants to talk about Tourette Syndrome.	https://www.tourettesyndrome.ca/

Appendix 21 – Online focus group guide (Chapter 7)

Introduction

Welcome to our research project!

- If you have any internet problems – don't worry, just come back when it's sorted
- Please think of something you'd like to tell the others in the group about yourself during introductions
- Remember you can turn your mic and video on/off
- If at any point you don't want to continue, that's fine – just leave the conversation and we will get in touch after to check you're okay

Notes

Ground Rules

Before FG starts:

- Pin our videos
- Turn on record video (and turn on dictaphone)
- Pop out our chat
- Get link ready to post post-Qs in the chat at the end

As people come in:

- Do introductions (change names on Teams)
- Ask people to use the functions on the video (to get used to Teams)

When everyone is in (after 5 minutes)

- Do introductions (give everyone chance to introduce themselves)
- One speaker at a time
- Withdrawing if want/ stop displaying video/ muting function (when ticking/ not speaking)
- If internet difficulties – can come back whenever they can
- Confidentiality and respect (no wrong answers)
- Each slide shows a part of the app young people and professionals agreed on. We want to know what you think is most important or how that should look. We will only spend a few minutes per slide, so your first thoughts are what we want to hear (we won't be offended!).

Reminder for after

- Amazon voucher AFTER Q's!
- Check recording on Teams/ edit anything they forgot/ want to remove (within 24 hours)

Schedules

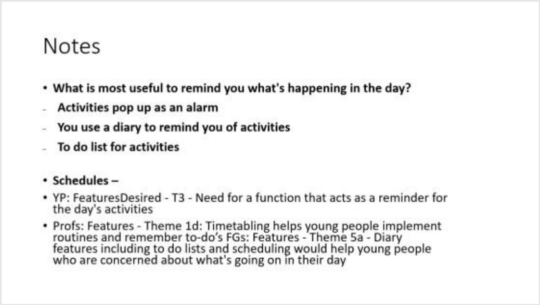
Scheduling

Notes

- **Schedules – Knowing what daily activities are planned for the day**
- **What would be useful in a diary or planner to help manage day to day life better?**
- **FGs: Features - Theme 5 - Diaries help young people's with their worries**
- **Profs: Features - Theme 1: Planning helps better manage day to day life leading to improved mood**

Reminders

Reminders

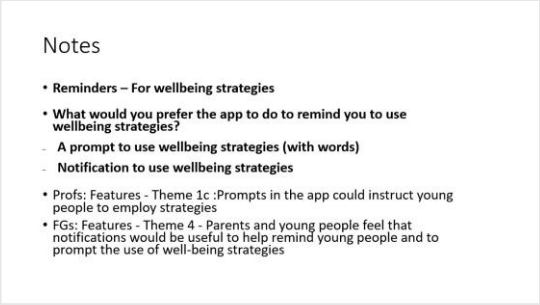


Notes

- What is most useful to remind you what's happening in the day?
  - Activities pop up as an alarm
  - You use a diary to remind you of activities
  - To do list for activities

- Schedules –
- YP: FeaturesDesired - T3 - Need for a function that acts as a reminder for the day's activities
- Profs: Features - Theme 1d: Timetabling helps young people implement routines and remember to-do's FGs: Features - Theme 5a - Diary features including to do lists and scheduling would help young people who are concerned about what's going on in their day

Reminders



Notes

- Reminders – For wellbeing strategies
- What would you prefer the app to do to remind you to use wellbeing strategies?
  - A prompt to use wellbeing strategies (with words)
  - Notification to use wellbeing strategies
- Profs: Features - Theme 1c :Prompts in the app could instruct young people to employ strategies
- FGs: Features - Theme 4 - Parents and young people feel that notifications would be useful to help remind young people and to prompt the use of well-being strategies

Notes

- Order of preference:
  - Daily schedules
  - Reminders
  - Reminders to do wellbeing strategies

Socialising


Socialising with others with tics

Notes

- **Socialising - Interacting with others with TS**
- **How would you like to socialise with others with tics on the app?**
- YP: Desired - T1a - Interaction with others enables learning more about Tourette Syndrome
- FGs: Functions - Theme 1 - The overarching experience of interacting with others with TS is positive for families with tics, and would be desired as a feature on the app

Wellbeing strategies

Wellbeing strategies

Notes

- **Coping - Sleep facilitating activities**
- **How could the app help with maintaining sleep hygiene or relaxing strategies to facilitate sleep?**
- Profs: Features - Theme 1b: Maintaining sleep hygiene helps the young person have a better day
- FGs: Features - Theme 6b - Relaxing strategies before bed help young people with sleep, as this can be a problem
-

Wellbeing strategies

Notes

- **Coping – Mood diaries to reflect on feelings**
- **How could mood diaries help you learn how to control and identify feelings and reflect on feelings?**
- Prof: Features - Theme 2c: Mood Diaries help young people to notice emotions, which can help identify and control feelings to lead to more positive outcomes

Wellbeing strategies

Notes

- **Coping - Confidence building**
- **How could the app help support your confidence by changing how you think about yourself? Build your selfesteem?**
- Prof:Features - Theme 2b: Strategies can be employed to improve self-esteem by changing the way the young person thinks about themselves and their tics
- FGs: Features - Theme 8 - Activities to improve confidence on the app would be useful

Wellbeing strategies

Thought

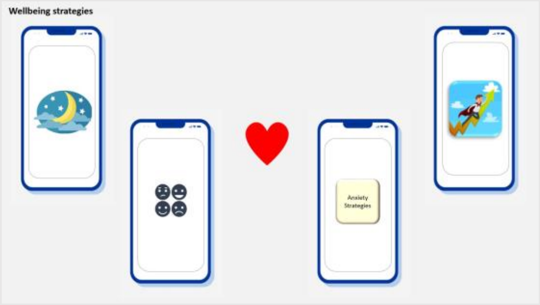
Emotion

Behaviour

Anxiety Strategies

Notes

- **Coping – Anxiety strategies**
- **How would you like to learn more strategies like this to support anxiety on the app?**
- Prof: Features - Theme 2e: For anxious young people the app should include CBT approaches



Wellbeing strategies

Anxiety Strategies

Notes

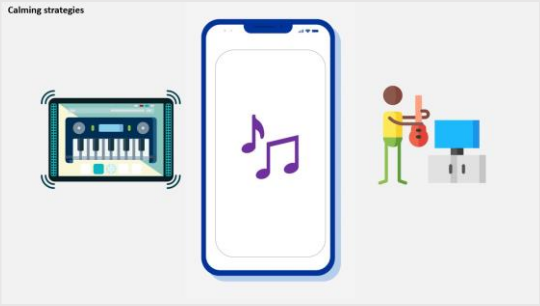
- **Order of preference of coping strategies**
  - **Sleep**
  - **Mood tracking**
  - **Confidence boosting**
  - **CBT strategies for anxiety**

Calming Strategies

Calming strategies

Notes

- **Calming – Playing games or puzzles**
- **What games/puzzles on the app would be calming/ help you to feel less stressed?**
- YP: ManagingMentalStates - T5a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress
- FG: Features - Theme 1 - Young people currently use and find certain games to be calming and make them feel better, which parents agree with

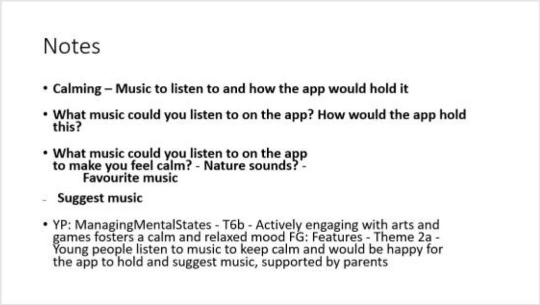


Calming strategies

Notes

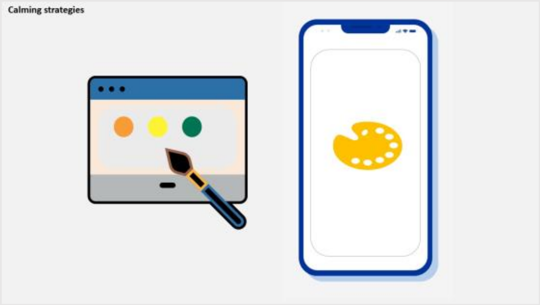
- **Calming – Playing music**
- **What music can you play on the app to be calming or help with stress?**
- YP: ManagingMentalStates - T5a - Active engagement with strategies such as playing music, games, puzzles or being creative reduces psychological distress symptoms associated with stress
- FG: Features - Theme 2b -Young people actively engage with music, such as through playing instruments and music games, which would be wanted on the app

Calming strategies

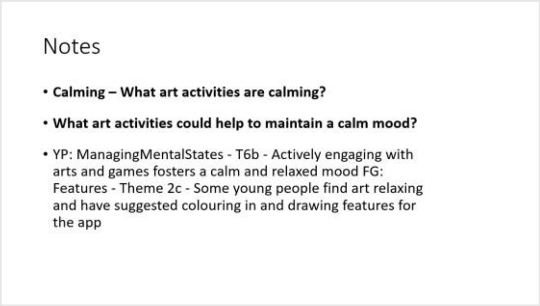


Notes

- **Calming – Music to listen to and how the app would hold it**
- **What music could you listen to on the app? How would the app hold this?**
- **What music could you listen to on the app to make you feel calm? - Nature sounds? - Favourite music**
  - **Suggest music**
- YP: ManagingMentalStates - T6b - Actively engaging with arts and games fosters a calm and relaxed mood FG: Features - Theme 2a - Young people listen to music to keep calm and would be happy for the app to hold and suggest music, supported by parents



Calming strategies



Notes

- **Calming – What art activities are calming?**
- **What art activities could help to maintain a calm mood?**
- YP: ManagingMentalStates - T6b - Actively engaging with arts and games fosters a calm and relaxed mood FG: Features - Theme 2c - Some young people find art relaxing and have suggested colouring in and drawing features for the app

Calming strategies

Notes

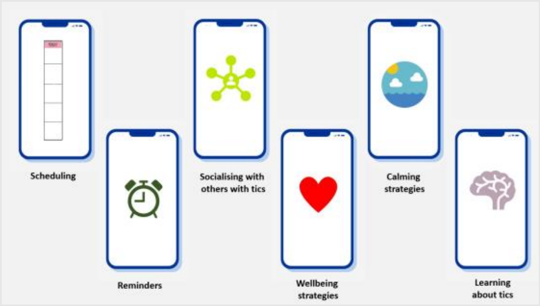
- **Order of preference of calming strategies:**
-
  - **Calming games**
  - **Calming music to play**
  - **Calming music to listen to**
  - **Calming arts**

Learning about tics

Learning about tics

Notes

- **Psychoeducation - Learning about TS from others with TS**
- **How and what information would you like to receive information from others with tics to help you learn about yours?**
- FGs: Functions - Theme 1b - Communication and sharing information with others on the app would be useful



Scheduling

Reminders

Socialising with others with tics

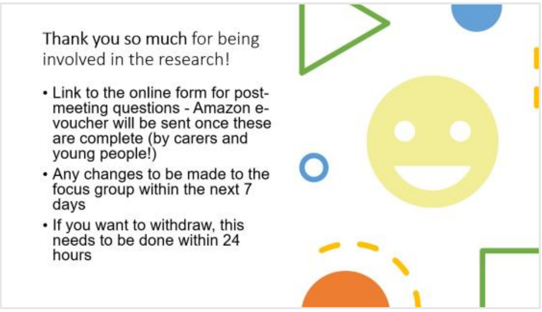
Wellbeing strategies

Calming strategies

Learning about tics

Notes

- **Order of preference:**
  - **Scheduling**
  - **Reminders**
  - **Socialising with others with tics**
  - **Wellbeing strategies**
  - **Calming strategies**
  - **Psychoeducation from others with tics**

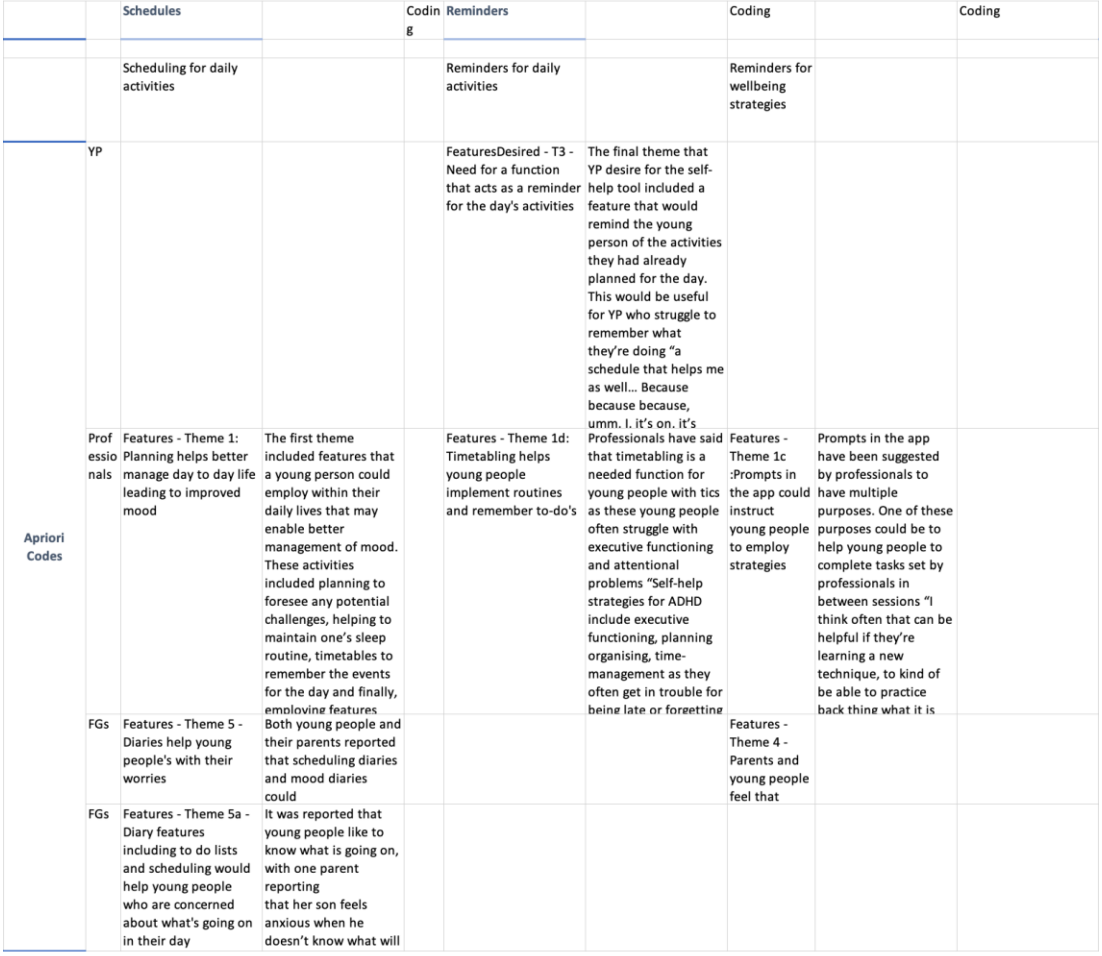


Thank you so much for being involved in the research!

- Link to the online form for post-meeting questions - Amazon e-voucher will be sent once these are complete (by carers and young people!)
- Any changes to be made to the focus group within the next 7 days
- If you want to withdraw, this needs to be done within 24 hours

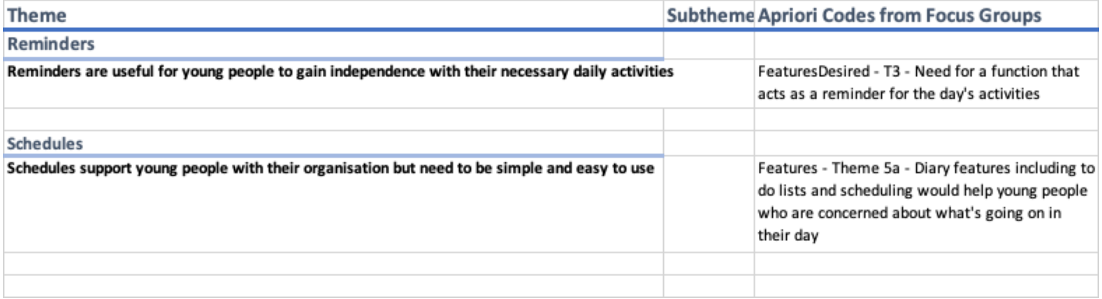
Appendix 22 – Example codebook for hybrid thematic analysis approach (Chapter 7)

Codebook of a priori codes for schedules and reminders (pre-coding)



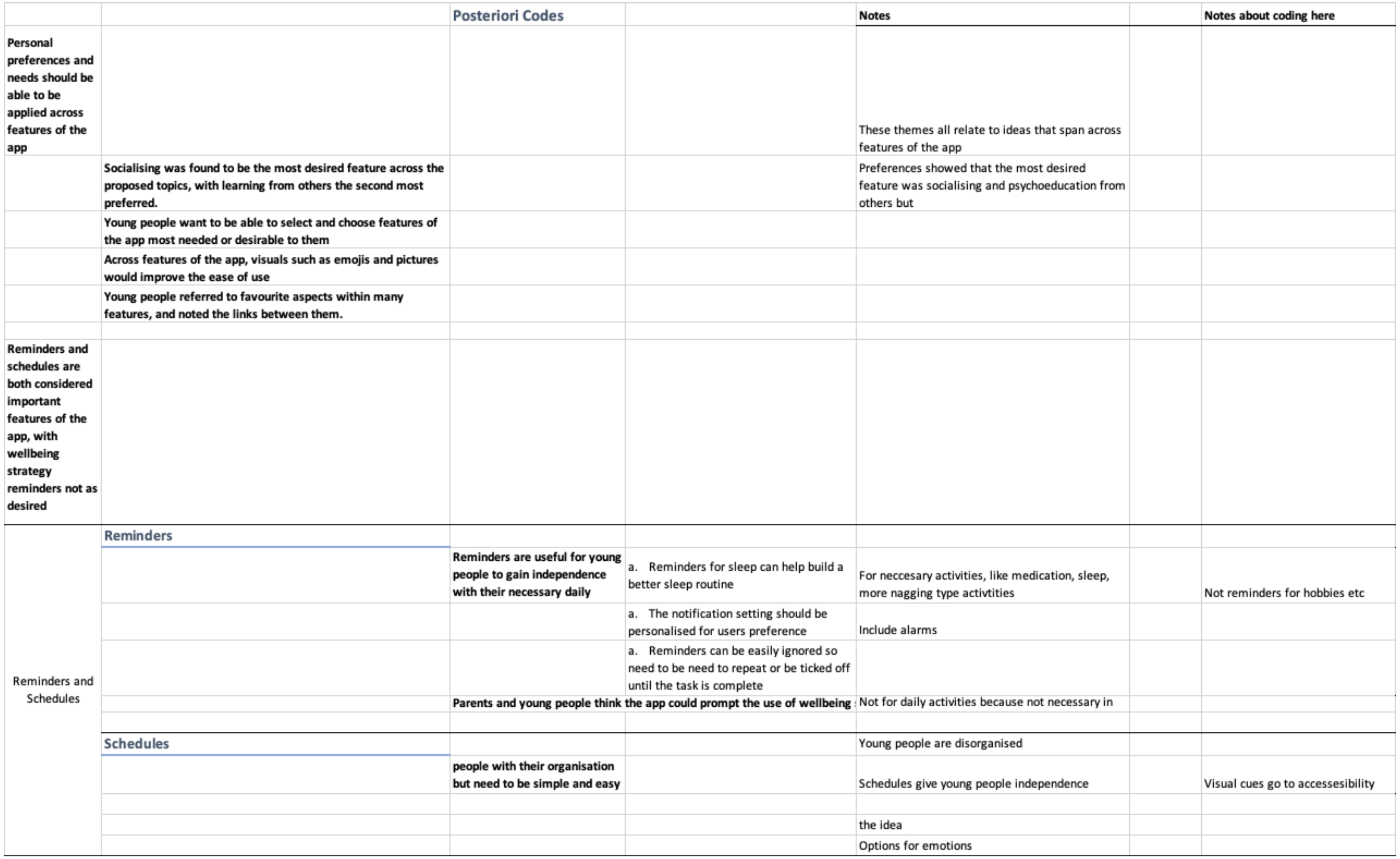
		Schedules		Coding	Reminders		Coding		Coding
		Scheduling for daily activities			Reminders for daily activities		Reminders for wellbeing strategies		
Apriori Codes	YP				FeaturesDesired - T3 - Need for a function that acts as a reminder for the day's activities	The final theme that YP desire for the self-help tool included a feature that would remind the young person of the activities they had already planned for the day. This would be useful for YP who struggle to remember what they're doing "a schedule that helps me as well… Because because because, umm. I. it's on. it's			
	Professionals	Features - Theme 1: Planning helps better manage day to day life leading to improved mood	The first theme included features that a young person could employ within their daily lives that may enable better management of mood. These activities included planning to foresee any potential challenges, helping to maintain one's sleep routine, timetables to remember the events for the day and finally, employing features		Features - Theme 1d: Timetabling helps young people implement routines and remember to-do's	Professionals have said that timetabling is a needed function for young people with tics as these young people often struggle with executive functioning and attentional problems "Self-help strategies for ADHD include executive functioning, planning organising, time-management as they often get in trouble for being late or forgetting	Features - Theme 1c :Prompts in the app could instruct young people to employ strategies	Prompts in the app have been suggested by professionals to have multiple purposes. One of these purposes could be to help young people to complete tasks set by professionals in between sessions "I think often that can be helpful if they're learning a new technique, to kind of be able to practice back thing what it is	
	FGs	Features - Theme 5 - Diaries help young people's with their worries	Both young people and their parents reported that scheduling diaries and mood diaries could				Features - Theme 4 - Parents and young people feel that		
	FGs	Features - Theme 5a - Diary features including to do lists and scheduling would help young people who are concerned about what's going on in their day	It was reported that young people like to know what is going on, with one parent reporting that her son feels anxious when he doesn't know what will						

Codebook of a priori codes for schedules and reminders (post-coding)



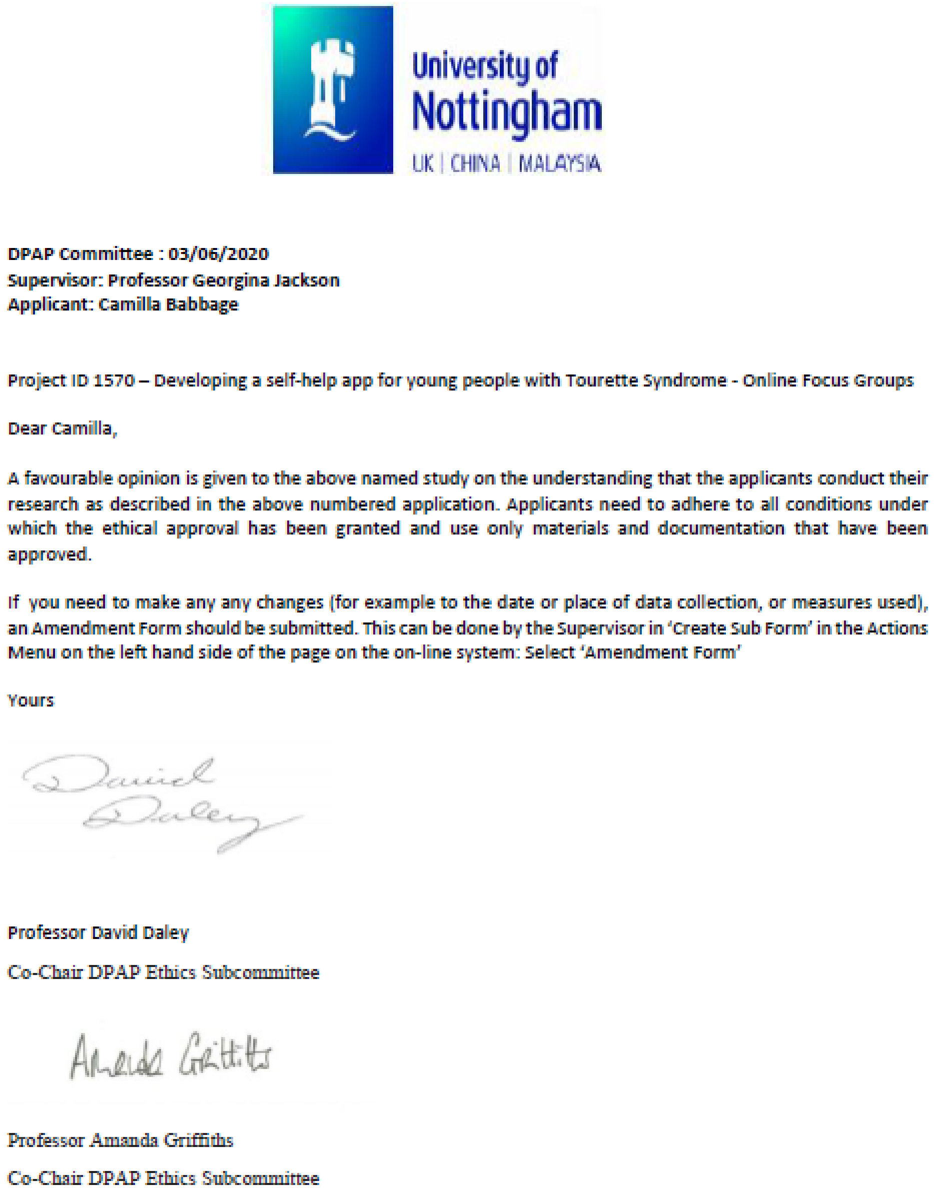
Theme	Subtheme	Apriori Codes from Focus Groups
Reminders		
Reminders are useful for young people to gain independence with their necessary daily activities		FeaturesDesired - T3 - Need for a function that acts as a reminder for the day's activities
Schedules		
Schedules support young people with their organisation but need to be simple and easy to use		Features - Theme 5a - Diary features including to do lists and scheduling would help young people who are concerned about what's going on in their day

Codebook of posteriori codes for schedules and reminders



		Posteriori Codes		Notes		Notes about coding here
Personal preferences and needs should be able to be applied across features of the app				These themes all relate to ideas that span across features of the app		
	Socialising was found to be the most desired feature across the proposed topics, with learning from others the second most preferred.			Preferences showed that the most desired feature was socialising and psychoeducation from others but		
	Young people want to be able to select and choose features of the app most needed or desirable to them					
	Across features of the app, visuals such as emojis and pictures would improve the ease of use					
	Young people referred to favourite aspects within many features, and noted the links between them.					
Reminders and schedules are both considered important features of the app, with wellbeing strategy reminders not as desired						
Reminders and Schedules	**Reminders**					
		Reminders are useful for young people to gain independence with their necessary daily	a. Reminders for sleep can help build a better sleep routine	For neccesary activities, like medication, sleep, more nagging type activities		Not reminders for hobbies etc
			a. The notification setting should be personalised for users preference	Include alarms		
			a. Reminders can be easily ignored so need to be need to repeat or be ticked off until the task is complete			
		Parents and young people think the app could prompt the use of wellbeing		Not for daily activities because not necessary in		
	Schedules			Young people are disorganised		
		people with their organisation but need to be simple and easy		Schedules give young people independence		Visual cues go to accessesibility
				the idea		
				Options for emotions		

Appendix 23 - Ethics Approval Letter (Ref: 1570)



University of Nottingham
UK | CHINA | MALAYSIA

DPAP Committee : 03/06/2020
Supervisor: Professor Georgina Jackson
Applicant: Camilla Babbage

Project ID 1570 – Developing a self-help app for young people with Tourette Syndrome - Online Focus Groups

Dear Camilla,

A favourable opinion is given to the above named study on the understanding that the applicants conduct their research as described in the above numbered application. Applicants need to adhere to all conditions under which the ethical approval has been granted and use only materials and documentation that have been approved.

If you need to make any any changes (for example to the date or place of data collection, or measures used), an Amendment Form should be submitted. This can be done by the Supervisor in 'Create Sub Form' in the Actions Menu on the left hand side of the page on the on-line system: Select 'Amendment Form'

Yours

David Daley

Professor David Daley

Co-Chair DPAP Ethics Subcommittee

Amanda Griffiths

Professor Amanda Griffiths

Co-Chair DPAP Ethics Subcommittee