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Exploring internet needs for the management of adolescent chronic pain: developing digital interventions in context

Volume 1 of 2

by

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Abstract

Chronic pain in children and adolescents is recognised internationally as a long-term health condition, which can have a substantial impact on the quality of life of young people and their families, as well as representing a substantial economic burden across healthcare sectors. The prevalence of chronic pain in children and adolescents varies across diagnoses, age groups and genders. Primary chronic pain is often idiopathic and secondary conditions range from chronic headaches to musculoskeletal pain. The overarching aim of the current thesis is to lay the groundwork for developing a novel online intervention for the management of adolescent chronic pain. The thesis firstly outlines the problem of paediatric and adolescent chronic pain and describes current evidence-based best practices for chronic pain management. This is followed by an outline of methodological approaches to online health intervention development, including the Medical Research Council guidance for developing complex health interventions and the Person-Based Approach to developing digital health interventions. An explanation of how these approaches were used in the thesis, and rationale underpinning the chosen methods, is provided. Theoretical models pertaining to the maintenance and management of chronic pain are outlined, followed by the presentation of three papers. Paper 1 presents a review and content analysis of online interventions that have been developed for the management of paediatric and adolescent chronic pain. Findings highlight that, whilst CBT-based interventions have been largely successful, most interventions do not encompass multidisciplinary pain management. The review identifies that a UK-centric online intervention for paediatric chronic pain has not yet been developed. Paper 2 presents a needs-assessment survey of adolescents with chronic pain and their parents. This study explores needs and preferences of this population for a novel intervention. Findings draw attention to the integration of internet and social media use by young people for pain management purposes. A qualitative content analysis of survey responses reveals that adolescents would endorse a new online pain management intervention. Paper 3 presents a qualitative interview study with adolescents with chronic pain, which further explores the context of internet and social media use in young people. An inductive thematic analysis presents four themes: ‘Trustworthy information, or experiences?’, ‘Diagnostic labels in a digital world’, ‘The online chronic pain community’, and ‘A mind and body approach to self-management.’ The general discussion presents guiding principles that intervention developers and chronic pain specialists may use when creating or adapting online interventions.

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Table of Contents

Table of Tables

Table of Figures

List of Accompanying Materials

This is Volume 1 of 2. Volume 2 provides the online only supplementary materials that accompany Paper 1 of this thesis.

Research data relevant to this thesis is available via the University of Southampton data repository, Pure. The following datasets are available:

- Intervention content coding for Paper 1, "Online multidisciplinary interventions for paediatric chronic pain: A content analysis". DOI: 10.5258/SOTON/D2075
- Qualtrics survey data extraction (SPSS and Excel) for Paper 2, "Online paediatric chronic pain management: assessing the needs of UK adolescents and parents, using a cross-sectional survey". DOI: 10.5258/SOTON/D2074
- Interview transcripts for Paper 3, "Trusting in the online ‘community’: An interview study exploring internet use in young people with chronic pain'. DOI: 10.5258/SOTON/D2073

Academic Thesis: Declaration of Authorship

I, Anna Hurley-Wallace, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

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I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

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Signed:

Date:

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Definitions and Abbreviations

CBT: Cognitive Behavioural Therapy

IASP: International Association for the Study of Pain

Interdisciplinary treatment: “Multimodal treatment provided by a multidisciplinary team collaborating in assessment and treatment using a shared biopsychosocial model and goals. For example: the prescription of an anti-depressant by a physician alongside exercise treatment from a physiotherapist, and cognitive behavioural treatment by a psychologist, all working closely together with regular team meetings (face to face or online), agreement on diagnosis, therapeutic aims and plans for treatment and review.” (IASP, 2018a)

Multidisciplinary treatment: “Multimodal treatment provided by practitioners from different disciplines. For example: the prescription of an anti-depressant by a physician alongside exercise treatment from a physiotherapist, and cognitive behavioural treatment by a psychologist, all the professions working separately with their own therapeutic aim for the patient and not necessarily communicating with each other.”(IASP, 2018b).

Multimodal treatment: “The concurrent use of separate therapeutic interventions with different mechanisms of action within one discipline aimed at different pain mechanisms.”(IASP, 2018c).

PBA: Person-Based Approach

Chapter 1 Introduction

Pain, whether acute or chronic, is a perception, not a sensation. From an evolutionary perspective, pain is a warning that we need to alter our behaviour in order to protect ourselves from danger. However, some pain signals do not have this function. In particular, pain that is chronic or persistent can prevent people from living their lives (Ogden, 2012). The International Association for the Study of Pain (IASP) defines pain as: “An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (IASP, 2020). This definition is expanded upon by six key notes, emphasising that pain is always a personal experience, and that pain and nociception (the detection of painful stimuli) are different phenomena.

As psychology has been integrated into theories of pain, the role of psychological and social factors and their contribution to chronic pain has been emphasised. Psychological factors include pain-related anxiety, fear, and catastrophizing (thinking that a situation is considerably worse than it actually is), and there are many other factors that are discussed in relation to theoretical models and approaches in subsequent chapters.

Chronic pain in children and adolescents (paediatric chronic pain) presents a complex and enduring issue to researchers, healthcare professionals, and the families and friends of these young people. Complexities in paediatric chronic pain often involve social factors such as schooling and parenting, as well as biological changes that occur throughout development, which are integrated into a young person’s perception and experience of pain. Early adolescence represents a key point of onset for chronic pain that may last for a lifetime. However, adolescence also presents a developmental window of opportunity for learning and consolidation of pain self-management skills. Inherently, paediatric chronic pain is an important condition to study, however complex.

1.1 What is chronic pain?

Chronic pain has been defined as persistent or recurrent pain lasting longer than three-months by the IASP Task Force for the International Classification of Diseases (ICD-11) (IASP, 2012; Treede et al., 2015). The ICD is the leading tool for coding diagnoses within healthcare systems internationally and is underpinned by the World Health Organization. This criterion of a pain duration lasting longer than three-months has been further emphasised by a systematic review investigating definitions of chronic pain in epidemiological studies (Steingrimsdottir et al., 2017). The review of epidemiological studies found that practically no two studies from separate research groups specified the same criteria for chronic pain, where one-third of studies included an assessment window of 12-months or less. Overall, the literature investigated in the review referred to a vast variety of taxonomies, durations, assessment windows, pain frequencies and intensities. The authors argue that that inconsistencies in definitions may undermine the case for chronic pain to be considered an important health condition and recommended that both clinicians and researchers align with the ICD-11 three-month definition.

Since the review by Steingrimsdottir et al. (2017), ICD-11 classifications of chronic pain have been updated to include chronic primary pain (Nicholas et al., 2019) and six secondary pain types (Treede et al., 2019). These are outlined as follows:

1. Chronic primary pain. This category includes chronic pain of unknown aetiology (idiopathic chronic pain). Pain may be area-specific e.g., low back pain, irritable bowel syndrome (IBS), or widespread e.g., chronic widespread pain, fibromyalgia.
    a. Chronic primary pain is only appropriate where pain cannot be better explained by categories 2-7 and is associated with significant emotional distress or functional disability (Nicholas et al., 2019; Treede et al., 2019).
2. Chronic cancer pain. Includes pain caused by cancer itself or by cancer treatments.
3. Chronic post-surgical or post-traumatic pain. This category describes pain that persists beyond normal healing time following a surgical procedure or tissue injury.
    a. Chronic post-surgical pain is often neuropathic in nature (Haroutiunian et al., 2013) (see point 4).
4. Chronic neuropathic pain. Neuropathic pain arises from damage to the somatosensory nervous system.
    a. Demonstration using imaging, biopsy, neurophysiological, or laboratory tests, in addition to negative or positive sensory signs, must be present for definitive identification as neuropathic.
5. Chronic headache or orofacial pain. This category includes including primary and secondary headaches, and orofacial pain e.g., temporomandibular disorder (TMD).

    a. Pain must be present on at least 50% of days to be classified as chronic within this category.

6. Chronic visceral pain. Describes pain originating from internal organs of the head and neck region and the thoracic, abdominal, and pelvic cavities. An example of chronic visceral pain is endometriosis.
7. Chronic musculoskeletal pain. This category describes pain arising as part of a disease process that affects the bones, joints, muscles, or related soft tissues. This includes conditions of persistent inflammation e.g., arthritis, as well as pain resulting from structural osteoarticular changes e.g., Ehlers-Danlos Syndrome(s) (EDS) or joint hypermobility syndrome(s).

Although chronic pain diagnoses are well-defined in the ICD-11 classification system, there are many cases where an individual’s chronic pain may fit into two or more diagnostic categories. In these cases it is useful to refer back to the more general definition of chronic pain, which specifies any pain that has a duration of longer than three-months (IASP, 2012).

1.1.1 Defining ‘paediatric’ in healthcare and research

The criteria defining chronic pain can be applied to both adults and children. Paediatric chronic pain refers to persistent or recurrent pain lasting longer than three-months (IASP, 2012), which is experienced by a child or young person. Whilst this may seem conceptually simple, the extensive and internationally spanning body of research on paediatric pain varies regarding which age range is considered to be ‘paediatric’. The following paragraphs outline: (1) the age at which chronic pain would be treated under paediatric services in the UK, (2) the paediatric age range as defined by clinicians and researchers in Canada and the United States (US), and (3) the issue of transitioning from paediatric to adult healthcare.

In the United Kingdom (UK), there is national-level clinical guidance on the management of chronic pain in adults over 16-years, which is provided by the National Institute for Health and Care Excellence (NICE, 2021). However, the management of chronic pain in children is based on international guidance provided by the World Health Organization (World Health Organization, 2020). This international guidance is adhered to by specialist paediatric pain clinics in the UK, such as Great Ormond Street Hospital’s Pain Control service. For referral into a paediatric chronic pain clinic, the young person must be 16-years or under. However, this guidance is flexible; patients aged 17 to 18-years may be accepted (Great Ormond Street Hospital, 2021).

Of particular importance to the current thesis is the extensive body of research conducted by the Canadian-led Pain in Child Health (PICH) consortium (SickKids, 2019; von Baeyer et al., 2014). In Canada, the paediatric age range is defined as 0 to 17-years-old. Research conducted with clinical samples of young people with chronic pain is hence based on this age bracket. Further, there have been collaborations between several Canadian and US hospitals on research involving young people with chronic pain. One example is the Pediatric Pain and Sleep Innovations Lab, based at Seattle Children’s Hospital (Seattle Children's®, 2021). This US-based group have produced an extensive amount of research with young people with chronic pain and, similarly to the Canadian group, define ‘paediatric’ as 0 to 17-years-old.

Literature has further suggested that the age of adolescence extends up to a cut-off age of 24-years (Sawyer et al., 2018). Experts have argued that the transition period from childhood to adulthood extends across a greater portion of the life span than ever before, due to delayed role transitions; for example, education is completed later, and parenthood is starting later than it has historically. A definition of adolescence ranging from 10 to 24-years fits better with societal understandings of this developmental stage (Sawyer et al., 2018). Indeed, chronic pain literature agrees with this definition and outlines the period of ‘older adolescence’ as being of critical interest to clinicians and researchers, where transitions of independence are typically delayed (Rosenbloom et al., 2017). This can be explained using known models of paediatric chronic pain, which are outlined in Chapter 3. Nonetheless, young people in the UK are usually treated under adult healthcare services from the age of 16; and as aforementioned, there is separate guidance for the treatment of chronic pain in adults (NICE, 2021). This presents an issue to researchers in the field, as there is a period between the age of 16 to 24-years where these young people can be considered dependents from a developmental perspective, yet they are usually considered independent with regards to managing their health. The Care Quality Commission (CQC) recognise adolescence and young adulthood as an important developmental stage and have suggested specific transitional services should be available, particularly for those with complex physical health needs, from the age of 14 to 25-years-old (CQC, 2014). The report from the CQC also noted that young people, their parents, and healthcare professionals delivering their care, often did not have a good understanding of the healthcare transition process.

In this thesis, adolescence has been defined as up to 24-years. The three papers shift from a child and adolescent population (0 to 18-years) to an adolescent population (12 to 18-years). Then, the third paper shifts to focus on transitional adolescents aged 16 to 24-years.

This decision was based on insights from Paper 1 and Paper 2 and draws from the methodological frameworks used in this thesis (outlined in section 2.1).

1.2 The problem of paediatric chronic pain

The following subsections provide an overview of the prevalence of paediatric chronic pain, including differences by age and by sex, followed by outlining the impact of pain on young people. The discussion of impact includes highlighting the issue of diagnostic uncertainty, the impact that pain can have on quality of life, and the economic cost of chronic pain to wider society.

1.2.1 Prevalence of chronic pain

The most recent systematic review investigating the epidemiology of chronic pain in children and adolescents indicated that chronic pain is highly prevalent, although prevalence estimates vary substantially between studies and across pain conditions (King et al., 2011). Chronic headache may be the most common paediatric chronic pain condition. Reported prevalence for paediatric headache ranges from 8% to 83%, followed by abdominal pain (4% to 53%), musculoskeletal pain (4% to 40%), and back pain (14% to 24%) (King et al., 2011). Chronic post-surgical pain in children at 12-month follow-up has an estimated prevalence of 20% (Rabbitts et al., 2017). Factors associated with pain persisting beyond the expected physical recovery time included: pre-surgical pain intensity, child anxiety, child coping ability, and parental pain catastrophizing. Psychological factors contributing to chronic pain such as anxiety, coping and catastrophizing are discussed further in relation to theoretical models in subsequent chapters (see section 3.2.2). Notably, an update to the epidemiological review investigating the prevalence of chronic pain in children and adolescents is imminent (Tutelman et al., 2021).

1.2.1.1 Age differences

Paediatric chronic pain is known to increase with age, where chronic pain and pain-related disability peak during adolescence (Palermo et al., 2014; King et al., 2011; Roth-Isigkeit et al., 2005). For many types of chronic pain (including primary pain and musculoskeletal pain), population-based studies indicate that prevalence peaks at 14 to 15-years-old, however studies of persistent headache indicate that prevalence peaks slightly later (16 to 18-years) compared to pain of other aetiologies (Stanford et al., 2008; Lateef et al., 2009). Newer evidence investigating self-reported chronic pain in adolescence, across 42 countries, found that 44.2% of adolescents reported chronic pain over 6-months (Gobina et al., 2019). This was based on nationally representative samples of 11, 13 and 15-year-olds. In the UK sample, 16-19% of adolescents reported experiencing multi-site chronic pain.

Whilst many cases of paediatric chronic pain are managed effectively across primary and secondary care, some patients develop complex presentations which are extremely challenging to manage effectively. An estimate of up to 3% of the paediatric population may experience severe and disabling chronic pain (Eccleston et al., 2006), which can have functional limitations that are significantly worse comparatively to other chronic health conditions seen in children (Oxford Centre for Children and Young People in Pain, 2019).

1.2.1.2 Sex differences

Across paediatric populations, females are more prone to chronic pain than males (King et al., 2011). For example, a meta-analysis of functional abdominal pain in children, which included 58 worldwide studies, found that functional abdominal pain (FAP) occurs significantly more in girls than boys (15.9% versus 11.5% respectively, pooled OR = 1.5) (Korterink et al., 2015). The meta-analysis also showed FAP was associated with anxiety and depression, stress, and traumatic life events. Further research into factors underlying sex differences in chronic pain in adolescence has found that coping strategies used by males and females are substantially different. In a sample of adolescents from Pain Management Unit at the Royal National Hospital for Rheumatic Diseases, UK, it was found that females with chronic pain more frequently engaged in social support, positive statements, and catastrophizing, however males more frequently engaged in distraction behaviours (Keogh & Eccleston, 2006). In this study, catastrophizing mediated the relationship between pain and sex. Inferentially, use of catastrophizing as a chronic pain coping strategy may be of crucial importance in understanding why young females experience more pain than males.

Notably, the difference in chronic pain prevalence between sexes is mirrored in adult reports of chronic pain, and in documented experiences of pain across life span (Keogh, 2013, 2010; Fayaz et al., 2016). More recently, the conceptualisation of gender versus sex and its impact on pain has been discussed (Boerner et al., 2018), however an in-depth discussion of gender conceptualisation is not within the scope of the current thesis.

1.2.2 Impact of chronic pain

The impact of long-term pain can be major. Even for young people who are able to manage pain very well, significant adjustments are often required to reduce pain to manageable everyday levels. Young people with chronic pain often present with high ‘functional disability’ across physical, psychological, and social domains (see section 1.4.1). High levels of disability reflect a poor quality of life, which often ripples through the family unit. The next subsections briefly highlight: (i) the issue of diagnostic uncertainty, (ii) the impact of chronic pain on the quality of life of young people and their families, and (ii) the economic burden that treating paediatric chronic pain poses to healthcare systems.

1.2.2.1 Diagnostic uncertainty

Perceived diagnostic uncertainty in paediatric chronic pain is a common experience, where a diagnosis of idiopathic chronic pain can lead to an endless search for a clear cause (and cure) for pain by young people and their families (Pincus et al., 2018). There may also be the perception that a diagnosis that has been given is incorrect, where, for example, the level of pain experienced appears to be disconnected from clinically active disease (Schanberg et al., 2003). In a sample of 174 adolescents with chronic pain recruited from a tertiary clinic in Canada, 31% experienced diagnostic uncertainty (Neville et al., 2020). Additionally, diagnostic uncertainty was linked to increased catastrophic thinking, which can fuel the cycle of disuse and disability, and result in increasingly poor functioning in people with chronic pain (see Fear-Avoidance model, section 3.1.1).

A qualitative study exploring perceived diagnostic uncertainty in young people with chronic pain, from UK-based physicians’ perspectives, found that young peoples’ search for the ‘right’ diagnosis often continues despite physicians’ attempts to cease further diagnostic testing (Neville et al., 2021). This study found that physician’s attempts to ‘draw a line in the sand’ were often not final, especially in the absence of a supporting multidisciplinary team. Sometimes, more medical tests were ordered in an attempt to align with the family’s needs and improve the patient-physician relationship. On the other hand, some physicians felt that sharing their sense of uncertainty improved the therapeutic relationship through demonstrating humanity. Diagnostic uncertainty in young people with chronic pain is a difficult issue that requires attention in research and practice, where intolerance to uncertainty has been recently highlighted as a factor contributing to the maintenance of chronic pain and associated disability (Neville, Kopala-Sibley, et al., 2021) (see Interpersonal Fear-Avoidance Model, section 3.1.2).

1.2.2.2 Quality of life

Whether diagnosed or not, paediatric chronic pain can have detrimental impacts on the quality of life of young people and their families. Children and adolescents with chronic pain report substantially worse quality of life than their healthy peers in domains of physical and psychosocial functioning, as well as poorer performance in school and poorer relationships with peers (Dick & Riddell, 2010; Forgeron et al., 2010; Logan et al., 2008; Varni et al., 2007). Psychosocial factors, such as comorbid mood disorders (Vinall et al., 2016) and dysfunctional interpersonal relationships (Jordan et al., 2017), as well as kinesiophobia or 'fear of movement' (Al-Obaidi et al., 2000), can contribute to levels of functional disability in paediatric chronic pain. Many other factors that contribute to functional disability in chronic pain are discussed under the The biopsychosocial approach (section 3.2). Improving quality of life by reducing functional disability is a core focus of paediatric pain treatment programmes, above and beyond pain reduction (Lynch-Jordan et al., 2014).

In addition to having a negative impact on the quality of life of young people, paediatric chronic pain, particularly when complex in presentation, can also affect the family unit and individual family members. Children with chronic pain and their families report worse behavioural control, negative impacts on family cohesion and structure, an increased amount of family disturbances, and increased intra-family conflict than families without children with chronic pain (Lewandowski et al., 2010). Parents of children with chronic pain also report suffering higher levels of anxiety and depression than parents of healthy children, as well as feelings of helplessness and a lack of control (Palermo & Eccleston, 2009). Family systems are discussed further in section 3.2.3.

Adolescent chronic pain has also been associated with poor outcomes in young adulthood, such as reduced educational attainment, poor vocational functioning (e.g., lower chance of receiving benefits from an employer), and social impairments (e.g., poorer self-reported romantic relationship functioning) (Murray, Groenewald, et al., 2019). These outcomes together indicate a greater long-term risk of socioeconomic disparities in young people with chronic pain, compared to young people without chronic pain.

1.2.2.3 Economic costs

Paediatric chronic pain also presents a significant economic cost to healthcare services, families of young people with chronic pain, and to society. In addition to the healthcare service costs of treating pain itself, chronic pain adds complexity to other health and mental health conditions (Groenewald & Palermo, 2015). There has been little investigation of costs to healthcare systems, as only two studies have evaluated the economic burden of treating paediatric chronic pain:

1. The cost of adolescent chronic pain to UK society has been estimated at £3840 million per annum (Sleed et al., 2005). This estimate was extrapolated from a sample of 52 families. The average cost of a complete care package for each family was estimated at £8027 per annum. This included direct costs (e.g., cost of service use and medication, and out-of-pocket expenses to the family such as complementary treatments and non-prescription medication) and indirect costs (e.g., time taken off work to attend appointments). Adolescents with non-inflammatory pain who attended a specialist pain management clinic accumulated higher costs than adolescents with inflammatory chronic pain attending rheumatology clinics (£14160 versus £4495 respectively: $Z = -3.069$, $p < .01$).
2. The cost of providing paediatric pain treatment in the USA has been estimated up to $19.5 billion per annum, where a large proportion of this cost is attributable to high healthcare service use (Groenewald et al., 2014). This estimate was extrapolated from a sample of 149 young people presenting at US-based interdisciplinary pain clinics (10 to 17-year-olds). The mean total cost per participant over 12-months was $11787 (SD = $15809, range = $242 - $125149). The mean cost included medical and non-medical/ out-of-pocket expenses, though 68% went towards direct medical services.

1.3 Adolescent chronic pain

As mentioned in preceding sections, adolescence represents a critical risk period for the development of chronic pain, which may last a lifetime. Many scholars have speculated why this might be, as there are a variety of complex and interrelated biological, psychological, and social factors involved. These factors are discussed in in relation to the biopsychosocial model of chronic pain in Chapter 3. Nonetheless, a discussion of why the developmental stage of adolescence is particularly unique, and how this may relate to the manifestation of chronic pain, is warranted.

1.3.1 Adolescence, chronic pain, and developmental psychology

There are a variety of developmental changes that occur in adolescence, which beyond continuing cortical maturation also encompass distinct cognitive-affective (Lau et al., 2018), and social developmental changes (Sawyer et al., 2018). In terms of cortical development, the pre-frontal cortex matures later comparatively to other regions. The pre-frontal cortex is typically associated with complex functions such as reasoning and behavioural control (Fuster, 2002). Maturation of the pre-frontal cortex coincides with increased cognitive abilities in abstract reasoning, attentional shifting, response inhibition and processing speed (Yurgelun-Todd, 2007; Lau et al., 2018). Behaviourally, this maturation represents a marked increase in independent functioning (Spear, 2000), and is accompanied by improvements in emotional understanding and regulation, including some emotional (or ‘affective’) functions that research suggests are unique to adolescence. For example, recent studies on the amygdala (an area of the brain well-known to be involved in processing emotion) have consistently found adolescents are more reactive to facial expressions of emotion, compared to both adults and young children (Pfeifer & Blakemore, 2012).

In relation to chronic pain, developmental age-related changes may impact cognitive biases towards pain. It could be the case that when complex cognitive processes develop and become stable, continuous behavioural associations lead to biases in attention and interpretation (Lau et al., 2018). Such development-by-pain-by-cognitive bias interactions could also apply to pain outcomes, as age can impact catastrophizing, which in turn impacts a child or young person’s experience of pain. This predictive association of age by catastrophizing on pain has been found to be strongest in adolescents with chronic pain than in younger children (Tran et al., 2015). Biases in cognition, particularly biases in interpretation (via catastrophizing) (Lau et al., 2018), can be linked with cognitive and affective components of the The Fear-Avoidance model of pain (e.g. Vlaeyen et al., 2016).

Further, a diagnosis of chronic pain at a stage in social development where the main goal is to achieve autonomy and effectively transition social roles from child to adult, presents a critical issue to adolescents (Palermo et al., 2014; Sawyer et al., 2018). Parental involvement and over-protectiveness has been associated with higher levels of disability in relation to managing chronically painful conditions such as Sickle Cell Disease (Oliver-Carpenter et al., 2011). Low levels of adolescent autonomy have also been associated with increased functional disability in cases of chronic headache (Palermo et al., 2007). This association can be matched with the The Interpersonal Fear-Avoidance Model of chronic pain, which incorporates parental factors, including over-protectiveness, into the Fear-Avoidance cycle (see section 3.1.2). However, qualitative research exploring adolescents’ perspectives on how they make sense of their development in the context of chronic pain found that developmental trajectories were unique to the individual, where some trajectories were enhanced and others delayed (Jordan et al., 2018). For example, some adolescents with chronic pain appear to have developed excellent coping skills and flourish in interpersonal interactions, despite pain. Such findings reveal challenges in drawing normative comparisons between adolescents with chronic pain.

Considering the biological, cognitive-affective, and social developmental changes that occur during the period of adolescence, it is somewhat unsurprising that adolescence represents a critical risk period for developing chronic pain. The exact cause of chronic pain is often elusive, and in many cases is the result of multiple interacting factors. However, through understanding the underlying developmental factors that may be involved, treatments that specifically address these factors can be provided. For example, though there is no direct evidence to state that CBT is more effective in adolescents than adults, it may be optimal to target cognitive biases during adolescence, whilst there is greater plasticity of cognitive functions (Cohen Kadosh et al., 2013; Lau et al., 2018). Further, encouraging self-management within interventions for chronic pain may encourage greater autonomy in condition management, thereby helping to address the issue of delayed independence that is often seen in young people with chronic pain (Rosenbloom et al., 2017). Research which explored the self-management needs of adolescents with Juvenile Idiopathic Arthritis (JIA) found that developing self-management skills involved ‘letting go’ from others who have been managing their illness (parents, healthcare professionals) (Stinson et al., 2008). It is important, however, that pain management is tailored to the individual young person, and this is reflected in the latest clinical guidance (World Health Organization, 2020).

1.4 Evidence-based treatments

The following sections outline evidence-based approaches to paediatric and adolescent chronic pain assessment and management, which combine input from multiple disciplines, including medicine, physiotherapy, psychology, and other co-disciplines such as nursing and occupational therapy (Kaiser et al., 2017). This is reflective of the biopsychosocial approach, which is based on the biopsychosocial model of health (Engel, 1977), and is the recommended best practice for the management of chronic pain in children (World Health Organization, 2020).

Briefly, the biopsychosocial approach conceptualises that a complex interaction of biological (nociceptive), affective (emotional), sociocultural, behavioural, and cognitive factors shape an individuals’ pain perception (for further discussion of this approach, see section 2.2). In order to understand a child or young person’s subjective experience of pain, all of these factors must be formulated in an assessment framework and grounded within dimensions that are developmentally relevant (Liossi & Howard, 2016). For example, social roles differ substantially between a child in primary school and an adolescent in their late teens.

Paediatric pain formulation can be especially complex as parents play a key role in the management of their child's chronic pain, as well as having their own model of their child's chronic pain, which can impact the child's experience. This parent-child relationship is discussed further in relation to the Interpersonal Fear-Avoidance Model (Goubert & Simons, 2013) (section 3.1.1) and under the social domain of the biopsychosocial approach (section 3.2.3). Research indicates that mood disorders (anxiety and depression) are more prevalent in parents of children with chronic pain, compared to parents of healthy children (Palermo & Eccleston, 2009). Where poor parental mental health is apparent as part of a paediatric pain case formulation, parental mental health may also be targeted for improvement, most likely using psychological therapies, as part of the biopsychosocial approach to paediatric pain management.

Considering direct treatment approaches for young people with chronic pain, there are a variety of pain management techniques that could be applied in practice, ranging from pain education through to medical analgesia. The treatments for an individual young person are tailored based on an interdisciplinary clinical formulation (World Health Organization, 2020), and seek to address all aspects of the young person's wellbeing, considering their psychological, physical, and sociodemographic needs. This clinical guidance additionally emphasises that the combination of treatment modalities applied may differ for each individual case. Assessment of pain severity, and moreover, functional disability is essential in practice to determine the starting point for any treatment modality.

1.4.1 Assessing pain and functional disability

As explained above, pain is a subjective experience that is unique to individuals. When considering chronic pain in children and adolescents, it is important to remember that each individual's experience is subjective. Chronic pain and pain-related functional disabilities are evaluated in a variety of different ways, including the use of patient-reported outcome measures. Notably, many self-report measures for children and adolescents have a parent-report ('proxy') version.

A vast selection of visual, analogue, and numerical patient-reported outcome measures can be used to assess pain severity and intensity in children. Some examples of these assessments recommended for use in practice include the Pieces of Hurt Tool, the Faces

Pain Scale, the ‘Oucher’, or Visual Analogue Scales (Huguet et al., 2010). Additional assessments of pain, for example mapping pain location, as would be done using the Brief Pain Inventory (BPI) (Cleeland & Ryan, 1991), are frequently used in practice to complement scale measures.

In practice, assessment of ‘functional disability’ (or ‘quality of life’) is prioritised in paediatric chronic pain, as management should address all aspects of the young person’s wellbeing (World Health Organization, 2020). Assessments of functional disability encompass the physical, psychological, and social needs of patients. Chronic pain is assessed in this way because it is likely that pain severity will remain similar throughout treatment, whilst functional disability scores indicate improvements in the young person’s overall pain management (Williams, 2018; Lynch-Jordan et al., 2014).

A well-known functional disability assessment is the PedsQL™ 4.0 (Varni et al., 2003). The PedsQL™ core assessment has four facets: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). Each questionnaire is tailored for children aged 5 to 7 and 8 to 12-years, or adolescents aged 13 to 18-years, and there is a parent-proxy report to match each age range, which is worded slightly differently. The only exception to this is the parent report for ages 2 to 4-years, which is a standalone parent report. The PedsQL™ is also available in a variety of different languages, and the core assessment is regularly used by multi-modal paediatric pain services (Oxford Centre for Children and Young People in Pain, 2019; Great Ormond Street Hospital, 2018). The assessment can also be useful for assessing functional well-being in survivors of childhood cancer (Eiser et al., 2003), and hence may also be clinically useful in assessing paediatric chronic cancer-related pain, as well as pain of other aetiologies.

An additional benefit of using patient-reported outcome measures is that they can work to improve the clinician-patient relationship, as children are able to better communicate how they are feeling using self-reports (McNicholas, 2018). Using a measure such as the PedsQL™ 4.0 may also improve clinician relationships with parents, as the proxy reports also take the parental opinion into account. However, despite the potential advantages of using validated measures to assess pain and functioning, in many clinical cases questioning the young person directly may be the key to accurate assessment of the pain condition (Middleton, 2018).

1.4.2 Interdisciplinary treatments: clinical practice

IASP define interdisciplinary treatment as a multidisciplinary team delivering collaborative, multimodal treatment, and working towards the same biopsychosocial treatment goals (IASP, 2018a). Previously, this treatment approach for chronic pain has been termed ‘interdisciplinary multi-modal pain therapy’. Ideally, a team of healthcare professionals from medicine, psychology, physical therapy, and co-disciplines (often nursing or occupational therapy) backgrounds would be involved in chronic pain treatment (Kaiser et al., 2017). Only consultant doctors can make referrals to specialist paediatric pain clinics (Great Ormond Street Hospital, 2021), which in turn follow best practice guidance for the management of chronic pain in children (World Health Organization, 2020). The following paragraphs in this section outline some of the typical elements that may be included in an interdisciplinary, multimodal paediatric chronic pain treatment programme.

Treatment for paediatric chronic pain typically occurs in outpatient settings, and is focused on providing multi-modal treatment (World Health Organization, 2020), which can include physiotherapy, medication, and psychological treatment. The most commonly used psychological treatment is CBT (Miro et al., 2017). This is usually multicomponent CBT, which can be aligned with a 5-factor model of how thoughts, feelings, behaviours, and physical sensations are interlinked (Coakley & Wihak, 2017). There is no set protocol for CBT in practice, however CBT generally includes a combination of relaxation training, behavioural activation, problem solving, cognitive restructuring, and teaching coping skills (Ehde et al., 2014; Liossi & Howard, 2016), and may also include teaching young people self-management practices, such as activity pacing and sleep hygiene (Rajapakse et al., 2014). Other psychological therapies available in practice, depending on the clinical expertise available, include mindfulness, hypnosis, biofeedback techniques, and acceptance and commitment therapy (ACT) (Coakley & Wihak, 2017; Fisher et al., 2018). Biofeedback techniques involve actively monitoring physiological activity, such as heart rate, to increase awareness of and control over physiological processes. Notably, biofeedback is no longer recommended in the treatment of chronic pain for young people over 16-years-old (NICE, 2021); CBT and ACT are recommended for chronic primary pain.

There are a variety of safe and efficacious Complementary and Alternative Medicine (CAM) treatments that healthcare professionals may consider when treating young people with chronic pain (Evans et al., 2008). CAM encompasses both body-based and mind-body therapies, with acupuncture listed separately as an ‘alternative systems’ therapy. Acupuncture for chronic pain has been trialled with girls aged 6 to 18-years (Zeltzer et al., 2002). The treatment combined acupuncture and hypnosis in a series of 6 (weekly) 20-minute sessions, and was found to be feasible and acceptable, yielding significant improvements in pain intensity and functional disability. Acupuncture is also a recommended consideration for chronic pain in young people over 16-years-old (NICE, 2021). An example of body-based therapy is massage, which has been found to reduce pain and improve sleep and mood in children, particularly for JIA and fibromyalgia (Tsao & Zeltzer, 2005). Mind-body therapies include therapeutic yoga, music therapy and hypnotherapy, though the latter two options are usually utilised for procedure-related pain (Liossi et al., 2006; Caprilli et al., 2007). Notably, one mind-body technique that overlaps with psychological therapies is mindfulness. The effects of mindfulness meditation have been explored in adolescents with chronic pain (Ruskin et al., 2017). Adolescents participated in an 8-week group mindfulness programme, which was evaluated using focus groups. Overall, the intervention was found to be feasible, where adolescents expressed that they had developed a range of mindfulness skills (e.g., present-moment awareness and emotion regulation) that could be transferred to other aspects of their lives (e.g., sleep and school-related stress).

The delivery of pain education or 'pain neuroscience education' is also important in improving a patient's understanding that ongoing pain experience does not necessarily indicate that the body is in danger. Pain education can also complement CBT, as it promotes an understanding of the bi-directional relationship between pain and stress. This can also be mapped to the 5-factor model of CBT, where physical sensation is linked with the thoughts, feelings, behaviours that contribute to the overall experience of pain (Coakley & Wihak, 2017). Psychology-focused pain management programmes often call this pain 'psychoeducation'. In clinics, physiotherapy is central to the management of various musculoskeletal conditions, which often fall under the diagnostic category of chronic musculoskeletal pain (Odell & Logan, 2013). Physiotherapy treatment is often combined with exercise therapy and occupational therapy to create a holistic 'physical therapies' element within an interdisciplinary treatment approach. Alternative non-pharmacological physical therapies, such as transcutaneous electrical nerve stimulation (TENS) (NHS, 2019; Vance et al., 2014; Rajapakse et al., 2014), and desensitisation may also be used (Great Ormond Street Hospital, 2018; Oxford Centre for Children and Young People in Pain, 2019).

Pharmacological treatment, whilst not recommended as a standalone treatment for chronic pain (Caes, Fisher, et al., 2018), remains a vital component of any pain management service. This is because short-term pharmacological management to reduce pain intensity and severity can enable participation in other areas of pain management. For example, using medications may allow patients to engage better with psychological interventions and make physiotherapy more tolerable. There are some key differences in the pharmacological management of pain depending on aetiology. One example is neuropathic versus non-neuropathic pain. Neuropathic pain may be treated using antidepressants such as tricyclics or serotonin and norepinephrine reuptake inhibitors (SNRIs); this is targeted at reducing the pain response as opposed to treating anxiety or depression (Cooper, Heathcote, et al., 2017), although there may be an additional benefit of improved mental health if comorbidities are present (Hetrick et al., 2021; Ipser et al., 2009). On the other hand, non-neuropathic pain may be treated using non-steroidal anti-inflammatory drugs (NSAIDs) and paracetamol (Cooper, Fisher, et al., 2017; Eccleston et al., 2017). Additional medication may be useful in certain cases to aid other symptoms of pain that are specific to an individual child or adolescents pain formulation, for example melatonin may be prescribed as a sleep aid (Williams, 2018).

Importantly, pharmacological guidance for the treatment of chronic pain in individuals aged 16-years-and-over has been recently updated to state that: management using medication is not recommended, with the exception of antidepressants (Carville et al., 2021). This is particularly relevant to Paper 3 (Chapter 6) of the current thesis, which is conducted with a sample of older adolescent participants.

Depending on the hospital delivering treatment, the hospital’s in-house definition of a ‘biopsychosocial approach’, and the expertise available, interdisciplinary treatment may be delivered very differently between different services (Kaiser et al., 2017). For example, in paediatric pain services, some have a stronger focus on occupational therapy (Oxford Centre for Children and Young People in Pain, 2019), whilst others focus more on physiotherapy, including intensive in-patient rehabilitation programmes (Great Ormond Street Hospital, 2018).

1.4.2.1 Interdisciplinary treatments (in-person): current evidence

The use of interdisciplinary interventions for the treatment of paediatric chronic pain is supported by a recent review of treatments for paediatric musculoskeletal pain, which highlighted the lack of evidence supporting the use of pharmacologic treatment alone. The review also affirmed the strong evidence base for psychological treatments, and the promising yet limited support for the role of physiotherapy (Caes, Fisher, et al., 2018). Systematic reviews of interventions for paediatric chronic pain have investigated interventions combining at least two (Liossi et al., 2019) or three disciplines (Hechler et al., 2015). For interventions including two or more disciplines, significant improvements from pre to post-intervention were found for pain intensity (d = 0.42; 95% CI [0.14, 0.69]), functional disability (d = 1.11; 95% CI [0.70, -1.51]), and depression (d = 0.36; 95% CI [0.17, 0.55]) (Liossi et al., 2019). Randomised controlled trials (RCTs) of intensive interventions including three or more disciplines found large effects for improvement in pain intensity (d = -1.19; 95% CI [-1.56, -0.82]), and disability (d = -1.47; 95% CI [-1.87, -1.07]), at 3-month follow-up (Hechler et al., 2015).

1.4.2.2 Psychological treatments (in-person): current evidence

The most commonly used psychological treatment for paediatric chronic pain is CBT (Miro et al., 2017). ACT, mindfulness, and hypnosis may also be used (Coakley & Wihak, 2017). The review by Caes, Fisher, et al. (2018) notes the strong evidence base for psychological treatments. Psychological treatments can be delivered standalone or as part of a multi- or interdisciplinary treatment programme (see definitions). The most recent meta-analytic review of face-to-face psychological therapies for children and adolescents with chronic pain (Fisher et al., 2018) included 47 studies, which were split into mixed chronic pain and headache. The review included RCTs that compared a psychological treatment, or a compound (multi- or interdisciplinary) treatment with credible primary psychological component, to another active treatment, treatment-as-usual or wait-list control. Findings showed that psychological therapies moderately improved post-treatment pain severity (SMD = -0.43, 95% CI [-0.67, -0.19], *p* < .01) and disability in mixed paediatric chronic pain conditions (SMD = -0.34, 95% CI [-0.54, -0.15], *p* <.01). Headache conditions showed improvement in pain intensity at post-treatment only (RR = 2.35 95% CI [1.67, 3.30], *p* < .01). Most effects were not maintained at follow-up, with the exception that children with mixed chronic pain maintained improvements in disability scores (SMD = -0.27, 95% CI [-0.49, -0.06], *p* < .01). Authors note the quality of studies was low, and they therefore had little confidence in the effect estimates. This review is complemented by a sister review of remotely-delivered psychological therapies (Fisher et al., 2019), which is described in section 1.6.1.

1.5 Online interventions for paediatric chronic pain

The success of interdisciplinary paediatric pain management is apparent. However, there are several barriers that make attending interdisciplinary, multimodal pain services difficult for young people and their parents. This includes time taken out of school to travel to clinics and associated financial concerns (Bender et al., 2011; Caes, Fisher, et al., 2018). For young people living outside of major cities, specialist pain services may be too far away to travel to (Elgar & McGrath, 2003), especially in complex cases where high levels of disability are apparent.

A solution to this problem of accessibility to pain services is the provision of online interventions, which have the potential to support young people to manage chronic pain with greater autonomy and independence. Expert opinion has highlighted the expansion of digital healthcare in paediatric chronic pain, with emerging interest in mobile health (Richardson et al., 2020). The impact of the COVID-19 pandemic, including closure of in-person clinics, redistribution of healthcare staff to acute care services, and ‘stay at home’ guidance, has led to rapidly increased implementation of online modalities in the clinical treatment of paediatric chronic pain. Since the beginning of 2020, online modalities of care have been increasingly used to support the self-management of adolescents with chronic pain, where appropriate (Eccleston et al., 2020). Additionally, online interventions offer a format that children and adolescents of the ‘digital native’ generation can associate with (Bolton et al., 2013). The majority of young children and 99% of adolescents (under 16-years) are already online (Ofcom, 2017a, 2019). Similarly, 98% of the older adolescent population (16 to 24-year-olds) use the internet (Ofcom, 2020). There are, however, some limitations to using online interventions in clinical practice, particularly in paediatric care. This is discussed further in Paper 1 (see section 4.5).

Nonetheless, no online interventions that specifically target adolescents or young people have been developed in a UK healthcare context. The CQC note that transitional healthcare services should be targeting young people between the ages of 14 and 25-years, and it is important that specifically targeted services are available for young people with complex physical health needs (CQC, 2014). To develop an online (or ‘digital’) intervention for young people with chronic pain, their physical, psychosocial, and developmental needs must be considered. This warrants the use of established intervention development frameworks that (i) consider the complexity of chronic pain as a condition, including the complex nature of interdisciplinary treatment, and (ii) maintain a user-centred approach that carefully considers young people’s needs. These development frameworks, and their use in the current thesis, are explained in the proceeding Methodological Approaches chapter (Chapter 2).

1.6 Reviewing online interventions and internet use in young people with chronic pain

The first stage of the Medical Research Council (MRC) framework, and the Person-Based Approach (PBA) to digital health intervention development (described in 2.1), involve conducting literature review(s). The MRC framework seeks to gain an understanding of any similar interventions that have been developed and/or trialled (MRC, 2008), whereas the purpose of reviewing within the PBA is to collate studies that help to identify contextual issues, barriers, and facilitators, relevant to intervention development for the population of interest (Morrison et al., 2018).

Although Paper 1 (Chapter 3) presents a review, there are other systematic reviews that have been conducted in the area of online paediatric chronic pain management, which must also be considered in light of developing novel interventions. Additionally, other research that is of importance to contextual understanding prior to developing an online intervention, has been conducted in this area. The next sections provide a narrative overview of: (1) findings from other systematic reviews that have been conducted, (2) research relating to the expansion of mobile health in chronic pain, and (3) other research on internet use in adolescents with chronic pain.

1.6.1 Systematic reviews of online interventions

An in-depth review of existing online multidisciplinary interventions for paediatric and adolescent chronic pain, focusing on the content they include and development approaches used, is provided in Chapter 4 (Hurley-Wallace et al., 2021). The term ‘multidisciplinary’ is used in this paper, as there has been discussion between academics as to whether online interventions can be truly interdisciplinary, as this would involve collaboration between clinicians. However, the term interdisciplinary is used throughout the current thesis, as these interventions are indeed working towards the same biopsychosocial treatment goals (individual treatment modalities are not evaluated separately) (IASP, 2018a).

As aforementioned, there are other important systematic reviews, including meta-analyses that have been conducted, in the area of online paediatric pain management. These reviews focus on: (i) the availability of online assessment tools and interventions for paediatric pain (Higgins et al., 2018), and (ii) the efficacy of online psychological interventions for paediatric chronic pain (Fisher et al., 2019). The following paragraphs provide a summary of these two reviews.

A systematic review of the availability of ‘e-health’ tools (computer and app-based tools) for paediatric pain, including pain assessment tools and digital/ online pain management interventions, identified a total of 53 tools that had been developed. These tools were intended for a range of conditions, including acute procedure-related, cancer-related, disease-specific, postoperative, or chronic pain (Higgins et al., 2018). Twenty-six e-health tools focused on chronic pain conditions, and 15 of these were focused specifically on chronic pain management. Assessment tools and interventions were delivered using a mixture of technologies, including computers, mobiles, and other electronic devices. In terms of availability, only 13 tools out of 53 tools were found to be available to patients or the public. Time, infrastructure, and funding were highlighted as the main barriers to implementing e-health tools that had been developed by researchers.

The efficacy of online psychological approaches to paediatric chronic pain management has been investigated (Fisher et al., 2019). Similarly to its sister review of face-to-face interventions (Fisher et al., 2018), the online interventions in this review were required to primarily deliver psychological treatment and contain recognisable psychotherapeutic content. Studies were RCTs, and the intervention aim had to be on improving pain outcomes and functional disability (or both), as opposed to improving mood (Fisher et al., 2019). This review found 10 studies, which were split into mixed chronic pain and headache. All of the studies delivered CBT. No beneficial effects were found post-treatment for mixed chronic pain and there was a lack of follow-up data. For headache, there was a significant reduction in headache severity at post-treatment only (RR: 2.02, 95%CI [1.35, 3.01]). Authors highlighted findings were likely due to low quality evidence, and that more high quality studies in this field are needed to increase confidence in the use of online psychological interventions for young people with chronic pain.

1.6.2 Mobile health (m-health) in chronic pain

Expert opinion has highlighted emerging interest in m-health in the field of paediatric chronic pain (Richardson et al., 2020). The shift towards m-health has been explored in the adult pain literature, where online interventions targeting paediatric populations have only been adapted for mobile use in the last 1-2 years.

A critical appraisal of the content of currently available pain mobile apps (adults) has been conducted by Lalloo et al. (2015), finding that apps identified had not incorporated input from healthcare professionals in the field, and had not been tested for effectiveness. Another quality review of smartphone applications for pain management supports this evaluation, finding that apps had been developed with little input from healthcare professionals and required more rigorous testing to evaluate outcomes (Portelli & Eldred, 2016). These are important findings, highlighting that m-health applications for chronic pain tend not to follow intervention development guidance, and are often developed commercially.

There are two online, multimodal paediatric chronic pain interventions cited in Paper 1 (Chapter 4) of this thesis that have released trials of their mobile versions since the last update of the systematic review. Hence, these trials of the mobile versions of iCanCope and WebMAP are summarised under the next subsection.

1.6.2.1 M-health in paediatric chronic pain

First, iCanCope with Pain™ (Stinson et al., 2014) has recently placed increased emphasis on trialling of its m-health components. iCanCope is a self-management intervention, wherein the original program architecture included predominantly computer-based, as well as app-based components. Most recently, iCanCope has been developed as a smartphone-based app and has been successfully piloted in adolescents with JIA, indicating that implementation via a paediatric rheumatology clinic was feasible (Lalloo et al., 2019; Lalloo et al., 2020). Preliminary findings indicated clinically meaningful reductions in pain intensity (more than 1 scale point), thus indicating a future trial investigating effectiveness should be pursued.

Second, a key intervention that has recently adapted from being primarily computer-based to being mobile-based is the multimodal CBT intervention, WebMAP (or WebMAP2) (Palermo et al., 2009; Palermo et al., 2016). A multicentre RCT of the computer-based version of WebMAP has been conducted with 273 adolescents aged 11 to-17-years (Palermo et al., 2016). The intervention produced several beneficial effects, including significantly improved activity limitation (Child Activity Limitations Interview; CALI) (Palermo et al., 2004) from baseline to 6-month follow-up for the treatment group, compared to an internet-education-only group (p = .03, effect size (d) = -0.25). These findings indicate high efficacy. Several secondary analyses of the data from the multicentre RCT of WebMAP have been conducted (Law et al., 2018; Murray, de la Vega, et al., 2019; Chen et al., 2019).

Nonetheless, this successful intervention has now been adapted for mobile use (WebMAP mobile) and evaluated separately using a stepped-wedge cluster randomised trial (Palermo et al., 2020). The aim of the trial was to evaluate real-world usage and effectiveness of the intervention. Findings indicated that adolescents who used WebMAP perceived greater improvement in their pain condition at post-treatment (d = 0.54, p <.05) and 3-month follow-up (d = 0.44, p < .05), compared to the usual care group. Higher engagement with the intervention was associated with significant reductions in pain intensity and disability (CALI), which was maintained at follow-up (d = -0.57, p = <.05 and d = -0.38, p < .05, respectively) (Palermo et al., 2020). The research team used RE-AIM, a public health impact framework (Dzewaltowski et al., 2004) to evaluate implementation outcomes. These findings indicated that providers had positive attitudes about the helpfulness of the self-management focused digital intervention, with intentions to endorse the intervention, and all stakeholders found the treatment acceptable.

The trialling of WebMAP is a good example of iterative intervention development over several years, where the recent trial focusing on real-world usage in the mobile version (Palermo et al., 2020) is imperative to the intervention’s future success. This recent trial shows the importance of measuring engagement when trialling of online interventions in young people with chronic pain, as engagement was related to therapeutic outcomes.

1.6.3 Internet use in adolescents with chronic pain

Related to online interventions, researchers in paediatric chronic pain are beginning to acknowledge and investigate internet use for chronic pain education and pain management. This is arguably an important context for developing online interventions, as interventions must be able to be engaging and impactful comparatively to online resources that are already being used. As stated prior, adolescents and young adults of the current generation are heavy internet users (Ofcom, 2019, 2020), hence internet use should be considered as a vitally important context. The PBA emphasises the importance of understanding context when developing digital health interventions (Yardley et al., 2016; Yardley et al., 2015), and this has been echoed in recent guidance based on expert consensus (O'Cathain et al., 2019). In relation to adolescent chronic pain, only one relevant study of internet use has been conducted.

A scoping review and content analysis has specifically investigated YouTube videos that include adolescents with chronic pain (Forgeron et al., 2019). The search returned 18 videos, which primarily covered multidisciplinary and alternative treatments, although little detail was provided in the videos. The videos also discussed the impact of pain on daily life, and moreover, there was an overarching message in the comments section that adolescents with chronic pain are ‘not alone’. This is a clear reflection that adolescents are using YouTube as a platform for social support, rather than purely for information-seeking about pain or pain management. Crucially, this thesis adds to current knowledge of adolescent internet and social media use in relation to chronic pain management.

1.7 Thesis aims

The overarching aim was to lay the groundwork for developing a novel online intervention for the management of adolescent chronic pain. This was served by the following 6 aims and associated objectives:

1) Chapter 1: To summarise appropriate methodological approaches to online health intervention development and explain why particular approaches and methods were selected for use in the current thesis. Objectives included:
   a. To provide an overview of the Medical Research Council guidance and Person-Based approach and explain why these approaches were used in the current thesis, as opposed to alternatives.
   b. To describe the data collection and analysis methods chosen for the papers presented in the current thesis and explain why these methods were employed, in this particular order, as opposed to alternatives.
   c. To provide a brief commentary on how quality is demonstrated in qualitative research.
2) Chapter 2: To summarise theoretical models of chronic pain and provide an overview of the biopsychosocial approach to chronic pain assessment and management. Objectives included:
   a. To summarise theoretical models of chronic pain onset and maintenance and discuss how these models can be applied to adolescence.
   b. To provide an overview of the biopsychosocial approach to chronic pain assessment and management, with reference to paediatric and adolescent research that has been conducted in each domain (biological, psychological, social.)
3) Paper 1: To review and critically evaluate the content of online interventions that have been developed for the management of child and adolescent chronic pain. Objectives included:
   a. To identify which multidisciplinary chronic pain management strategies are reflected within the content of existing online multidisciplinary interventions for paediatric chronic pain management.
   b. To map the content of existing online interventions for paediatric chronic pain to evidence-based clinical guidelines for multidisciplinary pain management and evaluate how well each chronic pain management strategy is addressed by the identified interventions.

    c. To summarise and evaluate the development approaches used by the identified interventions and provide practical recommendations for intervention development teams.

4) Paper 2: To identify the needs of adolescents in the UK for a new online chronic pain management intervention. Objectives included:
    a. To investigate which online resources adolescents currently use to manage chronic pain and mental health.
    b. To investigate which online resources parents use to help them understand their child’s chronic pain
    c. To investigate which interdisciplinary techniques adolescents with chronic pain consider most helpful.
    d. To investigate what content and features adolescents and parents would like to see in a new online chronic pain management intervention.
5) Paper 3: To explore the experiences of adolescents with chronic pain when seeking information about chronic pain using the internet. This included experiences of searching the internet using search engines (e.g., Google), health information websites (e.g., the NHS website), and social media (Facebook, YouTube, Instagram). Objectives included:
    a. To explore adolescents’ experience of chronic pain management strategies, including pain management techniques and advice provided by healthcare professionals, self-management strategies, and any internet resources that have helped facilitate this.
    b. To explore which resources adolescents believe have been the most helpful, and/or may have been potentially helpful for managing chronic pain, if available.
    c. To understand why certain resources are viewed as especially helpful for managing pain, or are noticeably popular, and why young people turn to these resources as opposed to, or as adjunctive to, in-person or online alternatives.
6) To discuss findings from the research studies presented in the current thesis and provide recommendations for researchers and clinicians in the field of adolescent chronic pain management.
    a. To summarise the findings presented in papers 1, 2 and 3.
    b. To discuss findings in the context of other research that has been conducted on internet use with adolescents with chronic pain.
    c. To propose recommendations (guiding principles) for clinicians and researchers to help guide online intervention development for UK-based adolescents and young adults with chronic pain.

d. To reflect on how theoretical models could be utilised by development teams seeking to develop an online intervention for adolescent chronic pain.
e. To suggest improvements to the NHS website based on the needs of young people with chronic pain that have been identified.
f. To provide recommendations for clinicians working with 16 to 24-year-olds with chronic pain, based on findings from papers 2 and 3.
g. To identify potential areas of future research in adolescent chronic pain management.
h. To reflect on the strengths and limitations of the current thesis.

1.8 Thesis: summary of chapters

The introduction to this thesis (Chapter 1) has presented relevant background on chronic pain in paediatric and adolescent populations (up to 24-years) and discussed approaches to pain management as used in clinical practice. The need for online interventions for young people with chronic pain was discussed. A narrative review was used to provide an overview of systematic reviews that have been conducted in this area and summarise relevant existing literature relating to internet use in adolescents with chronic pain.

Chapter 2 presents the methodological approaches used in this thesis. This includes the intervention development approaches drawn upon, as well as a discussion of the research methods that were utilised to match these approaches. Descriptions of the intervention development approaches used, and potential alternative approaches are provided, alongside a rationale as to why the Person-Based Approach was selected as a central approach for this project. The initial vision for the online intervention this thesis lays the groundwork for, and how this changed, is described. The methods used within this thesis are explained and alternatives are briefly discussed. The order of studies, in-line with the selected approaches and methods, is rationalised. The chapter finishes with a commentary on how quality is assessed in qualitative research.

Chapter 3 presents theoretical models and approaches that are relevant to the management of chronic pain in young people. First, the Fear-Avoidance and Interpersonal Fear-Avoidance Models of chronic pain onset and maintenance are summarised. A discussion of how these models can be applied to adolescents with chronic pain is provided. The developmental model of family and parent influences in paediatric chronic pain is also explained. Second, the biopsychosocial approach to chronic pain assessment and management is summarised, with reference to paediatric and adolescent research that has been conducted in each domain (biological, psychological, social).

Paper 1 (Chapter 4) reviews existing online interventions that have been developed for paediatric and adolescent chronic pain and closely evaluates the content included in each. Across interventions, physiotherapy and non-pharmacological physical therapies were the least well represented chronic pain management strategies. The review identified that no interventions for paediatric chronic pain have been developed in a UK context, and that self-management and CBT-based interventions targeting adolescents have been largely successful (Hurley-Wallace et al., 2021). The review also found that only one intervention, developed in Canada, had utilised a user-based development approach.

An investigation of the needs of adolescents with chronic pain in the UK was pursued in Paper 2 (Chapter 5) (Hurley-Wallace et al., 2020). In this mixed-methods paper, needs for a novel online intervention were assessed by surveying UK-based adolescents (self-report for 16 to 18-year-olds) and parents (parent-proxy report for 12 to 15-year olds). Descriptive summaries of online resources use (for chronic pain management, and mental health management) are provided, as well as barriers and facilitators to using a new intervention, as identified by adolescents and parents. The survey also presents a qualitative content analysis to explore initial thoughts on a new online program for chronic pain management. Findings highlights a new resource would be endorsed by UK-based adolescents. The survey also identified a knowledge gap surrounding young people’s use of online resources for pain management.

In Paper 3 (Chapter 6), population-level contextual internet and social media use are explored using qualitative interviews with older adolescents (16 to 24-year olds). A reflexive thematic analysis was conducted, which identified four key themes. Three of the themes were strongly interrelated: ‘Trustworthy information, or experiences?’, ‘Diagnostic labels in a digital world’, and ‘The online chronic pain community’. The last theme, ‘A mind and body approach to self-management’, was indirectly related to the community theme. A discussion of findings is presented, focusing on clinical implications and application to intervention development.

A general discussion is presented in Chapter 7, which begins by summarising findings from papers 1, 2 and 3. The discussion follows to provide recommendations for researchers and clinicians in the field of adolescent chronic pain management. Guiding principles for intervention developers are outlined, and potential integration of theory (and which ones) into the design of a new intervention is discussed. Areas for future research are highlighted, and the strengths and limitations of the current thesis are reflected upon.

Chapter 2 Methodological Approaches

This chapter provides (i) an overview of the intervention development approaches used in the current thesis, including a discussion of potential alternative approaches, (ii) a description of the methods selected for use in the papers presented in the current thesis, including an explanation of why these methods were chosen, (iii) rationale as to why the chosen methods were employed in this particular order, and (iv) a brief discussion on how quality is demonstrated in qualitative research.

2.1 Intervention development approaches

A variety of frameworks and approaches can be applied to the development of interventions aimed at improving health (O'Cathain et al., 2019). Recent guidance has highlighted the importance of clarity in the reporting of intervention development studies in health research, which includes specifying the development approach that is being used (Duncan et al., 2020).

The current project draws from guidance provided by the Medical Research Council (MRC) for developing complex healthcare interventions (Craig et al., 2008; MRC, 2008). As recommended for complex health interventions (O'Cathain et al., 2019), the MRC 'development' stage guidance is supplemented with detailed guidance from the Person-Based Approach (PBA) to developing digital health-related interventions (Yardley et al., 2015). The subsections that follow provide: (i) an overview of the MRC guidance, (ii) an overview of the PBA, including research examples from projects that have utilised this approach, and (iii) an explanation of how these approaches were used in the current project, including a brief explanation of alternative intervention development approaches, and how these could be used synchronously or separately.

2.1.1 Medical Research Council guidance: developing complex interventions

The MRC guidance on developing and evaluating complex interventions outlines four key stages: development, feasibility and piloting, evaluation, and implementation. An intervention is considered complex when it contains several interactive components. There are several dimensions of complexity, which are outlined in Box 2 of the MRC guidance (MRC, 2008; Craig et al., 2008). Moreover, there are several implications of complexity that can impact development and evaluation. For example, lack of impact may reflect implementation failure, rather than indicating ineffectiveness. The following section focuses on the aspects of this guidance that relate specifically to the development of health interventions. Initially, the MRC guidance suggests six questions to ask oneself when developing an intervention aimed at improving health (Box 1 of MRC guidance) (MRC, 2008, p. 4):

- “Are you clear about what you are trying to do: what outcome you are aiming for, and how you will bring about change?
- Does your intervention have a coherent theoretical basis?
- Have you used this theory systematically to develop the intervention?
- Can you describe the intervention fully, so that it can be implemented properly for the purposes of your evaluation, and replicated by others?
- Does the existing evidence – ideally collated in a systematic review – suggest that it is likely to be effective or cost effective?
- Can it be implemented in a research setting, and is it likely to be widely implementable if the results are favourable?”

There are then three actions outlined for developing complex interventions, which should be completed before moving to any piloting or evaluation, to establish that the intervention is likely to have a worthwhile effect (Craig et al., 2008). In brief, these are:

- Identifying existing evidence about similar interventions, including conducting a systematic review if relevant.
- Identifying and developing theory about the process of change, which can be supplemented by new primary research where necessary.
- Modelling the process and outcomes through iterative design and refinement. This might also include prior economic evaluation. Any identified weaknesses can be refined at this stage, though if weaknesses are detrimental, it may be the case that a full scale evaluation should not be pursued.

Whilst the MRC guidance is a good starting point for developing health interventions, particularly as it also outlines what makes an intervention ‘complex’, the ‘development’ stage is markedly brief, and requires supplementation with more detailed approaches to help guide intervention design and development (O'Cathain et al., 2019). This rationale was affirmed in intervention development guidance that was formulated based on an expert consensus study (O'Cathain et al., 2019), which utilised reviews and qualitative interviews with people from development teams to create a framework of actions (intended for consideration by intervention developers). Involvement of stakeholders, including users of the intervention, was highlighted in the action points, as was undertaking primary data collection, understanding context, and use of theory.

2.1.2 The Person-Based Approach

The PBA (Yardley et al., 2015) provides specific guidance for the development of digital health-related behaviour change interventions. The approach provides a detailed description of how qualitative feedback from intervention stakeholders (for example patients, patients' families, and healthcare professionals) can be integrated iteratively into online interventions in three stages: planning, optimisation, and evaluation (Morrison et al., 2018). The planning stage focuses on collecting qualitative and mixed-methods research data, which can provide rich data on factors that impact engagement in potential users. The planning stage also recommends conducting a scoping review and, if appropriate, a systematic literature review. This can help to identify which barriers, facilitators and contextual issues have been reported by published studies conducted with the target population. Following the planning stage, guiding principles are formulated. These specify design objectives and key features of an intervention that will help to achieve these objectives (Morrison et al., 2018; Yardley et al., 2015). Guiding principles are intended to support engagement with intervention content by outlining core elements that should be included in the intervention design. The next stage of the PBA is optimisation. In this stage, interventions are modified based on user-feedback. Finally, the implementation and evaluation stages employ mixed-methods research to conduct process evaluations and understand individuals' experiences of a 'full' intervention.

In the process of intervention development, there is also recognition that the knowledge and expertise of healthcare professionals working in the area is important (Blandford et al., 2018). This expertise is often integrated through co-design of intervention content, sometimes called a partnership approach (O'Cathain et al., 2019). Healthcare professionals can also be identified as intervention stakeholders, using the PBA. Therefore, some aspects of intervention content that are developed can be non-dependent on user-views, and instead based on clinical expertise. Use of co-design was considered initially in the current project, however, this became less important as the project was adapted to focus on intervention planning only (see section 2.1.3.2).

The current thesis draws from the planning stage of the PBA to explore the context from which a UK-based online intervention for young people with chronic pain might be developed. To date, no such intervention has been developed in a UK context. It is arguable that the needs of adolescents in the UK may differ compared to adolescents in other western countries, such as the USA and Canada, based on their experiences of NHS healthcare and their experiences of chronic pain in different social contexts (Viner et al., 2012). Developing a deep understanding of target users' psychosocial context is central to the PBA (Yardley et al., 2015). There is also consensus among experts internationally that: (a) understanding context is important when developing complex healthcare interventions using any framework (O'Cathain et al., 2019), and (b) successful design of online interventions demands a user-centred approach (Yardley et al., 2016). Indeed, conducting qualitative research can provide population-level insights that may impact whether an intervention is successful or not (O'Cathain et al., 2019).

An important part of the psychosocial context that must be considered when developing an online intervention for adolescents with chronic pain is their use of the internet for seeking information about pain management. This is particularly important because adolescents are 'digital natives' (Ofcom, 2017a, 2019; Bolton et al., 2013). To be successful, any new intervention will need to be able to integrate with, and be equally as engaging as, online resources that are already being used. Similar qualitative research, drawing from the planning stage of the PBA, has investigated carers' experiences of using the internet to seek information about childhood eczema (Santer et al., 2015). The study followed previous qualitative research, which explored carers' experiences of managing childhood eczema in relation to treatment adherence (Santer et al., 2013). Arguably, understanding both the online and offline context of managing any health condition is important in shaping guiding principles for any digital health intervention.

Other research has utilised the PBA to explore the adolescents' values surrounding diet and physical activity, in light of developing health interventions (Strömmer et al., 2021). Qualitative interviews were conducted with adolescents aged 13 and 14-years. Thematic analysis found that the need to be healthy was not a strongly held priority by adolescents, and that improving health was only pursued if improvements could be achieved without compromising other things that they consider to be important, such as schoolwork and hobbies.

2.1.3 Use of methodological approaches in the current project

As described at the beginning of this section on intervention development approaches, the MRC guidance was supplemented with more detailed guidance from the PBA to determine the intervention development approach for the current project.

Nonetheless, there are a variety of alternative approaches to intervention development which may be used to enrich the MRC guidance (O'Cathain et al., 2019). This could include theory and evidence-based frameworks such as the Behaviour Change Wheel (BCW) (Michie et al., 2011; Michie et al., 2014) or the Theoretical Domains Framework (French et al., 2012). The guidance by O'Cathain et al. (2019) noted that theory-based interventions have been examined in a systematic review of reviews and were not found to be more effective than non-theory-based interventions (Dalgetty et al., 2019). However, theory use should still be considered, as long as supporting evidence of theory-effectiveness is clear.

The BCW is an important framework that could potentially be used, independently of other approaches (e.g., the PBA, or the MRC guidance), to develop an online intervention for young people with chronic pain, as the intervention would require young people to change their behaviour (Michie et al., 2011). A guide to designing interventions using the BCW has also been developed by Michie et al. (2014). According to the BCW, the first part of designing an intervention is understanding the target health condition and identifying which behaviours need to change. With regards to chronic pain, theoretical approaches are well-established, and the biopsychosocial approach underpins evidence-based interdisciplinary care. There is also some emphasis on stakeholder input in the BCW; the current thesis utilises some of the methods mentioned by Michie et al. (2014), including conducting interviews with young people. Because of this overlap, there is not necessarily a need to supplement the BCW with another user-centred approach such as the PBA.

A central framework for identifying target behaviours using the BCW is the COM-B model, which highlights three essential conditions for any behaviour to occur: capability, opportunity and motivation (Michie et al., 2014). One or more of these elements must be changed to successfully adjust behaviour for an individual, a group, or a population. Notably the components of the COM-B can also be integrated into an interview schedule; this is a key difference between conducting stakeholder interviews using the BCW verses the PBA, although both approaches recommend open-ended questions and an interpretative analytic approach.

The main reason the BCW was not central to the current project is because the BCW aligns better with changes to general health behaviours, which do not necessarily require input from medicine. In addition, the BCW is primarily a public health approach to intervention design, whereas the PBA is a psychology-based approach to development.

Alternatively, as in the current project, user-centred approaches, such as in the PBA (Yardley et al., 2015), may be employed, or any combination of published approaches may be used. The PBA is a psychology-based approach to intervention development, and thus has been central to the current research project. This approach was selected because it focuses on the psychosocial context of the person using the intervention, and how this may impact the health-related behavioural changes that the intervention is aiming to achieve. Improving chronic pain management requires a variety of behavioural changes, thus it is important to understand contextual factors that may hinder or support these changes. The PBA can also be easily integrated with psychological theories relevant to illness management, as well as with behavioural change techniques (BCTs), as is explained in the general discussion chapter of this thesis. Although the PBA is person-centred, the mechanisms of behaviour change that underpin digital health-related interventions remain important (Yardley et al., 2015).

2.1.3.1 Use of the PBA in the current project

The focus of the current project is on the planning stage of online intervention development, given that an in-depth exploration of psychosocial context had not yet been pursued for this UK-based target group. The exploration of context deepened as the project progressed, where Paper 2 in particular identified the use of a huge variety of online resources by young people for pain management. A summary of how the planning stage of PBA was used in this thesis, to formulate guiding principles, is provided in Figure 1.

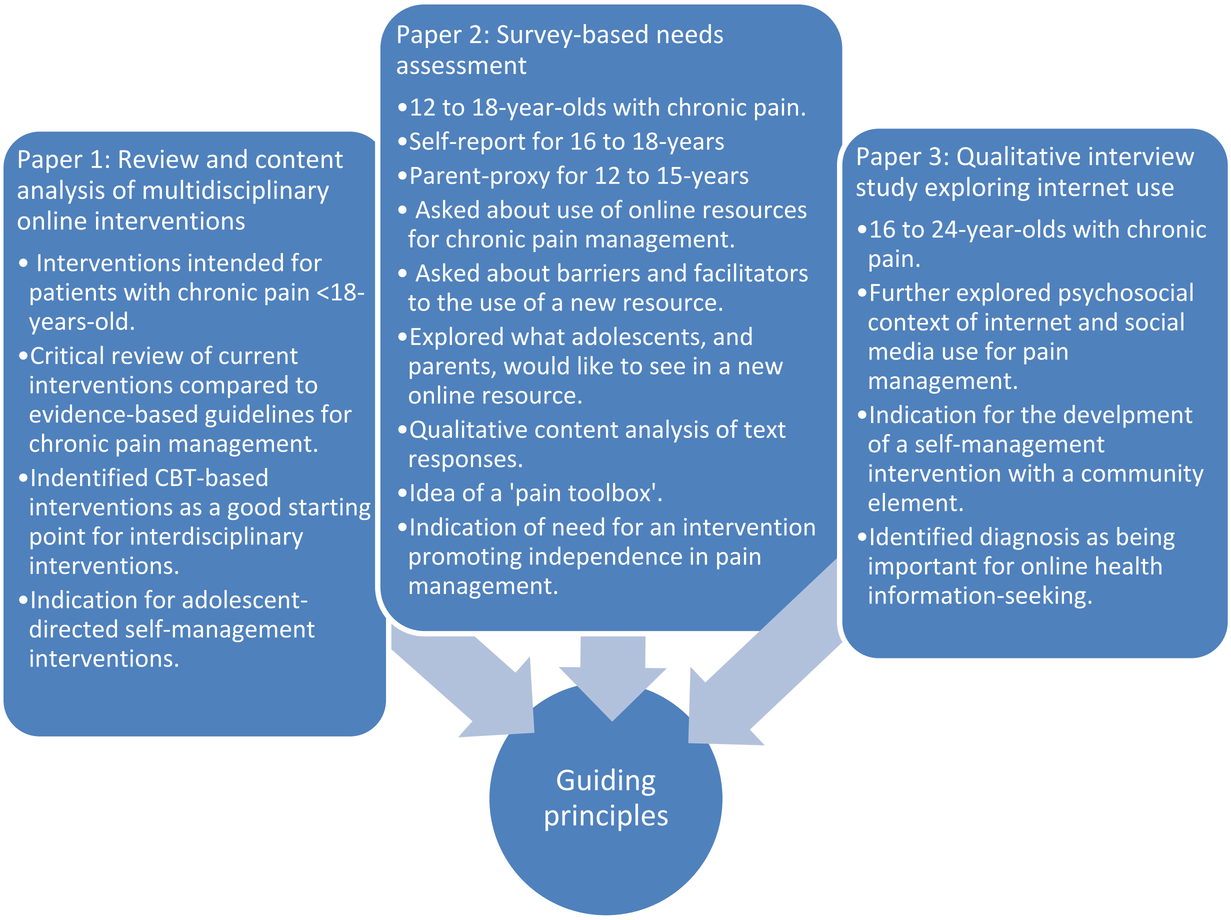

Figure 1. Summary visualisation of the planning stage of the Person-Based Approach (Yardley et al., 2015), as used in the current project.

In-line with the PBA, guiding principles are developed following the planning stage of development. Thus, guiding principles intended for intervention developers in the field of adolescent chronic pain are presented in the discussion chapter of the current thesis (see 7.3.1). These principles consist of the intervention design objectives and the key features of the intervention that will help to meet these aims (Yardley et al., 2015). Suggestions of how relevant psychological theories (and which ones) could be integrated into the development of interventions for adolescent chronic pain, in light of findings from the current thesis, are also discussed (see 7.3.2).

2.1.3.2 A flexible approach to intervention planning

Another point raised in the guidance developed by O'Cathain et al. (2019), was that developers often hold strong beliefs about the need for an intervention at the start of the process. It is important that intervention developers are open to change, which may include steps forward or backwards in the process. The next two subsections describe in detail what the vision for the intervention was, as well as how this changed, and why.

2.1.3.3 Initial vision for the intervention

The initial vision for the intervention for the current project was relatively vague, though the first thought was that this would be a web-based intervention, rather than app-based, because it would have contained a lot of content from several disciplines. As discussed in the introduction to this thesis, the gold standard of care in paediatric chronic pain is multi- or interdisciplinary, and so collaboration with specialists in chronic pain from medicine, nursing, and physiotherapy backgrounds (alongside the psychology team) was sought out to develop initial content ideas. The initial hope was that healthcare professionals would be involved in co-designing the intervention, after interviews with adolescents and parents had been completed. The collaboration was with the Pain Control Service at Great Ormond Street Hospital, where the behavioural target group were initially 12 to 17-year-olds. For this population, it was decided that development of some mirroring content for parents would also be important. In purely paediatric or younger adolescent populations, parental opinions are important to explore, as parents play a critical role in pain management at home, which is often overlooked (Palermo & Eccleston, 2009).

The physiotherapy and nursing team suggested creating physiotherapy videos for use within an online intervention; the addition of physiotherapy videos is also supported by research into interdisciplinary treatment options for paediatric chronic pain (Caes et al., 2018). In relation to patient safety, it was intended that information on medications and medical devices was to be outlined by the specialist clinicians only, and not informed by user views. Aside from this, the hope was that qualitative research with young patients and families attending the Pain Control Service would guide the first draft of content for the online intervention as the project progressed.

2.1.3.4 Adapting the project to situational changes: a new vision

Unfortunately, the collaborative project was halted due to the closure of the service during the COVID-19 pandemic in 2020. Because of this, the project had to be reconceptualised; this involved stepping back to focus on the planning stage of the PBA, rather than moving forward with content development and optimisation. This was decided due to the PhD timeline (and uncertainty surrounding funding extensions) and the lack of healthcare professional support available to co-design content. The mixed methods survey presented in Paper 2 was initially a background project, with the qualitative work at the forefront, in-line with the PBA and MRC guidance. Where qualitative interviews were not feasible within a hospital collaboration, findings from the survey were drawn upon to determine a new direction for the project. Quantitative findings from the survey revealed that 16 to 18-year-olds were using a vast array of online resources for pain management, and the qualitative content analysis also indicated that interventions including social support and encouraging self-management would be preferred. Thus, the qualitative study (Paper 3) was adapted to further explore the context of internet use in chronic pain, with the behavioural target group adjusted to this transitional care group of 16 to 18-year-olds. The development of content for parents was also dropped given new evidence (discussed in Paper 1), indicating that interventions with mirroring parent-facing content do not yield significant improvements in pain and disability in adolescents over 15-years (Murray, de la Vega, et al., 2019).

Young people in the UK are usually treated for chronic pain in accordance with adult healthcare guidance from age 16-years (NICE, 2021; Great Ormond Street Hospital, 2021). Context was therefore explored in relation to self-management in Paper 3, reflecting increased independence in condition management. Looking more closely at this age group and the literature on the age of adolescence (Sawyer et al., 2018), as well as CQC guidance on transitional healthcare for young people with complex physical health conditions (CQC, 2014), the behavioural target group was expanded up to 24-years.

The vision for the modality by which the intervention would be delivered also changed throughout the project. This started off as being a potentially ‘open to all’ online resource for young people with chronic pain, and their parents. This then changed, on clinician advice, to the development of an adjunctive resource for use within the Pain Control Service. When the project was reconceptualised, as described above, focus reverted back to an ‘open’ resource. However, the general discussion in the current thesis also proposes the potential for delivery via primary care services, based on insights from the qualitative interviews.

Lastly, over the course of the 4-years, the digital landscape has changed rapidly, and it is now clear that an online intervention developed for this target group would be best delivered in the form of a mobile application. As per the narrative review in the introduction, internationally-based interventions that are already successful are now being adapted from being web-based to being app-based (Palermo et al., 2020). The vision for a novel intervention for 16 to 24-year-olds with chronic pain, which is based on the guiding principles developed using insights from all three papers, is presented in section 7.3.4.

2.2 Methods

2.2.1 Data collection and analysis methods

The methods for all papers were carefully selected to follow the recommendations of the PBA. The use of a review and content analysis in Paper 1 stemmed from knowledge of the existing review by Higgins et al. (2018), which captured all of the relevant e-health interventions that have been developed in the field of paediatric pain. This same review search terms and databases were used, with adjustments to inclusion criteria to reflect interventions intended for chronic (rather than acute or procedure-related) pain. Indeed, the MRC guidance stipulates to conduct a systematic review if necessary (MRC, 2008; Craig et al., 2008), however, evaluation of intervention content and how content mapped to outcomes was also of interest. Unfortunately, the interventions that had been developed did not present process evaluations, so there was no feasible way to map content to outcomes.

A survey design was used in Paper 2 to gage initial thoughts on a novel intervention from target users, as no investigation had been done into this topic previously. Qualitative content analysis methodology (Elo & Kyngäs, 2008) was selected to analyse the open response question, which asked adolescents and parents their initial thoughts about a new online program to help with chronic pain. The analysis took a conventional approach to content analysis where coding categories were derived directly from the text data; this is the most appropriate approach when existing research on a phenomenon is limited (Hsieh & Shannon, 2005). Quantitative analyses were also conducted to gain a clearer descriptive picture of which resources were being used for pain management, as well as mental health management (due to high comorbidity of mood disorders in chronic pain, discussed in 3.2.2).

Semi-structured, individual interviews were used in Paper 3 to collect qualitative data. An interview guide was used to ensure topics explored during interviews were consistent with the aims of the research. However, a semi-structured guide is considered flexible enough such that interviewees may direct the conversation to related topical issues, which can then also be explored as appropriate. Semi-structured interviews were chosen for this study because interviews were intended to be steered by the research question (Willig, 2013b), and encourage storytelling about specific experiences of seeking chronic pain information online. Additionally, data from semi-structured interviews is compatible with reflexive thematic analysis (Braun & Clarke, 2019a), which was selected as the analytic technique for this study.

Qualitative data analysis followed the six stages of (reflexive) thematic analysis, as outlined by Braun and Clarke (2006). This included reading and re-reading interview transcripts, then systematically generating qualitative codes, using an inductive, data-driven approach. Data was coded in meaning units (Joffe & Yardley, 2004). Existing codes were iterated throughout the coding process, and notes about interesting features of the whole dataset were made throughout, as well as referring back to interview field notes. Once the coding manual had been finalised, codes were collated into clusters of meaning to create candidate themes (Braun et al., 2019). Candidate themes were tested out in relation to the dataset and research objectives, then expanded upon using quotes to evidence claims. Triangulation with the research supervisory team was done to ensure the overall fit of themes to the coded dataset. Themes were iterated, a thematic map was created, and theme names were finalised. The study report includes the use of quotes to evidence claims.

2.2.1.1 Alternative methods

A systematic review and subset meta-analysis exploring the effectiveness of online interventions in paediatric chronic pain was also considered for Paper 1. However, there are other reviews in this area that report efficacy of online interventions in paediatric and adolescent chronic pain in this way, and the current authors updated this review in the 2nd year of the PhD research project timeline (Fisher et al., 2019). As such, a review focusing on the efficacy of online interventions would not have added to current knowledge.

Focus groups were also considered as a data collection method for the qualitative study, however the research question was centred around individual experiences of internet use, for a wide variety of pain conditions, and the interaction among participants was not considered a data source of interest (Willig, 2013b). Focus group dynamics also have potential to cause distress in group members, particularly given the sensitive nature of chronic pain as a topic. Potential distress in an online focus group setting was additionally highlighted by the PPI group, thereby ruling out focus groups.

2.2.2 Order of studies within a mixed methods approach

As discussed in ‘A flexible approach to intervention planning’, the order of studies was adapted from conducting the qualitative study first, due to reconceptualization of the project following the impact COVID-19 on conducting this work. Mainly, the closure of the Great Ormond Street Pain Control Service. Initially, the qualitative study and the mixed methods survey were being conducted synchronously with the review study, in-line with the PBA.

As shown in Figure 1, although the target group has been adjusted upwards to focus on older adolescents, all three studies contributed to the guiding principles presented in the general discussion (Chapter 7). It was also necessary to reconceptualise the qualitative study after the initial project plan was interrupted. This included re-gaining ethical approval via a new application for a new target user group; this was absolutely necessary due to the uncertainty of when the hospital clinic would reopen, in the context of a global pandemic. By chance, the review of interventions presented in Paper 1 contains a majority of interventions that are targeted at adolescents, and therefore, these insights remain useful for the development of guiding principles for a 16 to 24-year-old target group. Because of the way the survey was designed for Paper 2, with 16 to 18-year-olds self-reporting, the insights from the qualitative content analysis also relate to this older age group.

In summary, and as in Figure 1, these studies should be considered as contributing together to the formation of guiding principles, rather than as a sequence of studies that leads to the insights found in the qualitative interviews in Paper 3. Focusing on the psychosocial context of internet use in Paper 3 aligns with the PBA. Whilst the focus of the interview study changed slightly based on insights from Papers 1 and 2, it also became clear that the interview questions needed adapting as a more thorough understanding of the PBA was gained throughout the course of PhD learning.

2.3 Quality in qualitative research

Demonstrating quality in qualitative research is markedly different compared to how quality is assessed in quantitative work. Where qualitative research is interpretative, such as in reflexive thematic analysis (Braun & Clarke, 2006, 2019a), constructs such as reliability and replicability are inappropriate, as the researcher offers just one of many interpretations of a phenomena (Yardley, 2000). Hence, when conceptualising and conducting a qualitative research study, it is important to ask oneself several questions about how the research demonstrates quality. This can be done by ensuring the research adheres to one of the available quality of reporting checklists, such as the JARS-qualitative (Levitt et al., 2018), CASP or COREQ (Tong et al., 2007), which have recently been summarised and discussed in an editorial by the British Journal of Health Psychology (Shaw et al., 2019). The JARS-qualitative was recommended as a robust way of assessing the quality of qualitative research, which is applicable across different qualitative methods and epistemological stances. The JARS-qualitative checklist was utilised in the interview study presented in Paper 3 of the current thesis.

Yardley (2000) also provided an in-depth discussion of the issue of quality in qualitative research, outlining four key characteristics of good qualitative research, which are adaptable to a variety of different methods and stances. First, ‘sensitivity to context’ refers to exploring knowledge that already exists and developing a robust conceptual and theoretical (if appropriate) understanding of the phenomena, prior to undertaking the research itself. In addition, qualitative researchers should consider the context of the work, such as social and cultural settings and potential ethical issues. Another important consideration is the relationship between the researcher and the participant, as well as the recruitment strategy and how this may affect respondents. Qualitative analyses should also include some reflection on the context of the study, especially if there is unexpected or unique data – this should be thoroughly thought through and discussed in the study report. Second, the characteristic of ‘commitment and rigour’ is important. This considers the researchers engagement with the research, as well as their competence and skill. For example, it should be clear that the researcher has been immersed in the data, and the analysis is not superficial. Rigour also includes triangulation of the researcher’s interpretation with others’ interpretations. Third, ‘transparency and coherence’ stipulates that the researcher should be able to demonstrate clearly how they got from point A to B, such as proving a coding manual as a supplement to a thematic analysis, for example. There should also be an open reflection in the research report on how researcher’s viewpoint (including their context and epistemological standpoint) impacted the qualitative analysis. Lastly, the fourth characteristic ‘impact and importance’ asks in which ways the research enriches our understanding and emphasises a consideration of the scope of the impact. For example, qualitative researchers should consider who is it important to present the findings to, and whether this can impact change to policy or practices.

The characteristics of good qualitative research outlined above (Yardley, 2000) are reflected in the aforementioned quality checklists for qualitative research. However, this demonstration of quality look vastly different between reports of different qualitative methods. For example, demonstrating quality in a framework analysis would look different to how quality is demonstrated in a thematic analysis. Even within types of thematic analysis, there are styles such as ‘codebook’ style thematic analysis, which would require less information about the perspective on an individual researcher (as this is usually done in a team), although greater consideration is needed regarding how the ‘codebook’ is developed (Braun & Clarke, 2021), and this must be reported clearly. This is an example of where some qualitative methods are less interpretative than others, with one of the most interpretative approaches being Interpretative Phenomenological Analysis (IPA) (Smith, 1996), and the least interpretative being ‘coding reliability’ thematic analysis, which is considered to have quantitative underpinnings (Braun & Clarke, 2021; Braun et al., 2019).

Chapter 3 Theoretical Frameworks

3.1 Theoretical frameworks of chronic pain

This chapter seeks to summarise theoretical models of chronic pain and provide an overview of the biopsychosocial approach to chronic pain assessment and management. First, this chapter summarises the Fear-Avoidance and Interpersonal Fear-Avoidance Models, which are models of chronic pain onset and maintenance that can be applied to childhood and adolescence. The developmental model of family and parent influences in chronic pain is also explained. Second, this chapter provides an overview of the biopsychosocial approach to chronic pain assessment and management, with reference to paediatric and adolescent research that has been conducted in biological, psychological, and social domains.

3.1.1 The Fear-Avoidance model of pain

The Fear-Avoidance (FA) model, originally referred to as an ‘exaggerated model of pain perception’ (Lethem et al., 1983), explains that both pain sensation and an individual’s emotional reaction contribute to pain perception. The FA model highlights that fear of pain represents a key emotional component of pain perception, where there are two coping responses available: confrontation or avoidance (Lethem et al., 1983). In updated terminology this is known as approach or avoidance coping, where avoidance coping strategies leads to maintenance and exacerbation of fear, and therefore maintenance of pain. On the other hand, using approach coping strategies allows for a rational assessment of the pain experience, which is likely to result in effective rehabilitation.

The most well-known model of FA is was developed by Vlaeyen and Linton (2000). In this model, pain catastrophizing (i.e., when pain is interpreted at threatening) leads to a vicious cycle of fear-avoidance, negative affect, and pain. This results in further catastrophizing, thereby continuing the cycle. The most recent version of the FA model for chronic pain has been outlined by Vlaeyen et al. (2016), where it has been argued that the model needed to be related to the experience of chronic pain and the cycle of pain-related disability (Crombez et al., 2012). This latest version of the FA model starts with nociception (physiological response to a pain stimulus), followed by the experience of pain. Catastrophizing then leads to pain-related fear, resulting in avoidance and/or hypervigilance (increased awareness and attention towards pain). This then leads to interference with valued life activities (or ‘pain interference’), negative affect (e.g., depression), and disuse of the painful area. Disuse is likely to result in increased pain and disability; combined with negative affect and declines in other areas of functioning (e.g., psychosocial) the experience of pain is likely to worsen as the cycle continues (Vlaeyen et al., 2016). This model helps to explain how pain can become chronic in nature, as well as how chronic pain is maintained - through a continuous cycle of fear and avoidance.

3.1.1.1 The FA model in children

The FA model has been investigated with application to children and adolescents using multiple structural equation models. This investigation used a cross-sectional sample of 350 young people aged 8 to 17-years, recruited from a multidisciplinary pain clinic. Measures included child-reported pain intensity, pain catastrophizing, pain-related fear, functional disability, and depressive symptoms. Findings indicated that pain severity predicted pain catastrophizing, which predicted pain-related fear, which predicted avoidance, which predicted functional disability (Simons & Kaczynski, 2012). Analyses found that this model, predicting functional disability, was a good fit for children and adolescents. However, developmental differences were apparent between older and younger children in the study. Pain-related fears had a high impact on avoidance of activities for adolescents (13 to 17-years), compared to younger children (8 to 12-years). There was also a stronger indirect relationship between catastrophizing and activity avoidance for adolescents, compared to younger children. Pain duration had a greater influence in the model for younger children, compared to adolescents, where shorter pain duration was associated with higher pain intensity.

The FA model is applicable to children and adolescents, however developmental differences in cognition and emotion must be considered when this theory is applied in a clinical context. Additional research provides some indication that developmental age-related changes impact cognitive biases in relation to chronic pain. In particular, age can impact catastrophizing, which in turn impacts a child or young person’s experience of pain; this predictive association of age by catastrophizing on pain was found to be strongest in adolescents with chronic pain than in younger children (Tran et al., 2015; Lau et al., 2018). This insight can be matched with findings from Simons and Kaczynski (2012). Cognitive biases are more likely to develop with increasing cortical maturity in adolescence, which explains why cognitions about pain (pain-related fears and catastrophizing) may have more influence on the maintenance of chronic pain in adolescence.

3.1.2 The Interpersonal Fear-Avoidance Model

Of key relevance to the current thesis, Goubert and Simons (2013) have outlined the Interpersonal Fear Avoidance Model (IFAM) of pain in children and young people, which incorporates additional family systems factors. Parents play an important role in shaping their child's experience of pain; the IFAM is an extended Fear-Avoidance model that includes parent cognitive, affective, and behavioural factors, which are widely theorised to impact child pain and disability outcomes.

The IFAM is depicted in Figure 2. In the centre of the model is the FA cycle experienced by a child or young person; this is an adaption of the vicious cycle described in the model by Vlaeyen and Linton (2000). Around the outer edge of the IFAM are the parents' perceptions of their child's pain, as well as impacts of a child's pain on parents, where the direction of the arrows shows where these impacts on parents' feedback into the child's FA cycle. For example, child pain catastrophizing is interpreted through both a child's pain expression and through a parent's own lens of catastrophic thinking. Parental pain catastrophizing can then lead to fear, and thereby result in protective behaviours towards the child. Protectiveness may then potentially lead to greater functional disability if this limits the child's activities. Parents are also prone to getting caught in their own cycle of avoidance and activity restriction, as a consequence of their child's chronic pain (Simons, 2016).

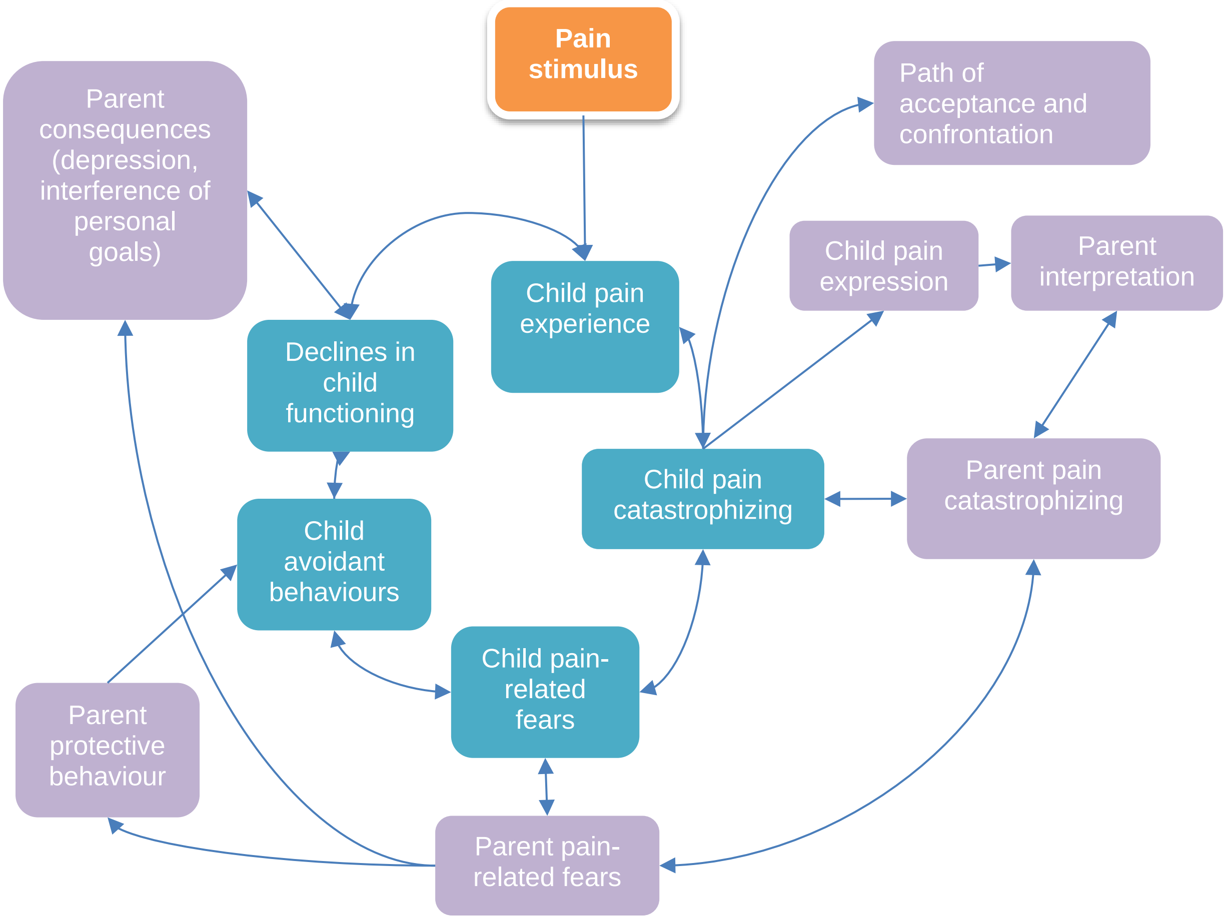

Figure 2. The Interpersonal Fear-Avoidance Model of Paediatric Chronic Pain (Goubert & Simons, 2013)

A recent longitudinal examination of the IFAM (Neville, Kopala-Sibley, et al., 2021) has also investigated the roles of parent and child intolerance to uncertainty as factors in the model. Intolerance to uncertainty (parent and child) was found to contribute to increased pain interference (increased child disability/ declines in child functioning) via parent protectiveness, and the child's pain catastrophising and pain-related fears.

3.1.3 The developmental model of family and parent influences

A developmental model conceptualising family and parent influences on paediatric chronic pain and disability has also been outlined (Palermo et al., 2014). In this conceptualisation, developmental factors involved a child's perception and response to pain (physiological, psychological, social, and emotional changes) have a bi-directional impact on both family-level functioning, and parent-level functioning. Interruptions to family functioning are also theorised to have a bi-directional impact on the functional disability of parents (Palermo et al., 2014). As such, the parents' emotions and behaviours can impact both family-level and child-level functioning. In this model, changes to the developmental goals of the child can change the goals of the family system. In particular, the transition to independence that occurs during adolescence is often delayed in chronic pain (Rosenbloom et al., 2017), thereby impacting the functioning of the family as a unit. For example, research on sickle-cell disease has indicated that parents tend to play a significant role in managing their child's healthcare into young adulthood (Oliver-Carpenter et al., 2011). This developmental conceptualisation of chronic pain is supported by a systematic review, which found that adolescents with chronic pain have poorer family functioning compared to families of healthy children and adolescents. Poorer general family functioning was indicated by less cohesion, less organisation and more intra-family conflict (Lewandowski et al., 2010). This developmental model reveals complex cycle of impact that often begins with pain, where many types of chronic pain conditions tend to cluster in families (Palermo et al., 2014).

Indeed, both the developmental model and the IFAM overlap substantially with Family Systems Theory, which stipulates that families are an interactive collection of subsystems; changes in one subsystem influence changes in all others (Guite et al., 2018; Kazak, 1989). The concept of 'chronic pain contagion' in family units, as outlined by Simons et al. (2016), also compliments developmental models that consider the family-level factors involved in chronic pain. At first glance a biological concept, chronic pain contagion argues that chronic pain in children can result in brain circuit changes, leading to stressful parent-child interactions or suffering that is jointly experienced. These continuous stressful interactions result in deviations to the parent's neural processes, which are then reflected by physiological, behavioural, and emotional changes in the caregiver. The concept of chronic pain contagion is particularly useful in explaining changes in parental behaviours and functioning, which occur initially as an empathetic response to their child's pain.

3.2 The biopsychosocial approach

Practices in child and adolescent chronic pain are centred around the biopsychosocial model of health and illness (Engel, 1977), which marked a shift in healthcare practices away from a purely medical model of health. Historically, medical models have had the tendency to dichotomise chronic pain as being of either functional or physical origin; this is unhelpful as categorising pain as biological in this way may result in a treatment plan which is unimodal and will likely be unsuccessful (Liossi & Howard, 2016). The biopsychosocial approach conceptualises that a complex interaction of biological (nociceptive), affective (emotional), sociocultural, behavioural, and cognitive factors shape an individual's pain perception. This model is particularly useful when considering chronic pain, as emerging research indicates that our experiences of social pain (for example alienation, rejection or bullying) are underpinned by neurobiological substrates which overlap with the same substrates that underlie physical pain (Eisenberger, 2012). Hence, biological, social and affective factors are intertwined to shape our experience of pain, and chronic pain of any aetiology should not be considered as a purely physiological or psychological phenomenon (Liossi & Howard, 2016).

3.2.1 Biological domain

3.2.1.1 Pain neuroscience

Nociception refers to the biological nature of the sensory nervous system's response to harmful stimuli; whether this be due to injury, illness, or a treatment or procedure that has the potential to harm the body. When sensory nerve cells ('nociceptors') are stimulated, they produce neurochemical signals that relay information to the brain, triggering physiological and behavioural responses which, in combination, create an acute (short-term) pain response.

However, in cases of chronic pain this usually acute response to harmful stimuli becomes persistent. Indeed, IASP have noted in recent definition of pain that nociception and pain are not the same phenomena (IASP, 2020). Research has shown that the development and maintenance of chronic pain involves long-term changes in multiple central and peripheral neural networks, creating a complex interaction in which the pain neuromatrix or 'pain matrix' brain network (Melzack, 1999) is accessed during nociceptive processing. This is, however, far from a single centre of pain. A meta-analysis of neuroimaging data collected during acute pain experiences has shown the pain response involves widespread activation of multiple cortical and subcortical regions, including the thalamus, insular and prefrontal cortices (Apkarian et al., 2005). Other areas are also involved, and exactly which areas are active depends on other interacting factors that shape the pain experience, such as cognition and mood. Conceptually, this can be envisioned as a pain signature that is entirely unique to an individual person at a particular moment in time (Tracey & Mantyh, 2007; Liossi & Howard, 2016).

Across chronic pain conditions, the brain regions that are engaged during emotional states tend to become more involved in processing pain as chronicity increases (e.g., Hashmi et al., 2013). These regions differ from those that are usually involved in processing the sensory component of pain. It is thought that this is related to cognitive and emotional problems commonly experienced in chronic pain (Liossi & Howard, 2016), which are described in subsequent sections of the current chapter. The developmental changes that occur during adolescence and the impact these changes have on cognitive-affective processes relating to chronic pain are outlined in section 1.3.1.

3.2.1.2 Biological factors

Other elements of an individual's medical history may influence the onset and maintenance of chronic pain. These include medications and past treatments, genetic predisposing factors such as joint hypermobility, posture and muscle strength, inflammatory disease markers, among other factors that can vary drastically between individuals (Liossi & Howard, 2016).

Arguably, one of the most important contributing factors to chronic pain is sleep. There is a growing body of evidence to support the link between sleep disorders and physical, psychological and social development (Roberts et al., 2001; Roberts et al., 2002), including the development of mood disorders (Kanstrup et al., 2014) and increased disability in adolescents with chronic pain (Palermo et al., 2008). Pain can directly affect sleep by prolonging onset and interrupting sleep states, where pain (headache) intensity has been positively correlated with sleep disturbances in children and adolescents (Miller et al., 2003; Gilman et al., 2007). Bi-directionally, it has been found that sleep deprivation produces hyperalgesia (Kundermann et al., 2004), though such findings have only been seen in healthy adults. There is also a complex interaction between sleep, pain, and mood. One study of children aged 7 to 17-years found that negative affect partially mediates the relationship between poor sleep quality and increased pain, and poor sleep quality and functional disability (Evans et al., 2017).

3.2.2 Psychological domain

Many of the psychological factors involved in paediatric chronic pain maintenance have already been discussed in the previous section on The Fear-Avoidance model of pain (section 3.1.1), including cognitive factors such as attention and interpretation biases, and catastrophizing (Lau et al., 2018). The following sections primarily discuss the relationship between chronic pain and mood disorders in young people, and further explain the specific cognitions involved in chronic pain.

3.2.2.1 Mood disorders and emotional functioning

High comorbidity of anxiety and depression is seen in various types of paediatric chronic pain. The prevalence of co-occurring mental health disorders (including anxiety, depression, behaviour disorders, substance use disorders, and eating disorders) in adolescents with chronic pain has been found to be as high as 26% in a large US national cohort study (Tegethoff et al., 2015). There is also a shared neurobiology between chronic pain and mental health conditions, which may partially explain high comorbidity (Vinall et al., 2016)

In a large sample of children and adolescents attending a multidisciplinary pain clinic, approximately 11% were found to have clinically significant anxiety. Anxiety symptom scores were elevated within several dimensions, where 27% of the sample reported clinically significant physiological anxiety, 15% reported clinically significant worrying and 14% reported clinically significant social anxiety (Simons et al., 2012). This study also found anxiety to be associated with increased functional disability in paediatric chronic pain patients. A similar study that investigated children and adolescents recruited from an interdisciplinary chronic pain clinic found that 31% of young people met the clinical criteria for diagnosis of an anxiety disorder, with females reporting higher anxiety than males overall (Tran et al., 2016). Further research using semi-structured diagnostic interviews has indicated that more than 80% of chronic pain patients meet criteria for an anxiety disorder (Liakopoulou-Kairis et al., 2002; Jastrowski Mano, 2017).

Other research has shown that there are significant differences in anxiety and depressive symptoms (emotional functioning) between sub-groups of paediatric pain patients. One study investigating young people with juvenile fibromyalgia versus chronic migraine using the PedsQL™ found that juvenile fibromyalgia patients had significantly higher symptoms of both depression and anxiety, whereas young people with chronic migraines had better emotional functioning, but experienced decreased school functioning (Kashikar-Zuck et al., 2013). Review of school-related anxiety in paediatric chronic pain further highlights that roughly a third of patients show anxiety-related school avoidance (Khan et al., 2015) and that absenteeism is particularly high compared to young people with other chronic health conditions (Palermo, 2000). More generally, anxiety is a predictor of difficulties with concentration and keeping up at school, hence it is unsurprising that comorbid anxiety and paediatric chronic pain create a high-risk for impaired school functioning (Jastrowski Mano, 2017).

Earlier research on paediatric chronic headaches has noted sex differences in the relationship between mood disorders and chronic pain, where girls with depression and anxiety disorders were found to have a greater prevalence of headaches, compared to girls who were not diagnosed with a mood disorder. In boys, the presence of conduct disorder (antisocial behaviour) was significantly associated with higher headache prevalence, however there were no significant associations found between headaches and mood disorders (Egger et al., 1998).

The relationship between chronic pain and mood disorders in young people does not imply that mental health diagnoses cause chronic pain or vice versa; mood and pain influence each other bi-directionally. However, a national study of chronic pain and comorbid mental disorders and adolescent pain (Tegethoff et al., 2015) showed that, chronologically, mental health disorders tended to precede the onset of chronic pain, and specifically affective disorders were predictive of any type of chronic pain or headache.

3.2.2.2 Cognitions

Cognitions that are essential to the assessment and treatment of chronic pain include pain catastrophizing and pain-related coping (Liossi & Howard, 2016). Pain catastrophizing is characterised by rumination about pain, negatively-biased thoughts, and magnification of problems, where presentations of catastrophizing are usually situation-dependent (Sullivan et al., 2001). Catastrophizing in children has been found to be distinct to anxiety (Tran et al., 2015), and is a strong predictor of pain and functional disability in paediatric chronic pain. CBT is an effective treatment for childhood and adolescent anxiety disorders (Fisher et al., 2014; James et al., 2015); hence, using CBT techniques to reduce anxiety may provoke the additional benefit of reduced catastrophizing, resulting in reduced pain. CBT can also be used to directly address pain catastrophizing in children and adolescents.

Improving coping skills is a key focus of psychological treatment for paediatric chronic pain (Liossi & Howard, 2016), and teaching coping skills falls within the remit of CBT. Employing multi-component CBT techniques (see Ehde et al., 2014) represents a form of secondary control coping i.e., making a purposeful effort to self-regulate when under stress (Skinner et al., 2003). ACT and distraction techniques can also be useful for improving secondary control coping. Secondary control coping strategies are associated with an overall reduction in affective symptoms and physiological complaints in children with chronic pain (Dufton et al., 2011), comparably to using primary control coping strategies such as isolating and catastrophizing.

3.2.3 Social domain

Psychological and social factors are often inseparable in the biopsychosocial formulation of complex conditions such as chronic pain. Family and parent factors in relation to their child's chronic pain are re-visited in this section, and the impact of adverse childhood experiences is discussed in relation to chronic pain onset. Lastly, the nature of interpersonal and peer relationships in chronic pain, and how young people with pain process social interactions is discussed.

Family and parent influences contributing the onset and maintenance of chronic pain have been explained using The Interpersonal Fear-Avoidance Model (IFAM) (section 3.1.2) (Goubert & Simons, 2013), and the developmental model of chronic pain (section 3.1.3) (Palermo et al., 2014). Both of the aforementioned models can be related back to Family Systems Theory, such that when a young person experiences chronic pain, there are consequences for the whole family unit (Kazak, 1989). The impact of a child or adolescents' chronic pain within their family unit is often reflected in the mental health of their parents, as they report suffering higher levels of anxiety and depression compared to parents of healthy children (Palermo & Eccleston, 2009). There is also some evidence that chronic pain is more common in children whose parents have chronic pain. One study, conducted with data from 5370 adolescents and young adults, found increased odds of adolescent nonspecific and multi-site chronic pain when both parents reported chronic pain (Hoftun et al., 2013). Together, these findings show the bi-directional impact of chronic pain between children and parents within family units.

Adverse childhood experiences, or cumulative trauma throughout childhood and adolescence, can influence the development of chronic pain and associated mood disorders (Vinall et al., 2016). Research has found that young people with chronic pain reported cumulatively more stressful life events than pain-free peers, and this was associated with elevated symptoms of post-traumatic stress disorder (PTSD) (Noel et al., 2016). In this cohort, increased PTSD symptoms were common and negatively impacted functional disability. Other research has found specific childhood adverse events (abuse, parental psychopathology, and early parental loss) to be significantly associated with the development of painful medical conditions (Sachs-Ericsson et al., 2017). Low-level anxiety and mood disorders partially moderated the relationship between adverse childhood events and painful conditions. Such research shows the clear overlap between social contextual factors and psychological factors in young people with chronic pain.

Many young people with chronic pain struggle with social interactions and feel misunderstood by others in their social world. As well as their parents/caregivers, this includes their friends and classmates. A systematic review of social functioning in children and adolescents with chronic pain (Forgeron et al., 2010) found that adolescents with chronic pain were reported to have fewer friends, were perceived as less likeable and more isolated, and were subjected to more peer victimisation compared to healthy peers. More recent research examining peer victimisation in adolescents with chronic pain found that daily peer victimisation had a negative impact on next-day activity limitations, which was mediated by negative mood (Fales et al., 2019). This research clearly shows the link between psychological and social factors in chronic pain maintenance.

Regarding social information processing in adolescents with chronic pain, research has found that adolescents with chronic pain are more likely to interpret non-supportive social interactions with close friends as more distressing, compared to peers without pain. Further, they tend to endorse supportive friendship interactions, and are likely to expect social support from friends (Forgeron et al., 2011). Considering adolescents' perspectives on social interactions, a qualitative synthesis of interpersonal relationships in adolescent chronic pain found discrepancies between adolescents' and others' perception of the impact of pain on daily life (Jordan et al., 2017). Although the impact of chronic pain on relationships was largely unfavourable, some relationships were strengthened through overcoming challenges associated with living with chronic pain. Future research on specific factors that reduce or enhance interpersonal relationships in young people with chronic pain is warranted.

To complete this section on social and psychosocial factors that contribute to chronic pain in young people, it is important to recognise that an important part of adolescents' social world is social media and the internet. Young people of generation Y (born after 1981) have been termed 'digital natives' (Bolton et al., 2013), and indeed generation Z (born after 1995) use the internet more than any generation before (Ofcom, 2019, 2020). Very little is known about interactions between young people with pain on social media, though there has been agreement between academics that research with young people often misses out this important aspect of their daily lives (Caes, Jones, et al., 2018). The current thesis addresses this in Paper 3 (Chapter 6) which seeks to contribute to knowledge on internet use for chronic pain and pain management information-seeking in young people.

3.3 Summary

First, this chapter discussed the FA and IFAM models, which relate to chronic pain onset and maintenance. The explanation of these models has focused on their application to chronic pain in children and adolescents, where the IFAM, as well as the developmental model, are of particular relevance in paediatric chronic pain research. Second, this chapter provided an overview of the biopsychosocial approach to chronic pain assessment and management. The biological domain discussed the neuroscience of pain and chronic pain, as well as biological factors that should be considered when working with young people with chronic pain. The psychological domain provided an explanation of comorbid mood disorders commonly seen in young people with chronic pain, outlined cognitions that are likely to be present, and how these cognitions might be addressed in practice. The social domain described family and parent influences in chronic pain with reference to Family Systems Theory. The impact of adverse childhood experiences and the nature of interpersonal relationships in young people with chronic pain was also discussed. Internet use was additionally highlighted as an important part of psychosocial context for chronic pain management in young people.

Chapter 4 Online multidisciplinary interventions for paediatric chronic pain: a content analysis

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Significance: This content analysis of online interventions for paediatric chronic pain highlights the need for multidisciplinary practices in pain management to be translated into online interventions. Improving the availability of pain management resources is essential for many families who cannot attend specialist pain clinics, particularly in the context of the COVID-19 pandemic. There is potential for new resources, as well as for established resources, to be further developed to deliver a broader range of pain management content.

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[1] Supplementary tables (tableS1, S2, S3, S4 and S5) for this manuscript (Chapter 3) are provided in Volume 2 of this thesis.

Abstract

Background: Many online interventions for paediatric chronic pain have been developed and evaluated. In accordance with the biopsychosocial model, the recommended treatment approach for chronic pain is multidisciplinary. Despite this, multidisciplinary components within existing online interventions have not been examined. The objective of the present review was to summarise and evaluate the content of existing online interventions for paediatric chronic pain by mapping intervention content to evidence-based guidelines for chronic pain management.

Methods: Interventions were identified using an updated systematic review. Nine chronic pain management strategies that reflect evidence-based guidance for multidisciplinary chronic pain management were defined by the authors, examples of which include ‘pain education’, ‘activity pacing’ and ‘physiotherapy’. Identified interventions were then coded against the target strategies. These codes were compiled descriptively to provide an overview of how well each chronic pain management strategy was represented across the dataset, and which interventions represented the most strategies.

Results: Thirty-five articles, relating to 13 unique interventions for paediatric chronic pain management were identified; few encompassed a complete multidisciplinary approach. Many CBT-based interventions included multidisciplinary elements. Across interventions, physiotherapy and non-pharmacological physical therapies were the least represented chronic pain management strategies.

Conclusions: The content analysis revealed a lack of online interventions encompassing complete multidisciplinary pain management. It is important that new interventions for paediatric chronic pain management are evidence-based and reflect current best practice guidelines. Established intervention development approaches should be utilised and include a process evaluation to help identify which intervention components are effective in which contexts.

4.1 Background

Paediatric chronic pain is prevalent (King et al., 2011; Gobina et al., 2019). As understanding of chronic pain has shifted to a biopsychosocial model, the recommended assessment and management approach is multidisciplinary, with equal focus on biological, psychological and social factors (Liossi & Howard, 2016; World Health Organization, 2020). Intensive interdisciplinary treatment, where clinicians from multiple disciplines work collaboratively towards the same biopsychosocial treatment goals (IASP, 2018a), can significantly improve functional disability (Harrison et al., 2019). Indeed, multidisciplinary treatment for chronic pain aims to improve the quality of life of children and adolescents by attending to all aspects of their development and wellbeing (World Health Organization, 2020). Many multidisciplinary interventions have been developed and evaluated. However, multidisciplinary components within online interventions have not been examined.

Systematic reviews have investigated face-to-face interventions for paediatric chronic pain combining at least two (Liossi et al., 2019) or three disciplines (Hechler et al., 2015). Randomised controlled trials (RCTs) of intensive interventions including three or more disciplines found large improvements in pain intensity, and disability, at 3-month follow-up (Hechler et al., 2015). Interventions including two or more disciplines showed significant improvements pre to post-intervention for pain intensity and functional disability (Liossi et al., 2019). Despite benefits of face-to-face interventions, there are barriers to attending pain services for children and parents, including school absence and financial costs of travel (Bender et al., 2011; Caes, Fisher, et al., 2018). One solution is to provide online interventions.

The efficacy of online psychological approaches to paediatric chronic pain management has been investigated (Fisher et al., 2019). This systematic review found 10 studies, which were split into mixed chronic pain and headache. No beneficial effects were found post-treatment for mixed pain and there was a lack of follow-up data. For headache, there was a significant reduction in headache severity at post-treatment only. Authors highlighted findings were likely due to low quality evidence (Fisher et al., 2019). Another systematic review of the availability of ‘e-health tools’ for paediatric pain, including pain assessment tools and online/ digital pain management interventions (Higgins et al., 2018) identified 53 tools, including 26 tools for chronic pain. Thirteen tools out of 53 were available to patients, with barriers including time and funding. Despite this, a survey of adolescents and parents indicated that new, accessible online pain management interventions would be welcomed (Hurley-Wallace et al., 2020).

Internet use has rapidly increased over the past several years, especially since the introduction of smartphones in 2009/ 2010 (Ofcom, 2017b). Recent statistics indicate that 93% of 8 to 11-year-olds go online for more than 13-hours a week, and 99% of 12 to 15-year-olds for more than 20-hours (Ofcom, 2019). Expert opinion recently highlighted the expansion of digital healthcare in paediatric chronic pain, with emerging interest in mobile health (Richardson et al., 2020). Therefore, it is important that available online resources for paediatric chronic pain reflect evidence-based pain management practices, with the aim to encompass current best practice recommendations for multidisciplinary chronic pain management in children (World Health Organization, 2020). The current study evaluates which existing interventions reflect multidisciplinary chronic pain management strategies, with a focus on individual multidisciplinary components, which has not previously been investigated. Recommendations for the improvement and expansion of online pain management interventions are provided based on the findings of the current study. Such recommendations are timely given the context of the COVID-19 pandemic, where online resources have become integral to chronic pain management (Eccleston et al., 2020).

This study aimed to 1) identify which multidisciplinary chronic pain management strategies are reflected within the content of existing online multidisciplinary interventions for paediatric chronic pain management, 2) map the content of existing online interventions for paediatric chronic pain to evidence-based clinical guidelines for multidisciplinary pain management, and evaluate how well each chronic pain management strategy is addressed by the identified interventions, 3) summarise and evaluate the development approaches used by the identified interventions, and provide practical recommendations for current and future intervention development teams.

4.2 Methods

4.2.1 Search strategy

A previous systematic review of e-health tools for paediatric pain (Higgins et al., 2018) was updated for the period 3rd May 2017 to 1st April 2020, using the same search terms and databases (tableS5). Additional inclusion and exclusion criteria were added in-line with the aims of the current study. The systematic review by Higgins et al. (2018) reviewed e-health tools for paediatric pain assessment and/or management and paired this with a survey completed by the authors of the identified tools, regarding the availability of each tool. As the current study investigated pain management interventions only, the inclusion and exclusion criteria were adjusted accordingly to exclude pain assessment tools. The previous review chose to use a 10-year timeline, given rapid changes in technology outlined above. Hence, the current study updated the search from the time-point selected by the previous review, in-line with this rationale.

4.2.2 Inclusion and exclusion criteria

Inclusion criteria were: 1) the article described an empirical study, written in English and published from 1st January 2007 to 1st April 2020, 2) the article described the development of an online intervention for paediatric chronic pain management*, and/ or evaluated its use in the target population, 3) the intervention was studied in children and adolescents aged 0 to 18-years (sample median age less than 19-years), or their parents/ caregivers, 4) interventions were intended for the management of chronic pain lasting three-months or longer, 5) interventions either contained content from two or more disciplines or contained multi-component CBT.

Exclusion criteria were: 1) interventions were intended for pain assessment, 2) interventions were intended for the management of acute pain only, 3) interventions were targeted for use by adults, aged 19-years or over, that were not parents/ guardians of children with chronic pain, 4) interventions did not have set content (e.g., peer support platforms).

*A chronic pain management intervention was defined as any form of intervention which targeted a chronic pain condition, as listed in the ICD-11 (Treede et al., 2019; Treede et al., 2015), with the aim to reduce pain intensity or improve pain-related functional disability.

4.2.3 Accessibility

All authors/ intervention owners of identified interventions were contacted via email to request access to the intervention online on 25th March 2019. Authors were sent an additional reminder 2-weeks later, on 8th April 2019. Where access was not provided to online content, intervention content was evaluated based on descriptions from available published works.

4.2.4 Quality Assessment

Interventions were assessed for descriptive report and evaluation quality using the Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare, revised (CReDECI2) (Möhler et al., 2015). The CReDECI2 contains 13-items pertaining to the quality of reporting for development (4-items), feasibility (1-item), and evaluation (8-items) stages of the research, with reference to any published article that has described, developed, or evaluated the intervention in question. The checklist is completed by adding a reference example next to each item, indicating the publication(s) and/ or page number(s) where an example of each criterion can be found. The full checklist of items is provided in tableS3.

4.2.5 Content analysis: development of target strategies

The target chronic pain management strategies used in the content analysis were developed by the research team, drawing from the treatment guidelines for paediatric pain management in the UK, as outlined by the Royal College of Paediatrics and Child Health (RCPCH, 2018) and guided by clinical expertise from two paediatric pain psychologists in the research team (CL and EN). The RCPCH course is one of only two resources that adopts a biopsychosocial approach to chronic pain management and is freely available to professionals (Hurley-Wallace, Wood, et al., 2018). A biopsychosocial approach to the management of chronic pain in children is the recommended best practice. Any combination of physical, psychological, or pharmacological interventions should be tailored to the individual child and their family, rather than to the pain type (World Health Organization, 2020). The selected guideline from the RCPCH is a clinician-directed e-learning course entitled ‘Pain Management’ (https://rcpch.learningpool.com). The alternative resource is the Canadian online paediatric pain curriculum (SickKids, 2019), which includes similar topics, with the addition of pain in paediatric palliative care and ethical considerations for children with pain (https://www.sickkids.ca/en/care-services/centres/pain-centre/#oppc).

The RCPCH course is selected to guide the target strategies for this content analysis as it covers a wider range of specific psychological and physical therapies and has a stronger focus on chronic pain, compared to the Canadian resource. In the RCPCH course, chronic pain management strategies are outlined broadly under ‘psychological and physical therapies’ (Liossi et al., 2015), and ‘pharmacology and prescribing’ (Zarnegar et al., 2015) in modules four and five of the ‘Pain Management’ course, respectively. A full breakdown of the course modules is outlined in Box 1 of the report by Hurley-Wallace, Wood, et al. (2018).

An advantage of drawing from the RCPCH course is that analyses can be used to investigate whether evidence-based chronic pain management strategies, outlined in clinician-directed courses, are mirrored in online patient-directed interventions. This represents an assessment of knowledge translation from research to practice (Scott et al., 2012), as the clinician-directed course is based on research evidence and established theoretical frameworks in paediatric chronic pain management.

4.2.6 Target chronic pain management strategies

Interventions were coded for nine target chronic pain management strategies, as follows:

1. Pain education, including psycho-education
2. Goal-setting, including SMART (specific, measurable, achievable, realistic, and timed) goals
3. Sleep hygiene (or sleep routine)
4. School support
5. Multi-component CBT
6. Activity pacing, including e-diaries and symptom tracking
7. Physiotherapy
8. Non-pharmacological physical therapies e.g., massage, desensitisation, TENS (transcutaneous electrical nerve stimulation), thermal analgesia
9. Medications (evidence-based pharmacological advice or advice from clinician)

4.2.7 Analytic approach

The current study utilised a similar approach to a recent content analysis of pain neuroscience education on YouTube (Heathcote et al., 2019). In this study, each chronic pain management strategy was evaluated for each intervention. To evaluate how well each pain management strategy was represented, content codes were assigned ordinal ratings (0 = ‘no, this strategy is absent’, 1 = ‘yes, this strategy is vaguely represented’, 2= ‘yes, this strategy is clearly represented’). Coding was performed by two separate individuals, using a spreadsheet (Microsoft Excel), which was pre-piloted by the research team. The two coders included one PhD student specialising in chronic pain research (AHW) and one clinical psychologist specialising in paediatric chronic pain management (EN).

There was a possibility for a total of 117 matched codes for all nine chronic pain management strategies across 13 interventions. Raw scores from the coders resulted in 107 matched codes; a high level of agreement was present between the two raters (K = 0.86). As the level of agreement was high, all discrepancies (n = 10) were discussed between the two coders to reach 100% consensus. This data was then analysed by i) providing a descriptive summary of all the final agreed codes as an overview of representation across the dataset, and ii) graphically presenting the number of interventions that addressed each strategy ‘clearly’.

4.3 Results

4.3.1 Included studies

Ninety records cited by the previous review of e-health tools (Higgins et al., 2018) were screened for inclusion/ exclusion by AHW. From the previous review, 26 articles were included in the current study. 666 new records were identified through electronic database searching, covering the review update period 3rd May 2017 to 1st April 2020, and by hand-searching reference lists of records identified through database searching. New records were screened for inclusion/ exclusion by AHW, and full-texts were then assessed for eligibility by AHW and DS. Nine new articles were identified in the review update, resulting in a total of 35 included articles, relating to 13 unique interventions.

All included articles are summarised within the evaluation of intervention development approaches and efficacy (tableS2). Only one new intervention was identified (Cunningham et al., 2018), where 12 out of 13 interventions were identified in the previous version of the review. A PRISMA flow diagram of the updated review is provided in Figure 3 (Stovold et al., 2014).

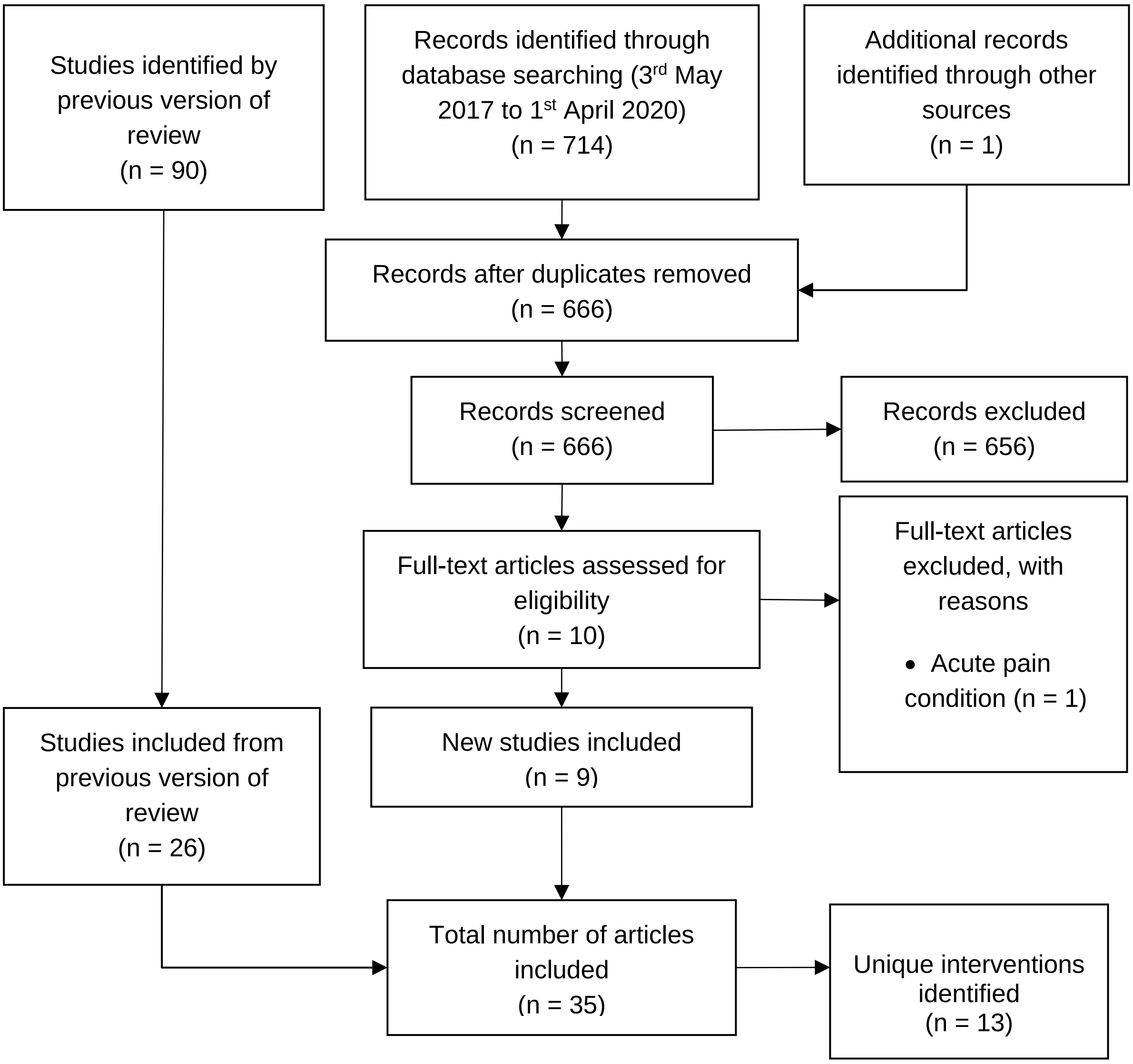


Figure 3. PRISMA flow diagram of the updated systematic review.

4.3.2 Summary of identified interventions

Thirteen unique interventions met the eligibility criteria for this content analysis. The content of each of the interventions, including the number of modules, the structure of the intervention, overall duration, appearance, and mode of delivery, including human support offered (if any) is outlined in tableS1. The primary study reference for the intervention description and hyperlink to the study is also included, where available.

Four of the interventions found were developed in the United States (Palermo et al., 2016; Cunningham et al., 2018; Donovan et al., 2013; McCormick et al., 2010). Two interventions were from Canada (Stinson et al., 2010b; Stinson et al., 2014). Two were from Sweden (Lalouni et al., 2017; Flink et al., 2016), and two were from The Netherlands (Voerman et al., 2015; Armbrust et al., 2015). The remaining interventions were developed in Spain (Nieto et al., 2015), Germany (Trautmann & Kröner-Herwig, 2010), and Taiwan (Yeh et al., 2013).

A variety of chronic pain conditions were addressed in these interventions; mixed chronic pain was addressed by four interventions (Voerman et al., 2015; Flink et al., 2016; Stinson et al., 2014; Palermo et al., 2016). One intervention was aimed at recurrent headache (Trautmann & Kröner-Herwig, 2010), and one at migraines (Donovan et al., 2013). Two interventions focused on juvenile idiopathic arthritis (JIA) (Stinson et al., 2010b; Armbrust et al., 2015). Two interventions addressed functional abdominal pain (Cunningham et al., 2018; Nieto et al., 2015), one targeted pain associated with gastrointestinal disorders (Lalouni et al., 2017), one intervention looked specifically at irritable bowel disease (McCormick et al., 2010), and one intervention was aimed at dysmenorrhea (Yeh et al., 2013).

4.3.2.1 Accessibility

Eight authors (62%) responded to the request for access; online access was granted by four authors, and additional transcripts and information were provided by two of these authors. Two authors advised that the best description of the intervention in English was provided in the article already found, and one author could not allow access outside of the research team. One author responded advising that the website had been decommissioned. Two authors were uncontactable (email address not recognised) and the remaining three authors did not respond.

4.3.2.2 Quality assessment

CReDECI2 checklists for all interventions that were included in the content analysis are available (tableS3), and a colour scale visualisation is provided (tableS4). Overall, the assessments of reporting quality indicated that 11 out of 13 (85%) of the interventions had been evaluated in either a pilot or large-scale RCT (tableS2). Though almost every article mentioned that online interventions can be cost-effective, only one intervention (no specific name) (Lalouni et al., 2017) presented a breakdown of financial costs for personnel, materials, or other development costs. This intervention, which targeted different types of abdominal pain, was evaluated for cost-effectiveness using healthcare cost estimates in US dollars within two separate trials (Sampaio et al., 2019; Lalouni et al., 2019). Only one intervention underwent a process evaluation (Murray, de la Vega, et al., 2019) according to available published works, though many captured usability data.

The content of each of the interventions, including the number of modules, the structure of the intervention, overall duration, appearance, and mode of delivery, including human support offered (if any) is outlined in tableS1. The primary study reference for the intervention description and hyperlink to the study is also included, where available.

4.3.3 Intervention development and evaluations of efficacy

Details of the development process for each intervention, including the development approach and theoretical frameworks used, any professional input, development team details, and details of user-feedback are outlined in tableS2. This table includes 35 studies that report on the development or evaluate the efficacy of the 13 included interventions.

4.3.3.1 Theoretical frameworks

Most of the interventions included in the content analysis did not reference theoretical frameworks explicitly; however, many did include components pertaining to well-known frameworks. Eleven (85%) of the identified interventions used multimodal CBT, including elements of mindfulness (tableS2). The internet intervention for functional gastrointestinal disorders (Bonnert et al., 2014; Bonnert et al., 2016; Lalouni et al., 2017), used CBT and mindfulness, with the addition of exposure-based therapy techniques, and behavioural analysis using an Antecedent-Behaviour-Consequence model, which was specific to the intervention (see Bonnert et al., 2014). The Health Promotion Model (Srof & Velsor-Friedrich, 2006), stemming from Social Cognitive Theory (Bandura, 1977), were referenced to support the use of CBT within the Rheumates@Work intervention (Lelieveld et al., 2010; Armbrust et al., 2015). Notably, iCanCope™ was the only intervention that presented a ‘theoretical rationale’ section distinctly in published works (Stinson et al., 2014). Both iCanCope™ and Web-MAP referenced CBT in combination with Social Learning Theory, which can be theoretically related to children's pain behaviours as a result of parent behavioural modelling (Palermo et al., 2014; Palermo et al., 2016; Stinson et al., 2014). Web-MAP also mentioned integration of Family Systems Theory from the second iteration (Web-MAP2), which a well-known theory that can be used to explain pain-focused family patterns of behaviour (Lewandowski et al., 2007).

4.3.3.2 Development approaches

Only one intervention referenced an established development approach (O'Cathain et al., 2019); this was the user-centred design approach, outlined in the development study for iCanCope with Pain™ (Stinson et al., 2014). This intervention was developed with input from focus groups with adolescents and health care professionals, followed by individual interviews with adolescents. Within the same research group, 'Teens Taking Charge' adopted an iterative qualitative approach to development by using a mixture of individual interviews (Stinson et al., 2008) and think-aloud interviews with adolescents in separate studies (Stinson et al., 2010a). However, no specific approach was referenced for 'Teens Taking Charge'.

4.3.3.3 Evaluations of efficacy

The current study focuses on evaluating the content of online interventions for paediatric chronic pain, and the development approaches used. Meta-analytic reviews of the efficacy of psychological approaches to online paediatric chronic pain management (Fisher et al., 2019), and in-person interdisciplinary interventions (Hechler et al., 2015; Liossi et al., 2019) have been published elsewhere. Efficacy evaluations, however, remain an important part of developing complex health interventions (final stage of development), according to Medical Research Council (MRC) guidance (O'Cathain et al., 2019). A summary of evaluation studies for the two most rigorously trialled interventions identified in the current study is included below.

The intervention which has undergone the most rigorous testing in terms of randomised controlled trials (RCTs) is Web-MAP2, which is a multimodal CBT-based online intervention. The earliest RCT evaluated the first iteration of the intervention (Web-MAP) (Palermo et al., 2009). The latest iteration, Web-MAP2, was first mentioned in published work referencing an ongoing multicentre RCT (Palermo et al., 2015). The multicentre RCT of Web-MAP2 used a parallel-groups design, in which one group received the Web-MAP2 intervention, and the other received internet-delivered education (Palermo et al., 2016). Findings from 273 adolescents aged 11 to 17 years produced a number of beneficial effects, including a significantly improved functional disability from baseline to 6-month follow-up for the Web-MAP2 treatment group, comparatively to internet education. There were also significant improvements in sleep outcomes, and significant reductions in parent miscarried and parental protective behaviours for the Web-MAP2 group. Overall findings indicated a high level of efficacy. Several secondary analyses of the data from the main Web-MAP2 trial have been conducted (Law et al., 2018; Murray, de la Vega, et al., 2019; Chen et al., 2019).

Teens Taking Charge, an online intervention for managing JIA, has also undergone rigorous trialling. An initial pilot RCT of ‘Teens Taking Charge’ found significantly better post-treatment outcomes in the experimental group, who received an internet-based intervention for JIA (Stinson et al., 2010b). The experimental group had a lower average weekly pain intensity, however there were no significant differences between-groups for functional disability, self-efficacy, adherence, or stress in the internet intervention group compared to the control group, who had received a telephone-delivered attention control intervention. This intervention has since been evaluated in a multisite RCT, comparing the self-management program with an online education-only program over 12-weeks (Connelly et al., 2019). The main outcomes for the study were pain intensity, pain interference and functional disability, and outcomes were also assessed at 6-month and 12-month follow-up. Participants in both groups showed small, yet significant improvement in the main outcomes, with no significant between-group differences. Predictors of pain and functioning were also analysed, finding that self-efficacy, disease knowledge, anxiety and depression were significant predictors for both groups.

Other trials include iCanCope with Pain™, which targets mixed chronic pain, and has been tested in a parallel groups RCT. Only the mobile symptom-tracking app was investigated (Lalloo et al., 2019), finding that pain-related variables were stable over time (55 days) and adherence to symptom-tracking was moderate-high. The ‘Move It Now’ self-management intervention for adolescents with mixed chronic pain (Voerman et al., 2015) found pain intensity, general behaviour, mental health, family activities all significantly improved during the intervention; this investigation was intended to be an RCT however the design was altered to within-participants due to high attrition rates. The only study included in the content analysis that investigated dysmenorrhea undertook a non-randomised controlled trial to investigate the effectiveness of auricular acupressure combined with internet interactive instruction (Yeh et al., 2013). This study found that the internet intervention with auricular acupressure was significantly better at improving pain and menstrual distress post-intervention compared to acupressure alone.

4.4 Content Analysis

A compilation of all the content codes is presented in Figure 4. Final agreed scores from the two coders are available in Figure 6. Across all the interventions and chronic pain management strategies, 47% of the agreed codes were ‘yes, clearly represented’, 13% of the codes were ‘yes, vaguely represented’, and 40% were ‘no, absent’ (Figure 4). The only chronic pain management strategy that was represented (‘clearly’ or ‘vaguely’) by all of the interventions was pain education or psycho-education. The chronic pain management strategy that was the least well represented across the interventions was physiotherapy, which was only referenced in two interventions, followed by non-pharmacological physical therapies, which was referenced in three interventions.

Figure 5 displays the number of interventions that achieved the highest possible score for each chronic pain management strategy. In these cases, an agreement was reached between the two coders that the target chronic pain management strategy was ‘clearly’ represented. The most ‘clearly’ addressed strategies were pain education and CBT; there were no codes for ‘vaguely’ for CBT. Physiotherapy, non-pharmacological physical therapies, and medications were the least ‘clearly’ represented. Medications were coded as ‘vaguely’ represented most frequently (five out of 13).

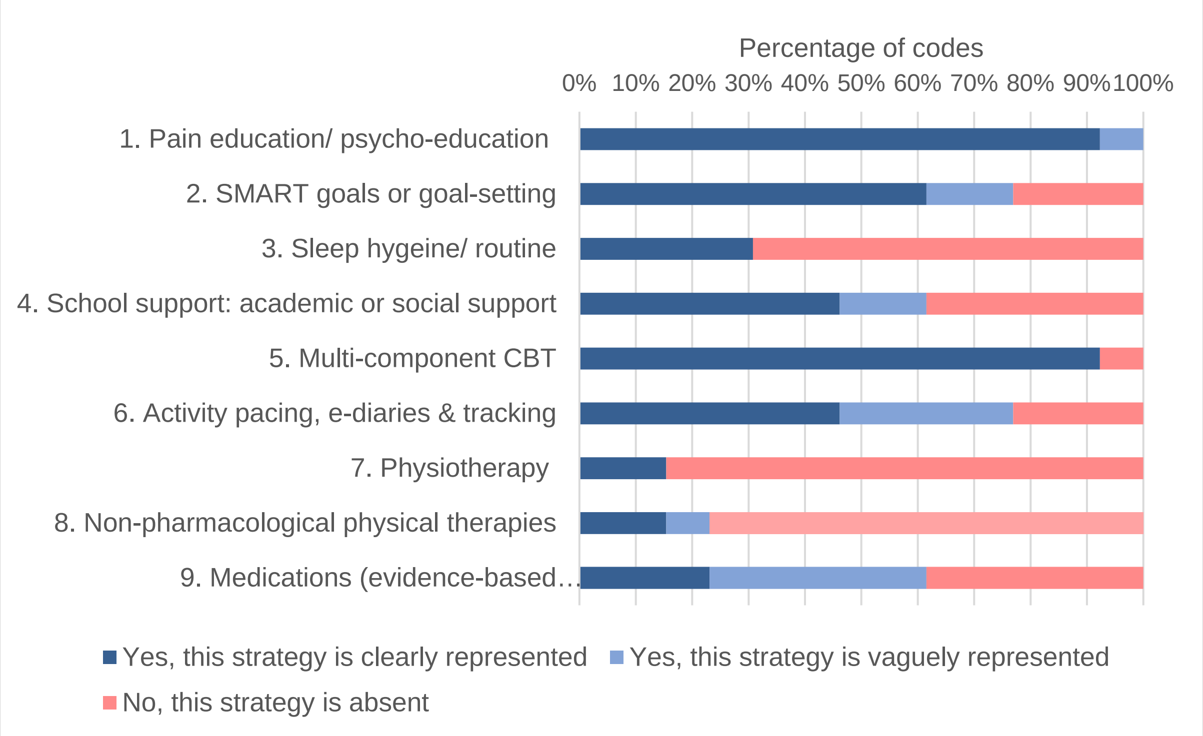


Figure 4. Percentage of final codes for all target chronic pain management strategies.

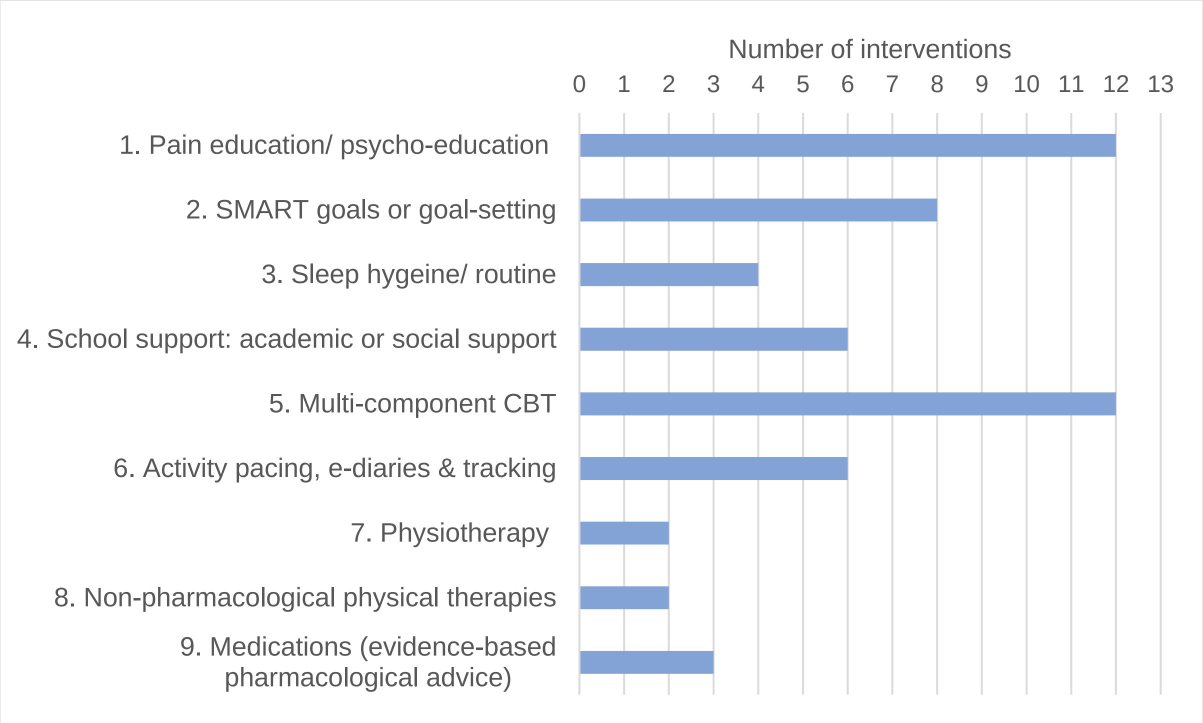
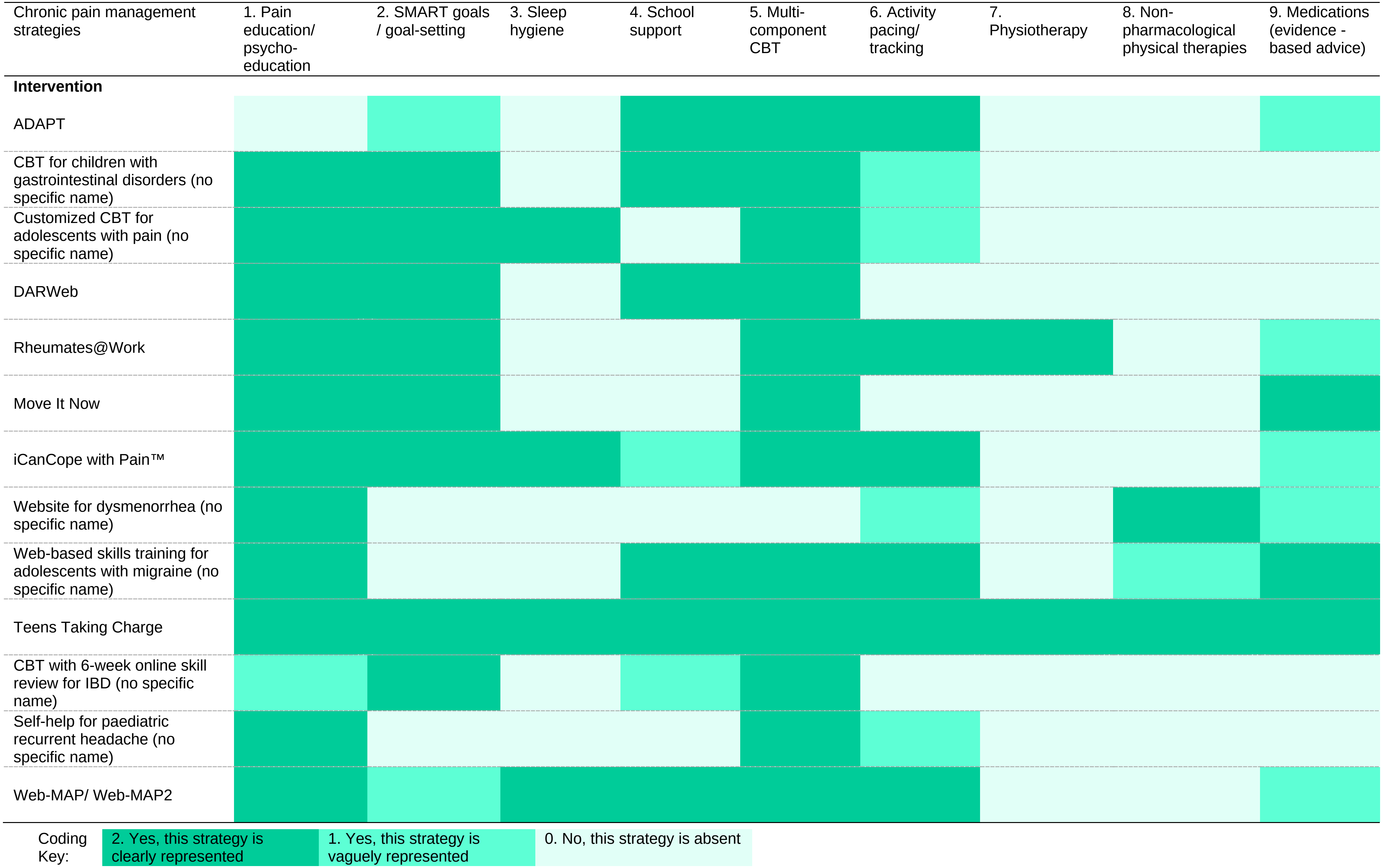


Figure 5. Number of interventions that ‘clearly’ represented each chronic pain management strategy.

All codes for all included interventions are displayed in Figure 6; all of the interventions addressed at least two chronic pain management strategies clearly. One intervention clearly represented all nine strategies; this was ‘Teens Taking Charge’ for adolescents with JIA (Stinson et al., 2010b). The majority of interventions (69%) represented between four and five strategies clearly in their content. The interventions that addressed five strategies clearly were Web-MAP (Palermo et al., 2016; Palermo et al., 2009), iCanCope™(Stinson et al., 2014), the website for adolescents with migraine (Donovan et al., 2013), and Rheumates@Work (Armbrust et al., 2015; Lelieveld et al., 2010).



Chronic pain management strategies	1. Pain education/ psycho-education	2. SMART goals / goal-setting	3. Sleep hygiene	4. School support	5. Multi-component CBT	6. Activity pacing/ tracking	7. Physiotherapy	8. Non-pharmacological physical therapies	9. Medications (evidence - based advice)
Intervention									
ADAPT	□	▨	□	■	■	■	□	□	▨
CBT for children with gastrointestinal disorders (no specific name)	■	■	□	■	■	▨	□	□	□
Customized CBT for adolescents with pain (no specific name)	■	■	■	□	■	▨	□	□	□
DARWeb	■	■	□	■	■	□	□	□	□
Rheumates@Work	■	■	□	□	■	■	■	□	▨
Move It Now	■	■	□	□	■	□	□	□	■
iCanCope with Pain™	■	■	■	▨	■	■	□	□	▨
Website for dysmenorrhea (no specific name)	■	□	□	□	□	▨	□	■	▨
Web-based skills training for adolescents with migraine (no specific name)	■	□	□	■	■	■	□	▨	■
Teens Taking Charge	■	■	■	■	■	■	■	■	■
CBT with 6-week online skill review for IBD (no specific name)	▨	■	□	▨	■	□	□	□	□
Self-help for paediatric recurrent headache (no specific name)	■	□	□	□	■	▨	□	□	□
Web-MAP/ Web-MAP2	■	▨	■	■	■	■	□	□	▨

Coding Key:	■ 2. Yes, this strategy is clearly represented	▨ 1. Yes, this strategy is vaguely represented	□ 0. No, this strategy is absent

Figure 6. Colour scale table displaying which chronic pain management strategies were 'clearly' or 'vaguely' represented, or 'absent', for each intervention.

4.5 Discussion

The current review and content analysis found 13 online interventions for paediatric chronic pain management, with 35 studies relating to development and trialling of these interventions. The content analysis indicated that whilst many online paediatric chronic pain interventions included content from several disciplines, there were few that encompassed a complete multidisciplinary approach (IASP, 2018a; World Health Organization, 2020) to paediatric chronic pain management. There was limited translation from evidence-based clinical guidelines (RCPCH, 2018) to online chronic pain management interventions. Specifically, there was a lack of physiotherapy content within interventions reviewed, as well as non-pharmacological physical therapies. There was also a lack of content on sleep hygiene, and medications were vaguely addressed.

Chronic pain management strategies that were the most commonly represented by identified interventions were pain education and multi-modal CBT, where all interventions included pain education, and 12 out of 13 included elements of CBT. Of the interventions that were labelled as CBT-based, including Web-MAP (Palermo et al., 2009; Palermo et al., 2016) and the unnamed internet intervention for abdominal pain (Lalouni et al., 2017), several of the other multidisciplinary strategies were also covered, such as school support and goal setting (Figure 6). Hence, in terms of encompassing a biopsychosocial approach in online interventions for chronic pain, established CBT-based interventions may serve as a good base from which to expand on content to include medication and physical therapies, if appropriate. There was a significant proportion of abdominal and gastrointestinal-related pain interventions (31%), including the most recently developed intervention (Cunningham et al., 2018); this is likely a reflection of high prevalence of paediatric functional abdominal pain, where meta-analyses have estimated a global pooled prevalence of 13.5% (Korterink et al., 2015). Whilst tailoring to a pain condition may be useful in some contexts, current best practice guidelines recommend a biopsychosocial, multidisciplinary approach to paediatric chronic pain management in general (World Health Organization, 2020). An example of tailoring to a specific pain condition whilst also embodying a multidisciplinary approach is provided by ‘Teens Taking Charge’ (Connelly et al., 2019; Stinson et al., 2010a). This intervention encompassed all target chronic pain management strategies, as defined by the current study, and was specific to JIA (https://teens.aboutkidshealth.ca/jiateenhub).

It may be beneficial for intervention development teams to consider whether online interventions that target a specific pain condition or focus on a specific technique (such as CBT) could be extended to incorporate a broader range of content on physical, psychological, and pharmacological components of pain management. This may be a cost-effective way to further develop online interventions such that they can be applied across a broader range of chronic pain conditions, rather than developing new interventions for specific conditions from scratch. An example of this is Web-MAP, which has been trialled for mixed chronic pain and headache (Palermo et al., 2016; Law et al., 2015). Further, online multidisciplinary interventions for chronic pain may be especially useful in adolescent populations, as the current adolescent generation are native internet users, with 99% of 12- to 15-year-olds accessing online content for more than 20-hours a week (Ofcom, 2019).

The rapid development of evidence-based online interventions is warranted in the context of the COVID-19 pandemic, which has resulted in further reduced access to specialist pain services in-person. Though many existing services have recently introduced online clinics, online interventions have the potential to support clinics as complementary resources by creating more flexible pain management plans and encouraging self-management (Eccleston et al., 2020). There has also been suggestion that the prevalence of chronic pain may increase as a consequence of the COVID-19 pandemic (Clauw et al., 2020), hence improving the availability of multidisciplinary interventions may become very important. However, the extent to which multidisciplinary pain management can be delivered online is highly dependent on patient needs. Online self-management of chronic pain should only be recommended to paediatric patients following assessment by a multidisciplinary team (Liossi & Howard, 2016), and formulation of a treatment plan that includes online intervention in an appropriate way. Parts of clinical assessment can be conducted remotely, as has been done throughout the COVID-19 pandemic (Eccleston et al., 2020). Additionally, there are treatment components that cannot be feasibly delivered online, such as tailored physiotherapy, and this may explain the finding of a lack of physiotherapy content in the current review. Although, as shown by 'Teens Taking Charge' (Connelly et al., 2019; Stinson et al., 2010a), high quality video examples of basic physiotherapy exercises can be included in online interventions.

Three interventions identified in the current study included peer support in the form of online groups or message boards (Yeh et al., 2013; Donovan et al., 2013; Stinson et al., 2014). Though peer support is not a treatment, it is a critical element of the social domain of the biopsychosocial approach (Liossi & Howard, 2016), and youth with chronic pain often struggle to form strong friendships (Forgeron et al., 2011). There is potential for encouraging peer support through use of online interventions, especially for adolescents, for whom social media is a core part of their daily lives (Ofcom, 2019). Recent research investigating the internet needs of adolescents with chronic pain and their parents has also highlighted social media as a resource that adolescents use to help with pain management (Hurley-Wallace et al., 2020). The exact pattern of usage of popular social media platforms, such as Instagram, and how it relates to pain management in this population is unknown, though warrants investigation in future research. One peer support platform that has been developed in an academic setting and applied successfully in adolescent chronic pain is iPeer2Peer, which was originally developed for JIA (Ahola Kohut et al., 2016; Stinson et al., 2016). The programme provides training for ‘peer mentors’ (16 to 25-year-olds) on a variety of topics, then mentors connect with adolescents using Skype calls.

Eight out of 13 interventions contained parent-facing content, which either directly mirrored or complimented the child or adolescent-facing content (tableS1). Theoretical models, such as the Interpersonal Fear-Avoidance Model (Simons & Kaczynski, 2012; Goubert & Simons, 2013), and research (Palermo et al., 2007; Simons et al., 2008; Logan et al., 2012; Palermo et al., 2014) have emphasised that parental factors play an important role in paediatric chronic pain maintenance. In relation to Web-MAP2 (Palermo et al., 2016), the effects of adolescent-parent agreement of treatment goals has been investigated (Fisher, Bromberg, et al., 2017). Whilst participating in the Web-MAP2 intervention, 122 adolescent-parent pairs were asked to select two treatment goals. Pairs that chose the same goals had reduced pain intensity post-treatment, which was maintained at follow-up. The strongest effect of goal agreement on pain intensity was found for physical activity goals (Fisher, Bromberg, et al., 2017). The success of incorporating of parent-facing modules in terms of improving treatment outcomes is likely to depend on the individual case of chronic pain. Current best practice for the management of chronic pain in children states that treatment should be child and family-centred (World Health Organization, 2020). However, whether parent-facing content is included may also depend on the target age range for the online intervention, as adolescents aged 15-years and up do not seem to benefit as much from this type of intervention (Murray, de la Vega, et al., 2019). There is also the option of providing the online intervention to the child or adolescent with adjunctive in-person parent or family-based therapy, though little guidance exists on how to adapt interventions for paediatric chronic pain to be developmentally appropriate (Palermo et al., 2014).

One of the interventions identified in the current study, ‘Teens Taking Charge’, contained a ‘looking forward’ component, consisting of guidance on vocational prospects for young people, as well as information about transitioning into adult healthcare (Stinson et al., 2010b; Stinson et al., 2010a). Similarly, the iCanCope™ design included a section on ‘transition readiness’. Transition from paediatric to adult care can be challenging for young people; research on JIA indicates that the perceived quality of healthcare during transitional stage is low (Shaw et al., 2007), and that an ideal programme would address psychosocial and educational/vocational needs (Shaw et al., 2004). From a developmental perspective, adolescents with chronic pain may struggle with vocational prospects as a result of poor school functioning, however more research on specific health systems factors that impact chronic pain treatment in older adolescents is needed (Rosenbloom et al., 2017). Research has identified a trend between paediatric chronic pain and psychiatric disorder lifetime prevalence (Campo et al., 2001). Cohort studies have also found that chronic pain and fatigue severity predicts impaired social functioning in adulthood (Westendorp et al., 2016). Part of the solution to this issue could be to bridge the paediatric-to-adult healthcare transition by providing continuation of multidisciplinary pain management to older adolescents online.

Overall, underpinning well-established theoretical frameworks were integrated in the majority of interventions reviewed, though many of the development papers did not explicitly reference these. Theoretical frameworks can be important in the implementation of evidence into practice as outlined by the Theoretical Domains Framework (French et al., 2012). However, basing intervention content on an underlying theoretical framework does not necessarily result in improved intervention effectiveness, as shown by a review of reviews (Dalgetty et al., 2019). In accordance with the MRC guidance (O'Cathain et al., 2019), it is recommended that stakeholder feedback is incorporated into the intervention development process. This can be done by supplementing development frameworks such as the Person-Based Approach (Yardley et al., 2015) (PBA). The PBA seeks to integrate stakeholder insights from intervention design through to evaluation. The development teams from iCanCope with Pain™ (Stinson et al., 2014) and 'Teens Taking Charge' (Stinson et al., 2010b) incorporated user feedback. However, there was a lack of specification of the development approaches being used, with only iCanCope stating 'user-centred'. New guidance on reporting intervention development studies has been released and can be used as a reference point for development teams (Duncan et al., 2020).

Considering the efficacy trials of the interventions included in the current study (tableS2) in relation to the content analysis of interventions, none of the interventions underwent a formal process evaluation, as revealed by the quality assessment (tableS3). Process evaluations are an evaluation of the intervention implementation process (Möhler et al., 2015) and seek to examine the impact of specific intervention mechanisms and contexts on participant outcomes, with an aim to gain insight into what parts of the intervention are effective, for whom and under what conditions (Craig et al., 2008; Bonell et al., 2012). Only one included intervention carried out any form of process evaluation (Murray, de la Vega, et al., 2019; Palermo et al., 2009), though this was an evaluation of contextual factors rather than intervention mechanisms .Consequentially, it was not possible to evaluate which content components relate to improvements in which outcomes, such as pain severity and functioning (Craig et al., 2008; Bonell et al., 2012). The secondary analysis of RCT data from Web-MAP2 explored who benefitted from treatment at 12-month follow-up (Murray, de la Vega, et al., 2019). An important finding was that pain-related disability improved over time for adolescents aged 11-14 years, compared to adolescents aged 15 -17 years, for whom there was no significant benefit of the intervention compared to the control group. Such findings emphasise the importance of complimenting RCTs with process evaluation, especially where no additional benefit of treatment was found (Law et al., 2015; Trautmann & Kröner-Herwig, 2010; Connelly et al., 2019). Further guidance on conducting process evaluations of complex interventions is provided by the MRC (Moore et al., 2015). For data analysis, a key recommendation includes integrating process data (for example, data about usage or context) into outcomes datasets, to explore whether effects differ by contextual moderators, and test hypothesised mediators. Pre-planning of how process data will be collected alongside outcome data in evaluation studies of online interventions is recommended.

Several limitations can be noted. Firstly, only studies published in the English language were included. This analysis does not include interventions that are only reported in non-English publications, which could vary in content due to cultural differences in approaches to chronic pain management (Perry et al., 2019). Secondly, as the current review is an update of an existing review which followed the same methodology, a protocol of the current review was not registered prior to commencement. Lastly, only four interventions were accessible online, therefore it is likely that evaluations of content were more accurate for these interventions, compared to those that were evaluated using published descriptions.

4.5.1 Conclusions

Multidisciplinary content included in existing online interventions for paediatric chronic pain management was evaluated with reference to evidence-based guidelines. The content analysis revealed a lack of online interventions which cover all aspects of multidisciplinary pain management. There is scope for existing online interventions that focus on a specific pain condition, or technique (such as CBT), to be further developed to include a broader range of content. Further development of existing online interventions is warranted in the context of the COVID-19 pandemic, to ensure multidisciplinary pain management content can be accessed from home. It is equally important that new interventions being produced are evidence-based and reflect current best practice guidelines. New interventions should aim to incorporate insights from children and adolescents with chronic pain, and their families, using a robust development approach. Pre-planning of process evaluation is recommended to allow investigation of which intervention components are effective for which users and in which contexts.

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Author contributions: All authors discussed the results and commented on the manuscript. AHW, CL and DS formulated the aims and approach of this study. AHW and EN conducted coding for the content analysis. The first draft of the manuscript was written by AHW.

Chapter 5 Online paediatric chronic pain management: assessing the needs of UK adolescents, and parents, using a cross-sectional survey

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Chapter 5/ Paper 2

Abstract

Background: Adolescent chronic pain is prevalent, and interdisciplinary treatment is recommended. Although it is well known that technology is a key part of adolescents' daily lives, there have not been any online, interdisciplinary interventions developed for adolescents with chronic pain in a UK healthcare context. Little is known about how adolescents currently use online resources to manage chronic pain, or what guidance they seek.

Methods: Ninety-five participants from the community answered this mixed-methods, online survey (adolescent n = 54, parent n = 41), which assessed the needs of UK-based adolescents for a new online chronic pain management resource.

Results: Findings indicated that at the time of the survey adolescents frequently used social media platforms, such as Instagram, for chronic pain management. Desired techniques for a new interdisciplinary resource for adolescents included 'advice on explaining chronic pain to others' (86.7% of adolescents), sleep hygiene (82.2% of adolescents), though access to a range of pain management techniques was desired. Qualitative results indicated endorsement of a new programme by adolescents and parents.

Conclusions: Adolescents and parents had a positive outlook towards the development of a UK-specific online resource to help manage chronic pain. Such an intervention should aim to be made accessible via the NHS. Adolescent use of social media platforms to seek support for chronic pain requires further exploration in future research.

5.1 Background

Paediatric chronic pain is an internationally recognised problem; recent estimates indicate 13.2% to 33.8% of adolescents experience multi-site chronic pain, including 16-19% of UK-based adolescents (Gobina et al., 2019). Paediatric chronic pain is often complex and can considerably impair a young persons' physical, social, emotional and school functioning (Dick & Riddell, 2010; Forgeron et al., 2010). Mental health comorbidities, including anxiety and mood disorders, are prevalent and can hinder recovery in children and adolescents with chronic pain (Vinall et al., 2016; Fisher, Heathcote, et al., 2017; Kashikar-Zuck et al., 2008; Blaauw et al., 2014; Cunningham et al., 2016). An interdisciplinary approach to paediatric chronic pain management is recommended (Liossi & Howard, 2016; Rajapakse et al., 2014), and evidence shows interdisciplinary treatments can improve functional outcomes (Hechler et al., 2015; Liossi et al., 2019). However, many families do not have access or cannot travel long-distances to clinics (Elgar & McGrath, 2003). Self-management using online, remotely-delivered, interventions can reduce the number of clinic visits.

A review of psychological interventions to child and adolescent chronic pain showed remotely delivered cognitive-behavioural therapy (CBT) is described positively by patients, with some evidence for reduced pain severity post-treatment for headache but not for mixed chronic pain (Fisher et al., 2019). Another review of the availability of e-health tools for paediatric pain identified 53 tools (Higgins et al., 2018), 12 of which were intended for chronic pain management. Online adolescent chronic pain programs successfully developed in the United States (US) and Canada include WebMAP (Palermo et al., 2016) and iCanCope™ respectively (Stinson et al., 2014; Lalloo et al., 2019). There has not however been an interdisciplinary multi-modal intervention developed for adolescent chronic pain in a UK context.

Insights from adolescents in the UK are important as their needs may differ based on their experiences of healthcare, along with their experiences of chronic pain in various social contexts (Viner et al., 2012). For example, in the UK, the NHS offers free access to chronic pain management programmes following GP referral, whereas in the USA insurance companies review requests for specialist consultation (Cucchiaro et al., 2017). At a population-level, adolescents may identify a range of different priorities and problems which require different solutions to successfully implement an intervention in the real-world (O'Cathain et al., 2019). Understanding the needs of this population and gathering their views as potential users of a new resource reflects the MRC guidance for developing complex interventions, and integrates the Person-Based Approach (Yardley et al., 2015). It is also intuitive to consider parents as stakeholders in development under these frameworks.

Whilst it is well-recognised that adolescents are native internet users (Ofcom, 2019), and social media platforms are a critical part of their daily lives (Caes, Jones, et al., 2018), little is known about online resources that adolescents use to manage chronic pain, as well as comorbid mental health issues (Vinall et al., 2016). Understanding adolescents' current use of online resources for these purposes is another important part of the context in which adolescents with chronic pain will potentially use a new resource (O'Cathain et al., 2019). Research investigating healthy adolescents' use of online resources for acute pain management identified that adolescents experienced anxiety around their use, including pain-related anxiety and a mistrust of content (Henderson et al., 2014). The use of online resources for pain management has not been investigated in adolescents with chronic pain.

Considering adolescent use of social media for chronic pain management, a scoping review of support-seeking on YouTube found 18 videos targeting adolescents with chronic pain (Forgeron et al., 2019). Most content covered multidisciplinary and alternative treatments, consistent with interdisciplinary approaches. The videos had 936 comments, and the main message was 'you are not alone'. These comments indicate many adolescents with chronic pain go online for peer support, and also reflect reports that 12 to 15 year-olds turn first to YouTube for content that is important to them (Ofcom, 2017a).

Exactly what guidance adolescents with chronic pain seek online remains unclear. There is also little indication which online resources are being used except YouTube. Adolescent usage and preferences must be explored to create a viable real-world solution (O'Cathain et al., 2019). This study conducted a needs assessment for a UK-based online, interdisciplinary intervention for managing adolescent chronic pain. The study aimed to investigate (i) which online resources adolescents currently use to manage chronic pain and mental health, (ii) which online resources parents use to help them understand their child's chronic pain, (iii) which interdisciplinary techniques adolescents with chronic pain consider most helpful, (iv) what content and features adolescents and parents would like to see in a new online chronic pain management intervention, and (v) if reporting high online resource use predicts overall positive outlook, versus negative outlook, towards a new intervention.

5.2 Methods

5.2.1 Design

The study was an online cross-sectional survey using Qualtrics®, including a mixture of closed and open-ended questions.

5.2.2 Participants

This was a UK-wide survey of adolescents aged 16 to 18 years and older with chronic pain and parents of adolescents aged 12 to 18 years. The survey was not distributed directly to 12 to 15-year-olds, as this would have required additional consent from parents. Whilst not impossible to attain, the research team decided that a dual consenting process would overcomplicate this study for participants and negatively impact recruitment. Hence, to avoid complication and maintain anonymity, the survey pathways were separated into 16 to 18-year olds self-reporting and parents reporting for the 12 to 18 age range. A power calculation was conducted, producing a target sample size of 385 (Appendix A).

For adolescents, inclusion criteria were: 1) aged 16 to 18-years, 2) currently experiencing pain of any aetiology which has lasted ≥ 3-months (Treede et al., 2015) and exclusion criteria: 1) aged ≤ 15-years or ≥ 19-years, 2) pain lasting less than 3-months total duration, 3) chronic pain had not been formally diagnosed by a healthcare professional.

For parents, inclusion criteria were: 1) parents/ guardians of adolescents aged 12 to 18-years, 2) adolescent pain of any aetiology that has lasted ≥ 3-months (Treede et al., 2015) and exclusion criteria: 1) parents of children aged ≤ 11-years or ≥ 19-years, 2) adolescent pain has lasted less than 3-months.

5.2.2.1 Recruitment

The survey was accessible via an open survey link from 30th May 2019 to 14th October 2019, and advertised UK-wide using posters, social media (Twitter, Facebook, and LinkedIn), relevant charities, patient (or parent) organisations, online forums, and 'letters' to 93 local newspapers.

Initial screening questions were used to ensure that only adolescents or parents who indicated that they met the inclusion criteria could proceed with the survey. A first-stage screening question (on the consent form) ensured all participants were ≥16 years old; this question also served as a branch to the adolescent or parent version of the survey. A second-stage of screening was used to clarify that the young people in question had a chronic pain condition with a duration of ≥ 3-months. Qualtrics validation ensured that participants who did not select a valid criterion could not continue the survey and were politely asked to exit.

5.2.3 Survey and procedure

There were 78 questions split between two branches: adolescent and parent versions. Questions in the two branches mirrored each other. The survey took approximately 30 minutes to complete. Participants could return to previous questions and could save the survey and return to complete it within 7-days. If no activity was registered for 7-days, the response was recorded as partially completed. The survey flow is represented in Figure 7.

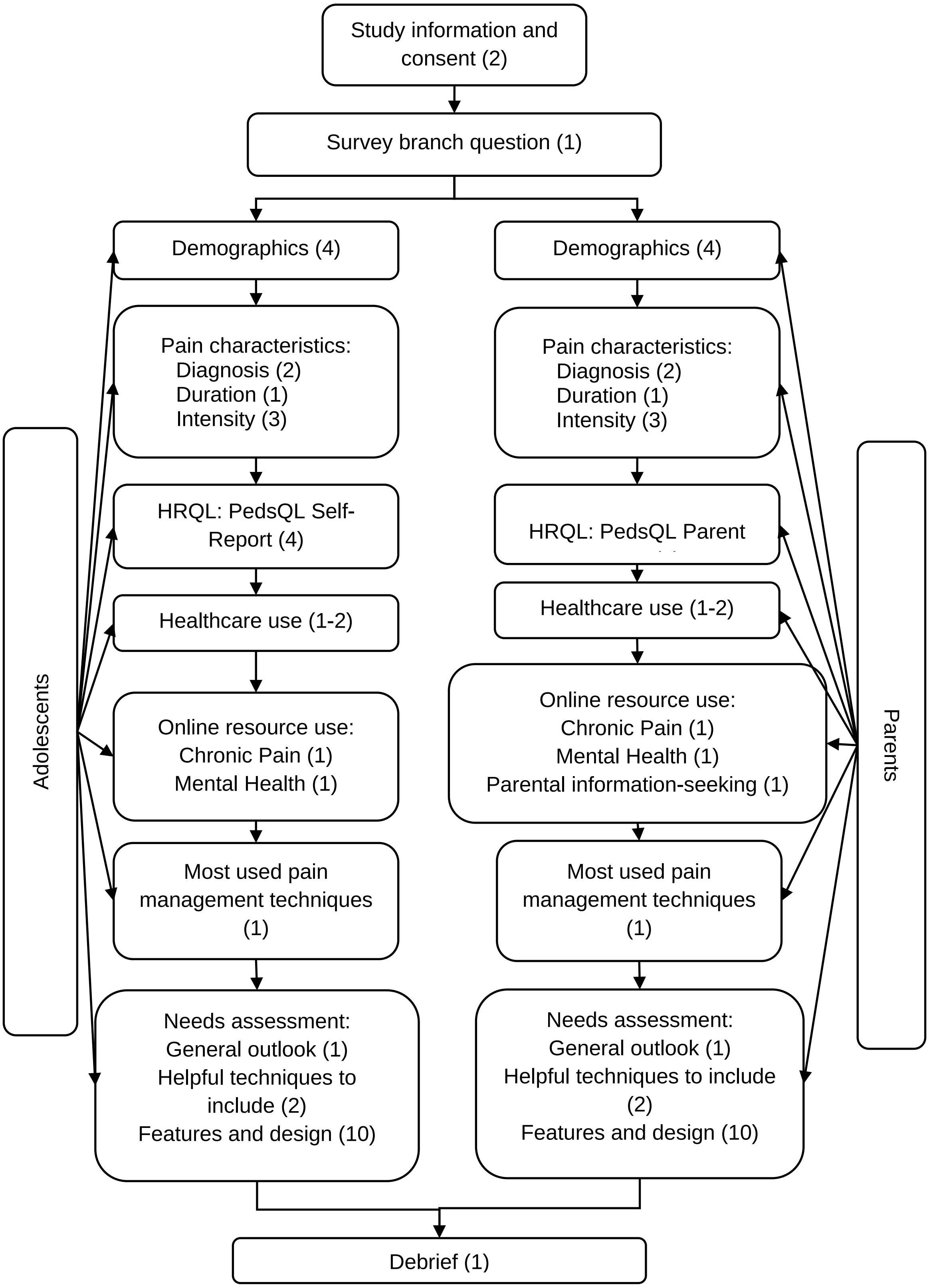

Figure 7. Survey flow for the current study. The diagram shows the survey blocks in flow order, with the number of questions per section indicated in parentheses.

Full questionnaire details are provided in Appendix B. Pain diagnoses were collected using the categories outlined for the ICD-11 (Treede et al., 2015), intensity was assessed using items from the Brief Pain Inventory (BPI) (Cleeland & Ryan, 1991). Pain duration was also collected. Health-related quality of life (HRQL) was assessed using the PedsQL™ 4.0 (Varni et al., 2003; Varni et al., 2001). Current resource use and needs assessment questions were developed specifically for this study.

5.2.4 Planned analysis

Statistical analyses were conducted using SPSS version 26. Multiple responses analyses were performed to descriptively summarize participants' use of online resources for chronic pain and mental health, as well as for preferred content and features (n, %). Pearson Chi-Square tests were used to explore differences between adolescents and parents in reported resource use and preferred content. Where between-group differences were significant, pairwise comparisons were adjusted using a Bonferroni correction. Note that Chi-Square tests performed on multiple response data are exploratory as opposed to confirmatory (Gray & Kinnear, 2012).

For most helpful pain management techniques, participants were asked to rank their top three out of a selection of 19. Responses left empty were considered tied for last place. Missing values were allocated a score of 11.5 in SPSS (mean score of the remaining available ranks [4+5+6...+19/16]). A rank score was calculated to ascertain the top ranked pain management techniques for adolescents and parent respondents, separately. Lower scores indicate higher ranking.

Independent t-tests were used to compare feature and design preferences between adolescents and parents for scale variables. Categorical responses were compared using Pearson Chi-Square, or Fisher's Exact Test where >20% of cell counts were <5.

Because 74 out of 78 participants that answered the qualitative question (95%) were positive towards the development of an online intervention, planned logistic regressions to identify predictors of preference became obsolete.

5.2.4.1 Qualitative exploration

To explore initial ideas and opinions that adolescents and parents had about a UK-based online chronic pain management program, a content analysis was conducted on the first question in the needs assessment: '*what are your initial thoughts about creating a new online resource that could help young people/ you manage chronic pain*?'. Responses were first exported to Nvivo 12 and cross-tabulated with demographic data, regarding whether the participant was an adolescent or parent, their sex, and age (QSR International Pty Ltd, 2012). The content analysis used an inductive approach, in which sentences were the units of analysis (Elo & Kyngäs, 2008). Open coding, followed by categorisation into generic categories and sub-categories was conducted by AH (PhD student researching paediatric chronic pain). Categories are labelled with content-characteristic words (Dey, 2003; Elo & Kyngäs, 2008).

5.3 Results

5.3.1 Participant demographics

A total of 95 UK-based participants, including 54 adolescents and 41 parents, completed this survey.

One-hundred and forty-five individuals accessed the survey, of which 112 completed it. Sixty-one adolescents and 48 parents provided their geographical location. The majority of these were valid UK postcode districts (81.2%) covering multiple regions (England, Wales, Scotland) (see Appendix C. UK Distribution Map). Participants that entered a numeric area code, which appeared to be from outside the UK, were excluded from analyses (n = 17). Participants that did not enter any location data were included. These participants met screening criteria for chronic pain, and any contributions remained potentially useful. There were eight matched postcodes by district, four of which were cross-matches between the parent and adolescent groups. These matches may or may not have been adolescent-parent dyads. As this was unknown, no additional measures were taken to account for this in data analyses.

Participant demographic and pain characteristic information from the UK sample is displayed in Table 1. Most adolescents were aged 17 (n = 20) or 18 (n = 21) years old. Participating parents and guardians were most commonly in the 36 to 55 years age category (95.1%). Most adolescents identified as girls (94.4%). There were three boys, and one person did not identify with any gender category. All of the parents in this sample were women.

Index of Multiple Deprivation (IMD) scores indicated that the sample were of varied socioeconomic status. The IMD ranks every neighbourhood in England from 1 (most deprived area) to 32844 (least deprived area). Neighbourhoods in Wales are ranked from 1 to 1909, and Scotland from 1 to 6976. Eighty participants in this sample were from England (IMD; M = 16521), two were from Wales (IMD; M = 967), and seven from Scotland (IMD; M =

4796). IMD rank scores for this sample ranged from 1388 out of 32844 (10% most deprived in England) to 32472 out of 32844 (10% least deprived in England) (Ministry of Housing, 2019).

The most frequent pain type reported by adolescents and parents was musculoskeletal (MSK) pain (77.8% and 92.7%, respectively). One parent selected cancer pain. The majority of adolescents had been experiencing chronic pain for longer than a year, according to adolescent self-reports (96.3%) and parent-proxy reports (95.2%). The most commonly selected pain duration for both respondent groups was five-years or longer (adolescents = 46.3%, parents = 48.7%). The HRQL total score for this sample of adolescents with chronic pain (self-reported M = 30.14, SD = 12.85) was low compared to other recent studies of adolescents with chronic pain (Yetwin et al., 2018) (self-reported M = 58.71, SD = 21.58), $t(90) = -7.79$, $p < .001$; and very low compared to a healthy 15-year-old sample (Lam et al., 2013) (self-reported M = 84.70, SD = 12.70), $t(335) = -27.52$, $p < .001$.

Table 1. Demographic and pain characteristics for adolescent and parent participants.

	Adolescents (n = 54)	Parents (n = 41)
Age: 16 years (n) (%)	13 (24.1)	---
Age: 17 years (n) (%)	20 (37.0)	---
Age: 18 years (n) (%)	21 (38.9)	---
Age: 18 to 35 years (n) (%)	---	1 (2.4)
Age: 36 to 55 years (n) (%)	---	39 (95.1)
Age: > 55 years (n) (%)	---	1 (2.4)
Birth sex (n) (%)		
Male	3 (5.6)	0 (0)
Female	51 (94.4)	41 (100)
Gender (n) (%)		
Man	2 (3.7)	0 (0)
Woman	51 (94.4)	41 (100.0)
Transgender	0 (0)	0 (0)
Does not identify as a man, woman, or transgender	1 (1.9)	0 (0)
Chronic pain type [a] (adolescent) (n) (%)		
Primary pain	31 (57.4)	21 (51.2)
Cancer pain	0 (0)	1 (2.4)
Post-surgical pain (PSP)	1 (1.9)	1 (2.4)
Neuropathic	8 (14.8)	4 (9.8)
Headache/ orofacial	19 (35.2)	9 (22.0)
Visceral	7 (13.0)	5 (12.2)
Musculoskeletal (MSK)	42 (77.8)	38 (92.7)
Pain duration (adolescent) (n) (%)		
≥ 3-months	2 (3.7)	1 (2.4)
≥ 6-months	0 (0)	1 (2.4)
≥ 1-year	15 (27.8)	6 (14.6)
≥ 3-years	12 (22.2)	13 (31.7)
≥ 5-years	25 (46.3)	20 (48.8)

Pain intensity - BPI (adolescent) (M) (SD)	Adolescents (n = 51)	Parent-proxy (n = 41)
Worst in last 24 hours	7.02 (1.33)	6.59 (1.69)
Least in last 24 hours	3.84 (1.77)	4.24 (2.46)
On average	5.59 (1.37)	5.51 (1.33)
Current healthcare use (attending an NHS pain management service (n) (%)	Adolescents (n = 50)	Parent report (n = 40)
Yes	11 (22.0)	9 (22.5)
No	39 (78.0)	31 (77.5)
HRQL – PedsQL™ (0-100), (M, SD)	Adolescents (n = 48)	Parent-proxy (n = 38)
Psychosocial summary	33.82 (14.57)	36.62 (14.70)
Emotional scale	31.98 (17.19)	38.03 (19.33)
Social scale	42.29 (20.50)	38.46 (20.17)
School scale	27.19 (17.01)	33.21 (18.33)
Physical summary	23.24 (13.47)	26.07 (17.30)
Total score	30.14 (12.85)	32.95 (14.44)

[a] Participants could select multiple categories for chronic pain type; percentages indicate percent of individual cases that selected the option.

5.3.2 Use of online resources

Descriptive information about frequency of various resources used to manage chronic pain and mental health is summarised in Table 2 and Table 3. Many participants selected multiple online resources for both chronic pain and mental health management. The most frequently selected response by adolescents was that they did not use any websites or apps for pain management (50.0%). The most frequently selected resource by adolescents for managing chronic pain was Instagram (n = 20), although this was not reflected in the parent responses for adolescent Instagram use (n = 5). The majority of parent participants (74.3%) indicated their child did not use any websites or apps for pain management. Exploratory comparison between adolescents and parents did not reveal a significant difference in multiple response entries for chronic pain resources, $\chi^2(8) = 15.30$, $p = .054$.

For mental health management, the most frequent response from adolescents and parents was that the adolescent did not use any websites or apps for mental health management (50.0% and 62.9%, respectively). The top three most selected resources for mental health management by adolescents were Instagram (n = 16), Headspace (n = 10), and YouTube (n = 9). These selections were not mirrored by the selections made by parents regarding their children’s usage. Adolescent and parent multiple response entries for mental health resources, however, were not significantly different upon statistical exploration, $\chi^2(10) = 16.58$, $p = .084$.

Table 2. Frequency of adolescent use of online resources and social media platforms for chronic pain management, according to adolescent and parent reports.

Chronic pain resources	Adolescents (n = 48), n (%)	Parents (n = 35), n (%)
Does not use websites/ apps	24 (50.0)	26 (74.3)
Instagram	20 (41.7)	5 (14.3)
YouTube	13 (27.1)	6 (17.1)
Facebook	8 (16.7)	4 (11.4)
Online forum	5 (10.4)	2 (5.7)
Uses a different website/ app	4 (8.3)	2 (5.7)
Twitter	4 (8.3)	3 (8.6)
Reddit	1 (2.1)	0 (0)
MeeTwo	0 (0)	0 (0)
PainBytes	0 (0)	0 (0)

Note: Participants could select multiple resources; percentages indicate percent of individual cases that selected the option. Resources are listed in descending frequency of selection by adolescents.

Table 3. Frequency of adolescent use of online resources and social media platforms for mental health management, according to adolescent and parent reports.

Mental health resources	Adolescents (n = 46), n (%)	Parents (n = 35), n (%)
Does not use websites/ apps	23 (50.0)	22 (62.9)
Instagram	16 (34.8)	2 (5.7)
Headspace	10 (21.7)	6 (17.1)
YouTube	9 (19.6)	4 (11.4)
Calm	6 (13.0)	3 (8.6)
Online forum	5 (10.9)	1 (2.9)
Facebook	4 (8.7)	1 (2.9)
Young Minds	2 (4.3)	1 (2.9)
Uses a different website/ app	1 (2.2)	2 (5.7)
Twitter	1 (2.2)	1 (2.9)
Reddit	0 (0)	0 (0)
MeeTwo	0 (0)	0 (0)

Note: Participants could select multiple resources; percentages indicate percent of individual cases that selected the option. Resources are listed in descending frequency of selection by adolescents.

The survey also investigated parent use of online resources to aid their understanding of their child's chronic pain. As shown in Figure 8, 45.9% of the parents that responded to this question used Facebook as an information resource. Seconding this was use of online forums (37.8%). In the alternative response box, two parents advised that they have used Ehlers-Danlos websites (https://www.ehlers-danlos.org/) as an information resource, and one parent indicated they used the NHS website (https://www.nhs.uk/).

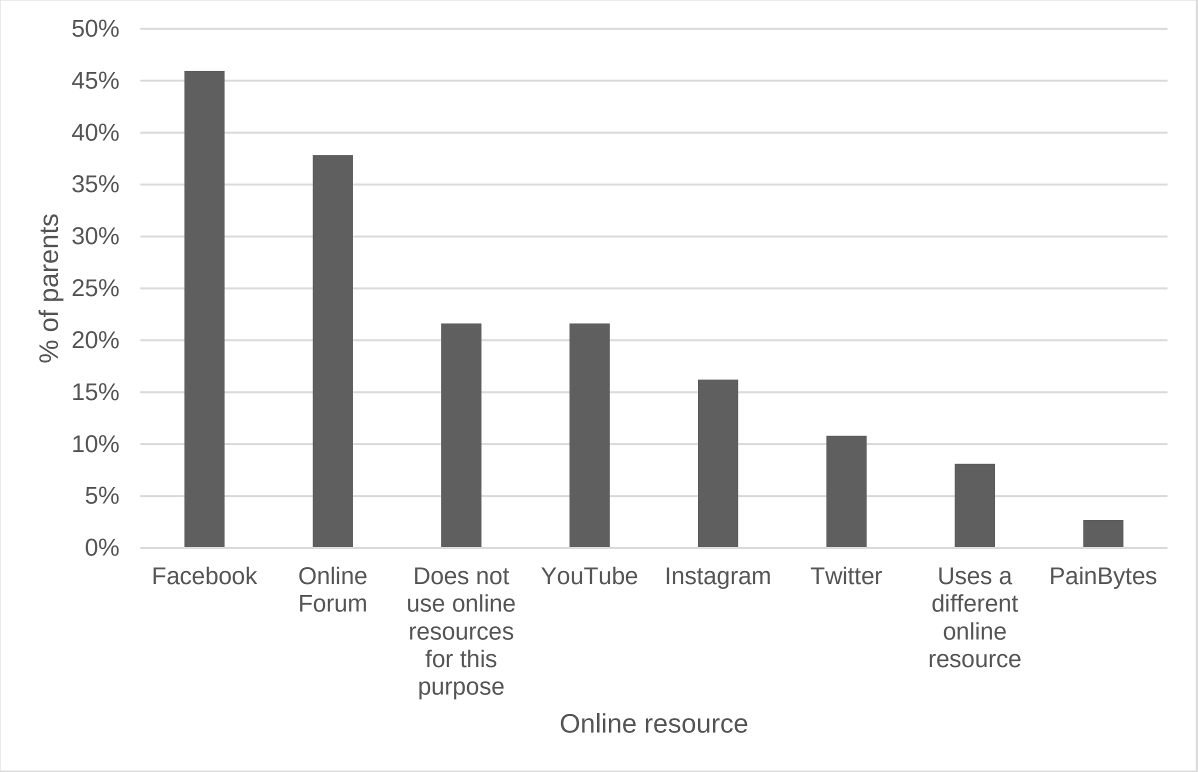

Figure 8. Parent use of online resources to help them understand or manage their adolescents' chronic pain.

5.3.3 Most helpful pain management techniques

The top three highest ranked chronic pain management techniques for adolescent respondents (n = 49), were pacing (M rank = 5.9, SD = 4.7), medication (M rank = 6.3, SD = 5.0), and rest (M rank = 6.9, SD = 4.8). Hypnosis and mindfulness were tied for last place within the adolescent group (M rank = 11.5), indicating that none of the adolescents ranked these techniques in their top three. The top three highest ranked chronic pain management techniques by parents (n = 36) were pacing (M rank = 5.9, SD = 4.6), rest (M rank = 7.2, SD = 4.9), and physiotherapy (M rank = 7.5, SD = 4.9). None of the parents ranked biofeedback or exposure therapy in their top three (M rank = 11.5).

5.3.4 Preferences for content and features in a new program

Descriptive information regarding the chronic pain management techniques that adolescents and parents indicated they believed would be helpful to include in a new online resource is summarised in Table 4. Many participants selected multiple pain management techniques, although ‘advice on pacing daily activities’ was the most frequently selected by parents (86.1%), followed by ‘methods to improve sleep (80.6%). The most frequently selected option by adolescents was ‘advice on explaining chronic pain to others (e.g., friends and family)’ (86.7%), followed by ‘methods to improve sleep’ (82.2%). Exploratory comparison between adolescent and parent multiple responses revealed a significant between-groups difference in preferences for content, $\chi^2(19) = 33.49$, $p = .021$. Pairwise comparisons using a Bonferroni correction indicated significant differences ($p < .003$) for hypnosis and guided imagery, where both options were more frequently selected by parents.

Table 4. Most helpful techniques to include in the content of a new online resource for managing chronic pain in adolescents, according to adolescents and parents.

Pain management technique*	Adolescents (n = 45), n (%)	Parents (n = 36), n (%)
Advice on explaining chronic pain to others	39 (86.7)	26 (72.2)
Methods to improve sleep	37 (82.2)	29 (80.6)
Advice on pacing daily activities	34 (75.6)	31 (86.1)
Advice on transitioning from ‘paediatric’ to adult healthcare	34 (75.6)	25 (69.4)
Guidance on pain medications	33 (73.3)	19 (52.8)
Pain education	32 (71.1)	20 (55.6)
Advice on pacing for exercise/ sports	30 (69.2)	22 (61.1)
Support for returning to school	30 (66.7)	22 (61.1)
Physiotherapy examples	28 (62.2)	18 (50.0)
Examples of other physical pain management techniques	27 (60.0)	23 (63.9)
Massage techniques	22 (48.9)	15 (41.7)
Relaxation and breathing	21 (46.7)	19 (52.8)
Challenging negative thoughts	20 (44.4)	26 (61.9)
Mindfulness/ meditation	19 (42.2)	21 (58.3)
Biofeedback	19 (42.2)	12 (33.3)

Exposure therapy	16 (35.6)	12 (33.3)
Art therapy	10 (22.2)	15 (41.7)
Guided imagery/ visualisation	5 (11.1)	12 (33.3)
Hypnosis	3 (6.7)	9 (25.0)

Note: Participants could select multiple options; percentages indicate percent of individual cases that selected the option. Items are listed in descending frequency of selection by adolescents.

Other techniques mentioned by adolescents in the optional text entry box included music therapy (n = 2), connecting with others with chronic pain (n = 2), and help with everyday tasks (n = 2). Parents mentioned occupational therapy (n = 1), other CAM techniques (n = 2), and the potential for an online peer support platform for adolescents (n = 2).

5.3.4.1 Functional features and design

Regarding program structure, the majority of adolescent and parent respondents selected they would prefer a ‘flexible structure’, where they could choose which sections they wanted to use (86.7% and 77.1%, respectively). However, when examining between-groups differences for all of the available choices for structure (see Appendix B) there was a statistically significant difference between which choices adolescents and parents selected, two-tailed Fisher Exact *p* = .030. The option that differed between respondent groups was ‘I do not mind how the resource is structured’, where 2% of adolescents selected this option compared to 20% of parents. Regarding preference for having professional support whilst using the intervention (1 = definitely yes to 5 = definitely not), for telephone support, there was a significant difference in preference between adolescent and parent participants, *t*(78) = 2.07, *p* = .042, where adolescents preferred to have telephone support (M = 3.56, SD = 1.08) comparatively to parents (M = 3.06, SD = 1.06). For online professional support, there were no significant differences in preference between adolescents and parents, *t*(78) = -1.31, *p* = .195 (M = 2.09, SD = 1.00 and M = 2.37, SD = .91, respectively). With regard to whether a theme would be appealing or not (response options = ‘yes’, ‘maybe’, or ‘no’), the most common adolescent response was ‘maybe’ (48.9%), and similarly ‘maybe’ was the most common response from parent respondents (40.0%). There was no significant difference between adolescent and parent responses; $\chi^2(2) = 2.08$, $p = .403$.

The importance of linking an online pain management program to a hospital or clinic (1 = extremely important to 5 = not at all important) was indicated by adolescent participants to be ‘moderately’ important (M = 3.04, SD = 1.19). There was no significant difference between adolescent and parent responses to the hospital link question, $t(78) = .90$, $p = .371$. The majority of adolescent responses to the question of whether they would prefer video demonstrations of techniques to include a healthcare professional, or a ‘teenage’ patient (there was also an option for no preference), indicated that they would prefer a patient (42.2%). Parent respondents also indicated that they would prefer a patient in video examples (65.7%); no significant between groups differences were indicated; $\chi^2(2) = 4.67$, $p = .106$. For whether people in video examples should be ‘male, ‘female’ or ‘no preference’, ‘no preference’ was most frequently selected (adolescents = 80.0%, parents = 94.3%), and none of the respondents in either group selected ‘male’. Adolescent and parent responses were not significantly different, Fisher Exact $p = .101$. Regarding what the ethnicity of the person/ people displayed in any video examples should be, the majority of respondents selected no preference (adolescents = 93.3%, parents = 85.7%), where the only other response that was selected was mixed/multiple ethnic groups (adolescents = 6.7%, parents = 14.3%). ‘White’, ‘Asian’ and ‘Black/African/Caribbean’ were not selected by any respondents, and there was no significant difference between respondent groups, two-tailed Fisher Exact $p = .288$.

5.3.4.2 Barriers and facilitators to using a new program

Considering facilitators, two adolescents commented they would like an online program to include reminders, and barriers mentioned included levels of pain and fatigue, as well as the program having too much text, or taking too long to work through. The parent comments emphasised to make sure the program was not patronising or condescending, which was also echoed in comments from two adolescent participants. One parent commented that a barrier to adolescent use might be monitoring, either by the hospital, school, or parents.

5.3.5 Qualitative content analysis

Seventy-eight respondents (adolescents, n = 45; parents, n = 33) answered the initial needs assessment question, ‘*what are your initial thoughts about creating a new online resource that could help young people/ you manage chronic pain*?’ The adolescent group that answered this question included 1 male and 44 females, and the parent group included 33 females only. The majority of the adolescent group were aged 17 years (42.2%) and the majority of parents were aged between 36 and 55 years (93.9%).

Four generic categories were identified within the data, where the main overarching category can be considered as ‘opinions about a new online resource for young people with chronic pain’, derivative of the research question itself. Categories and sub-categories were condensed from 91 codes identified from the qualitative dataset of responses from both adolescent and parent participants.

An exploratory subgroups analysis was conducted using the generic categories to compare responses from adolescents and parents. All four categories remained clear within parent and adolescent groups. The category that responses were most frequently classified under was ‘good idea’, with 17 responses from adolescents grouped under this category, and 21 responses from parents. Adolescents commented more frequently on age-specificity compared to parents (n = 13, and n = 4, respectively).

5.3.5.1 Category 1: Good idea

Participant responses were most frequently classified to this category (n = 38), representing the opinion that an online program for managing chronic pain in adolescents was generally a ‘good’, ‘great’ or ‘excellent’ idea, and that participants would be interested in such a program.

A56: “*I think a new online resource that could help young people with chronic pain is a brilliant idea.*” (Adolescent, 17 years, female)

Two respondents touched on the notion that it would be a good idea to link to NHS services, however there were not enough comments made about this for ‘NHS linking’ to be considered a sub-category alone.

There was also an element of excitement throughout these comments, indicated by use of superlatives (e.g., ‘amazing’, ‘fantastic’). A few of the adolescents used the word ‘cool’ to indicate excitement.

5.3.5.2 Category 2: Helpful

Thirty-five responses were classified under ‘helpful’. This included synonyms of helpful; the other key word used was ‘useful’. An example is quoted below. Some comments eluded that adolescents would try anything, rather than showing enthusiasm specifically towards a new resource (see A41). Overall, the comments were positive.

A45: “*I think it’d be very useful as finding out how to deal with chronic pain is very difficult.*” (Adolescent, 18 years, female)

A41: “*Anything to help even a few people.*” (Adolescent, 17 years, female).

5.3.5.2.1 Sub-category: Improving accessibility

This sub-category gave a sense that an online program would be helpful because it would create a way for adolescents to access help independently. The majority of these comments were from parents.

A23: *“I think it would help a lot of young people get the help they deserve*.” (Parent, 36 to 55 years, female)

A104: “... *Ease of access from home. Not reliant on GP referral etc. - self ownership/ management.*” (Parent, 36 to 55 years, female)

5.3.5.2.2 Sub-category: Increasing others’ understanding

A few of the participants’ initial comments revealed a preference for something within a new resource that could help other people understand the chronic pain experience. This is exemplified in the below quote.

A10: “*Could be useful about helping those without chronic pain to understand*.” (Adolescent, 18 years, female)

5.3.5.3 Category 3: Adolescent-specific

The need for an age-specific resource for adolescents came through strongly. This category was exemplified well by one of the adolescent participants.

A33: “*It would be fantastic as there are very little resources for people my age in my area.*” (Adolescent, 17 years, female)

5.3.5.3.1 Sub-category: Non-patronising

Within the adolescent-specific category, a few comments were made about ensuring a new program is not patronising. One participant highlighted whether an intervention is patronising or not depends on the group it is targeting.

A64: “*It could be good but only if it is targeted appropriately e.g., not patronising*.” (Adolescent, 16 years, female)

A42: “*It can come across offensive because people with chronic pain have tried a lot.*” (Adolescent, 17 years, female)

5.3.5.3.2 Sub-category: Connectedness

Under connectedness, there were comments about the need for something to help adolescents feel less alone, and about generally connecting with other adolescents who are going through a similar experience. This could be labelled as peer support; however, there was a clear emphasis on knowing people are there empathetically, rather than seeking advice. There were additionally a couple of comments made on social media integration as a way of establishing connections (see example quote A46).

A81: “... *a good idea so that they can compare and make friends with others who understand.*” (Parent, 36 to 55 years, female)

A46: “*It would be beneficial; using social media platforms would be good for that.*” (Adolescent, 16 years, female)

5.3.5.4 Category 4: Concerns

Whilst there were few concerns or negative comments made (n = 12), it is important that negative comments be acknowledged in light of developing an online intervention. Some respondents made comments that were too vague to interpret exactly what the concern was.

A30: “*It’s a good idea as long as it’s good, well-meaning and doesn’t do harm.*” (Adolescent, 18 years, female)

These types of comments could not be categorised under a specific sub-header. Many of these responses were juxtaposed, such as the comment by participant A30. Outside of more general comments, an underlying concern was the relevance of intervention content.

5.3.5.4.1 Sub-category: Content relevance

Concerns about the relevance of the content in an online resource for adolescent chronic pain management were evident. These included comments about the broad range of chronic pain conditions, and that different people manage differently. Participants also commented on tangible support over self-management.

A101: “*Not sure if really helpful – [a] lot of resources, no idea of reality - need practical help and a life.*” (Parent, 36 to 55 years, female)

A98: “*Would need to be wide-ranging to cover different causes of pain; could make it unwieldy to use.*” (Parent, 36 to 55 years, female)

5.4 Discussion

The aim of this study was to conduct a UK wide needs assessment for an online, interdisciplinary intervention for paediatric chronic pain management, the results of which offer valuable insight into the needs of adolescents regarding online chronic pain management. Even though the survey was conducted in the UK, the results can inform aspects of the development of online interventions in other western countries.

Considering online resources used to manage chronic pain and mental health issues, the majority of adolescents and parents indicated adolescents did not use online resources for either purpose. This is surprising given positive evaluations of mindfulness-based apps such as Headspace (Mani et al., 2015; Economides et al., 2018; Howells et al., 2016). Only 10 adolescents indicated they used Headspace, and one indicated ‘Calm’ (another commercially available app). Social media resources were selected much more frequently by adolescents than parents, possibly because parents are generationally less familiar with social media and do not necessarily know the resources their children use (Ofcom, 2019). Whilst psychological factors play a key role in the maintenance of paediatric chronic pain (Liossi & Howard, 2016; Simons et al., 2012), there seems to be low endorsement of available psychology-based tools to manage concurrent mental health issues.

Prior research reveals adolescents often access YouTube for important information, and specifically for chronic pain information (Ofcom, 2017a; Forgeron et al., 2019). The present results support this as 27% of adolescents indicated they use YouTube as a support resource. However, this study highlighted Instagram as another important resource for chronic pain, selected by 42% of adolescents. Whilst Instagram originated as a platform for uploading still photographs, the latest versions (2020) allow uploads of video content (up to 1 minute) and for direct messages between users. Additional video content can be uploaded by business users to Instagram TV. Mirroring the previous investigation of YouTube content (Forgeron et al., 2019), Instagram content on adolescent chronic pain warrants further exploration. It is concerning that the current lack of a trusted online resource for adolescent chronic pain management may lead to adolescents accessing content that is not evidence-based or accurate, which could perpetuate problems. Recent media reports note insufficient monitoring of harmful, self-injury promoting social media content, despite efforts to eradicate it (BBC News, 2019). A solution may be the creation of an evidence-based resource for adolescent chronic pain that can be made accessible via the NHS or a linked service.

Considering parent use of online resources to help them understand their child’s chronic pain, findings indicated 46% use Facebook as a support resource. This is another area of interest concerning whether information shared on Facebook groups is evidence-based. The second most used resource by parents was online forums. This supports previous investigations of parental online communication on forums for paediatric Complex Regional Pain Syndrome (CRPS) for informational and empathetic support (Navarro et al., 2018). It is possible that parents in the present study of mixed chronic pain used forums for similar reasons. Only one parent used the NHS website as an information resource, which may indicate an increased need for empathetic support over informational.

Interdisciplinary pain management techniques (not online) ranked as the most helpful differed somewhat between adolescents and parents. Medication was ranked as the second most helpful intervention by adolescents but was not highly ranked by parents. This may indicate medication use in older adolescents is high, despite a lack of evidence that pharmacological interventions are effective as a standalone treatment for chronic pain (Caes, Fisher, et al., 2018; Eccleston et al., 2019; Cooper, Fisher, et al., 2017; Cooper, Heathcote, et al., 2017; Eccleston et al., 2017). Pacing was the top ranked technique by both groups, and rest was also ranked in the top three for both groups. The majority of this sample were not attending a specialist pain clinic at the time of the survey, which may explain why medication and rest were ranked high, whilst psychological treatments were ranked low. Psychological techniques are less likely to be cited by healthcare professionals working outside of specialist chronic pain services (Hurley-Wallace, Wood, et al., 2018). However, data on whether participants attended a specialist clinic in the past was not collected.

Regarding preferred chronic pain management techniques adolescents and their parents wanted to see in a new program, many adolescents selected ‘advice on explaining chronic pain to others’ (87%). This may be because adolescents with chronic pain often struggle with social functioning (Forgeron et al., 2010; Forgeron et al., 2011; Eccleston et al., 2008), and are at increased risk of peer victimisation compared to healthy peers (Forgeron et al., 2010). Whilst it would be useful to include social advice in a new online program, this finding may reflect a need for community and school-based interventions that target peer understanding.

Most participants indicated they wanted access to ‘methods to improve sleep’ (82% of adolescents and 80% of parents), reflecting prior research findings that 54% of adolescents with chronic pain report insomnia symptoms (Palermo et al., 2011). In relation to online interventions, currently available CBT-based chronic pain management has not been found to significantly improve sleep outcomes in adolescents (Fales et al., 2015). Researchers from this study suggested that, as reductions in pain and disability were not associated with improved sleep, poor sleep is likely fuelled by a variety of factors. Content on improving sleep requires more focus in new programs; examples of sleep hygiene techniques for adolescents are available in the wider literature (Kotagal & Pianosi, 2006).

Concerning preferred interdisciplinary techniques for a new resource, the majority of participants selected several techniques out of the 19 available to select. Clearly, access to a range of techniques is desired, though it is debateable how many techniques can feasibly be included in one online resource. This need for choice of techniques is similar to the concept of a ‘pain toolbox’, which is successfully utilised in CBT-based online interventions for adolescent chronic pain (Palermo et al., 2016).

Whilst qualitative responses lacked depth, four clear categories were identified. The first two categories (‘good idea’ and ‘helpful’) were expressed strongly by both adolescent and parent respondents, indicating an overall positive outlook towards online modalities of pain management. New, evidence-based, targeted resources for chronic pain self-management are likely to be welcomed by adolescents and parents.

One pertinent response from the adolescent qualitative data was that there is nothing age-specific available. There is a clear need for resources aimed at adolescents, which is not patronising, and allows them to connect in a similar way to social media. Social media is a critical part of adolescent’s lives and different platforms are used for different purposes (Caes, Jones, et al., 2018). The current study indicates adolescents are seeking a platform that is specific to chronic pain. Recent reports of YouTube use in 12 to 15 year-olds note that 52% use vloggers as a source of online content and inspiration (Ofcom, 2019). An important part of chronic pain management for some adolescents may be through following others with painful conditions. Interactive, peer support platforms have been successfully developed for paediatric chronic pain and arthritis (iPeer2Peer) (Ahola Kohut et al., 2016; Stinson et al., 2016) as standalone programs. A pilot study of iPeer2Peer, including 28 adolescents with chronic pain, found those who completed the series of 10 Skype-based calls with a peer mentor significantly improved their coping abilities and self-management skills (Ahola Kohut et al., 2016). There is potential for elements of peer support to be integrated within interdisciplinary programs, which may help adolescents to feel more connected and supported in their self-management.

This need for an adolescent-specific resource may also highlight a lack of acknowledgement that adolescents and children have different needs. Previous research on health information-seeking found adolescents with pain seek information online as a way of assuming independence over their health (Henderson et al., 2014). Promisingly, the focus of online interventions that have been developed for adolescents with chronic pain in the US and Canada has been on self-management (Lalloo et al., 2019; Stinson et al., 2014; Palermo et al., 2016). The overarching message is that adolescence represents a unique stage of physical, social, and emotional development (Sawyer et al., 2018; Spear, 2000; Pfeifer & Blakemore, 2012), and interventions should be targeted appropriately.

Several study limitations should be noted. Firstly, the target sample size was not met, and therefore quantitative, descriptive results are unlikely to be generalizable to the wider population of UK-based adolescents with chronic pain, and only representative of respondents (Kelley et al., 2003). There were no implications of sample size for the qualitative content analysis. The content analysis answered the intended research question regarding adolescent and parent opinions towards a new online resource, thereby meeting the informational needs of the study (Bengtsson, 2016). Secondly, whilst it is expected an adolescent chronic pain sample would contain more girls than boys based on prevalence statistics (King et al., 2011), 94% of the adolescent sample were girls. Data regarding the sex of the adolescents that parents were responding about was not collected. As such, these findings should not be generalised to adolescent boys.

5.4.1 Conclusions

The results of the current study indicate that use of online resources and social media for managing chronic pain is common in adolescents, with many turning to Instagram and YouTube for content and support. Overall, development of a new online resource for chronic pain was endorsed by adolescents and parents, with a need for connectedness and age-specific content emphasised. Access to a range of interdisciplinary techniques is desired. New online interventions for adolescents in the UK should aim to be accessible via the NHS as an evidence-based resource. Novel research exploring how adolescents use social media platforms to manage chronic pain and seek support is recommended.

Chapter 6 Trusting in the online ‘community’: An interview study exploring internet use in young people with chronic pain

This study has been submitted for consideration by the British Journal of Pain (July 2021).

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Chapter 6/ Paper 3

Abstract

Background: Chronic pain in young people is prevalent in the UK. Young people are digital natives, yet there has not been any online intervention developed in a UK context to help them manage chronic pain. Key to understanding the context in which young people engage with online interventions is better understanding their internet use for chronic pain management. The overarching aim of this study was to explore young peoples' experiences of searching for information about chronic pain using the internet. This included experiences of using search engines (e.g., Google), health information websites (e.g., the NHS website), and social media (e.g., Facebook, Instagram).

Methods: Semi-structured interviews were conducted with young people aged 16 to-24-years-old (n = 24), online, via Microsoft Teams. The study was advertised online and via patient partner charities. Interview data was analysed using reflexive thematic analysis.

Results: Participants presented with a variety of chronic pain conditions, including joint hypermobility syndrome (n = 6), chronic headache and/or migraine (n = 4), and fibromyalgia (n = 3). Four themes were generated: 'Trustworthy information, or experiences?', 'Diagnostic labels in a digital world', 'The online chronic pain community', and 'A mind and body approach to self-management'. Young people trust advice from others in their online community, and having a diagnostic label helps them find relevant pain management strategies and support networks online.

Conclusions: This study is the first qualitative exploration of internet use in UK-based young people with chronic pain. Findings highlight the importance of considering internet use when developing new online interventions for young people with pain and that internet use, particularly social media use, is an important psychosocial consideration in pain management. Young people should be encouraged to verify practical pain management techniques found online with their doctor and be empowered in the safe use of appropriate psychology-based self-management resources.

6.1 Background

Chronic pain in adolescence is a globally recognised problem (Swain et al., 2014; Global Burden of Disease Pediatrics Collaboration et al., 2016; Tutelman et al., 2021; King et al., 2011). In the UK, 16-19% of adolescents experience multi-site chronic pain (Gobina et al., 2019), which is associated with considerable functional disability (Dick & Riddell, 2010; Forgeron et al., 2010). Interdisciplinary treatment (IASP, 2018a) reflects a biopsychosocial approach to chronic pain management and is recommended in practice for adolescents and young adults (Liossi & Howard, 2016; Caes, Fisher, et al., 2018; Carville et al., 2021). Adolescence has recently been defined as up to 24-years-old, which reflects later social development (Sawyer et al., 2018). Indeed, during 'late adolescence' the impact of chronic pain is likely to result in delayed independence (Rosenbloom et al., 2017). Despite this, UK-based adolescents aged 16-years and over are considered independent with regards to healthcare (CQC, 2014).

Online interventions for adolescents with chronic pain (Palermo et al., 2016; Grasaas et al., 2019) are increasingly used to support self-management and reduce strain on clinical services. In context of the COVID-19 pandemic, increasing access to evidence-based content for pain self-management, through technology, has become important (Eccleston et al., 2020). A recent trial of one such intervention, WebMAP (Palermo et al., 2009), indicated that higher adolescent engagement with the intervention was associated with significant reductions in pain and disability (Palermo et al., 2020).

There has not been a multimodal, interdisciplinary online intervention developed for UK-based adolescents with chronic pain. Needs of adolescents in the UK may differ to adolescents in other western countries, based on their experiences of National Health Service (NHS) healthcare and experiences of chronic pain in different social contexts (Viner et al., 2012; CQC, 2014). Understanding context is important when developing complex healthcare interventions and qualitative research can provide insights into population-level factors that may impact intervention success (O'Cathain et al., 2019). Experts agree that successfully designing online interventions demands a user-centred approach (Yardley et al., 2016). The Person-Based Approach (PBA) (Yardley et al., 2015) provides an overview of how qualitative feedback from intervention stakeholders can be integrated into online interventions throughout development (Morrison et al., 2018). The first stage (planning) focuses on conducting qualitative and mixed-methods research to understand the context in which users will engage with a novel intervention.

When developing online interventions for adolescents with chronic pain a key contextual consideration is how adolescents use the internet already in relation to chronic pain and pain management. This is important because adolescents aged 16 to-24 are heavy internet users; 95% have a social media profile and 98% use the internet (Ofcom, 2020). Prior qualitative research has explored use of online resources for pain management in adolescents without chronic pain (Henderson et al., 2014). Three themes were highlighted: drivers of internet use, barriers, and anxiety around use. Anxieties included mistrust in the quality of online content, and some adolescents linked pain severity to their decision of whether to seek help in-person. Further, mixed-methods survey-based research has identified social media platforms, such as Instagram and YouTube, as important resources in chronic pain management for adolescents aged 16 to 18-years in the UK (Hurley-Wallace et al., 2020). However, pain-related internet use among older adolescents with chronic pain has not been explored qualitatively. Such research can provide insights into which resources are already being used, and why. This research may reveal certain elements of pain management are not sought out or are already covered by existing resources.

The aim of this study was to explore the experiences of older adolescents (16 to 24-year-olds) with chronic pain when searching for information about chronic pain using the internet. This included experiences of searching the internet using search engines (e.g., Google), health information websites (e.g., the NHS website), and social media platforms (Facebook, YouTube, Instagram). Objectives were: (i) to explore young peoples' experience of chronic pain management strategies, including pain management techniques and advice provided by healthcare professionals, self-management strategies, and any internet resources that have helped facilitate this, (ii) to explore which resources young people believe have been the most helpful, and/or may have been potentially helpful for managing chronic pain, if available, and (iii) to understand why certain resources are viewed as especially helpful for managing pain, or are noticeably popular, and why young people turn to these resources as opposed to, or as adjunctive to, in-person or online alternatives.

6.2 Methods

6.2.1 Study design

This study used semi-structured, individual interviews. Interviews were intended to be steered by the research question (Willig, 2013b), and flexibly encourage talk about participants' experiences.

Interviews were conducted online using Microsoft (MS) Teams (Microsoft, 2021) during the COVID-19 pandemic in 2020. Participants also attended an initial online ‘screening’ interview. This familiarised interviewees with the software, addressed any concerns (e.g., data protection), and screened participants for eligibility.

This study was conducted from a critical realist epistemological standpoint. Critical realist epistemology suits the exploratory nature of the study objectives. Participant experiences were considered as approximations of reality, underpinned by existing social and psychological constructs (Willig, 2013a). AHW’s role as an interviewer was anti-authoritative, viewing participants as experts on their own condition, only shifting to the ‘outsider’ role when clarifying health/medical terminology. Interviews were analysed using an inductive approach to reflexive thematic analysis (Braun & Clarke, 2006, 2019a).

This article adheres to Qualitative Design Reporting Standards (JARS-Qual) (American Psychological Association) (Levitt et al., 2018).

6.2.1.1 Researcher description

AHW is a PhD student specialising in adolescent chronic pain research (3-years’ experience) at the University of Southampton. AHW has an academic background in Health Psychology and has personal experience of chronic musculoskeletal pain diagnosed in young adulthood. AHW’s academic and personal background was explained briefly to all participants during screening. This may have enhanced rapport and encouraged storytelling during interviews. Personal experience may also have influenced data analysis, improving data immersion, and leading to theme development through an empathetic lens.

6.2.1.2 Patient and Public Involvement (PPI)

A PPI group was recruited, via the University Hospital Southampton and Applied Research Collaboration (Wessex), to assist throughout the study. The group consisted of three individuals aged 16, 22, and 27 years, who experienced, or had experienced, chronic pain throughout adolescence. They attended bi-monthly meetings on MS Teams to discuss aspects of the project and responded to WhatsApp queries. Contributions and selected illustrative changes included: reviewing the research protocol and study advertisements (which resulted in mentioning ‘social media’ in study advertisements), offering suggestions for the recruitment strategy, and piloting the interview topic guide (which resulted in swapping the order of sections 3 and 4).

6.2.2 Recruitment

This study was approved by the University of Southampton Psychology Ethics Committee (reference: 56803).

This study used convenience and purposive sampling. Specific ages and chronic pain types that were underrepresented in the sample were targeted after the guide target of 16 interviews had been met. Recruitment occurred from 8th September 2020 until 9th December 2020. The study was advertised online, via relevant charities and through a sixth-form college. Participants were offered £20 shopping e-vouchers for their time.

Online advertising included social media platforms Facebook, Instagram, Twitter, Reddit, and LinkedIn (including Facebook and Instagram paid advertisements). Call for Participants (https://www.callforparticipants.com/) was used to co-ordinate social media advertising. Relevant charities were identified by AHW and the PPI group. The Hypermobility Syndromes Association (HMSA) (https://www.hypermobility.org/) was identified as a patient partner prior to the start of the study. Fibromyalgia Action UK (FMAUK) (https://www.fmauk.org/) were contacted following ethical approval. Both charities advertised the study via their respective websites and social media pages. AHW had personal contact with one UK-based sixth-form college. The study advert was circulated via email from the gatekeeper.

Potential participants that expressed interest were asked to provide their email address, were emailed the participant information sheet, and were invited to a ‘screening’ interview. The participant information sheet explained how to access MS Teams.

6.2.2.1 Eligibility

Inclusion criteria: (i) 16 to 24 years old (Sawyer et al., 2018), (ii) bodily pain lasting 3-months or longer total duration, (iii) chronic pain condition, including pain conditions listed on the chronic pain screening tool (Appendix D), or any other chronic pain condition diagnosed by a healthcare professional, as listed in the ICD-11 (Nicholas et al., 2019; Treede et al., 2019), (iv) permanent residence in the UK (target group for exploring internet use in a UK context), (v) access to the internet for the online call, (vi) ability to communicate in fluent, spoken English.

Participants with any type of self-reported chronic pain were eligible for inclusion in this study. Eligibility did not require a diagnosis of chronic pain by a healthcare professional, though clinically diagnosed conditions were noted. The research team had no prior relation to the study participants.

6.2.3 Participants

Twenty-four UK-based participants (median age: 21 years, range: 16 to 24 years) were interviewed. A summary of participant characteristics is presented in Table 5. An additional four individuals were screened. One did not meet age criteria, one did not attend interview, and two were screened and added to the wait-list during purposive sampling; no responses were received when later followed-up.

Table 5. Participant demographic and pain characteristics: descriptive summary

	Number of participants	% Participants in each category
Age (years)		
16	1	4.2
17	2	8.3
18	2	8.3
19	2	8.3
20	1	4.2
21	5	20.8
22	1	4.2
23	3	13.5
24	7	29.2
Chronic pain type [a]		
Primary	13	54.2
Cancer-related	0	0
Post-traumatic	3	13.5
Neuropathic	0	0
Headache and orofacial	4	16.7
Visceral	1	4.2
Musculoskeletal	9	37.5
Pain duration		
≥ 3-months	1	4.2
≥ 6-months	2	8.3
≥ 1-year	3	13.5
≥ 3-years	6	25.0
≥ 5-years	12	50.0
Gender		
Female	21	87.5
Male	1	4.2
Gender variant/ non-conforming	2	8.3

[a] Pain types defined using ICD-11 criteria for chronic primary pain and secondary pain types (Nicholas et al., 2019; Treede et al., 2019). Five participants presented with two or more pain types.

Twenty out of 24 participants had a specific diagnosis, and two had idiopathic chronic pain (investigations ongoing). Two self-diagnosed participants were interviewed. Thirteen participants met criteria for primary chronic pain, and five participants presented with two or more pain types (Table 1). Specific diagnoses varied greatly, including joint hypermobility syndrome (n = 6), chronic headache and/or migraine (n = 4), fibromyalgia (n = 3), Ehlers-Danlos Syndromes (n = 2), endometriosis (n = 1), and rheumatoid arthritis (n = 1).

This study initially aimed to interview approximately 16 individuals as a guide to achieve meaning saturation (Hennink et al., 2016). However, the decision to stop recruiting was flexible, where AHW made an interpretative decision about when to stop coding and start generating themes (Braun & Clarke, 2019b). The main factor in this decision was high coding saturation observed between interviews with 16 to 17-year-olds versus 18 to 24-year-olds, following purposive sampling of younger participants, after high initial interest from older participants. However, as has been noted by others, reflexive thematic analysis cannot reach a fixed end point; new meanings are always possible (Low, 2019).

6.2.4 Procedure

Interviews were conducted by AHW, online using MS Teams. All potential participants attended an initial screening interview, and eligible participants were invited to a research interview at a later date. Participants could choose to use video, or not, as best suited their preferences.

Screening interviews lasted for approximately 10-minutes. This study used a verbal consent form, which was recorded at the beginning of the screening; the remainder of the screening was not recorded, to allow participants to become acquainted with the researcher and the online setting. Participants were screened using the demographic questions and chronic pain screening tool developed for this study (Appendix D, Appendix E).

For the research interview, participants were invited to attend an MS Teams meeting at a mutually agreed time. Participants were greeted, and audio/ video consent was re-checked upon starting the recording. Interviews lasted for between 16 minutes and 72 minutes (M length = 35 minutes). The interview followed a semi-structured guide (Appendix F), and field notes were taken afterwards. At the end of the interview, the recording was stopped, participants were debriefed verbally and given opportunity to ask further questions. A written debriefing statement was emailed with the study reward after the interview.

6.2.4.1 Interview topic guide

An interview topic guide (Appendix F) was developed to ensure topics explored during interviews were consistent with the research objectives. Questions were asked in order by default; however, the order was used flexibly where participants naturally covered later topics. Topics that were initially skipped were returned to later on in the interview. Any other relevant topics that were brought into conversation by participants were explored as appropriate.

6.2.4.2 Recording and data transformation

Interview data collected in this study was initially reviewed by AHW using the video/audio recording and basic transcript, which is automatically generated in MS Teams (Microsoft, 2021). Video recordings were used to finalise field notes. Audio recordings were then extracted, and video recordings were destroyed. Audio-only recordings were pseudonymised, then sent to an external provider for transcription. Names, locations, and other identifying features were removed during professional transcription. Pseudonyms are used to present quotes in the results section of this paper.

6.2.5 Data analysis

Data collected in this study was analysed by AHW using an inductive approach to reflexive thematic analysis (Braun & Clarke, 2006, 2019a). Data was interpreted from a critical realist epistemological standpoint (Willig, 2013a). As such, the focus of the analysis was on interpretation of meaning in context.

Data analysis followed the six stages of thematic analysis (Braun & Clarke, 2006). AHW read and re-read interview transcripts, and re-listened to the audio data, comparing this with field notes, and adding further notes as needed. Finalised transcripts were imported to NVivo 12 (QSR International Pty Ltd, 2012). AHW then systematically generated codes, using an inductive, data-driven approach. Data was coded in meaning units and included in vivo codes. Existing codes were iterated throughout the coding process, and NVivo ‘memos’ were used to make notes about interesting features of the whole dataset.

Once coding was complete (coding manual provided in Appendix G), AHW searched for themes. Codes were collated into clusters of meaning to create candidate themes (Braun et al., 2019). Candidate themes were tested out in relation to the dataset and research objectives, then expanded upon using quotes to evidence claims. Themes were reviewed by FB and AHW to ensure overall fit to the coded dataset. Themes were iterated, a thematic map was created, and theme names and details were finalised. Lastly, the research team created this report (first draft by AHW).

6.3 Results

Four themes were generated: ‘Trustworthy information, or experiences?’, ‘Diagnostic labels in a digital world’, ‘The online chronic pain community’, and ‘A mind and body approach to self-management’. Figure 10 presents a thematic map.

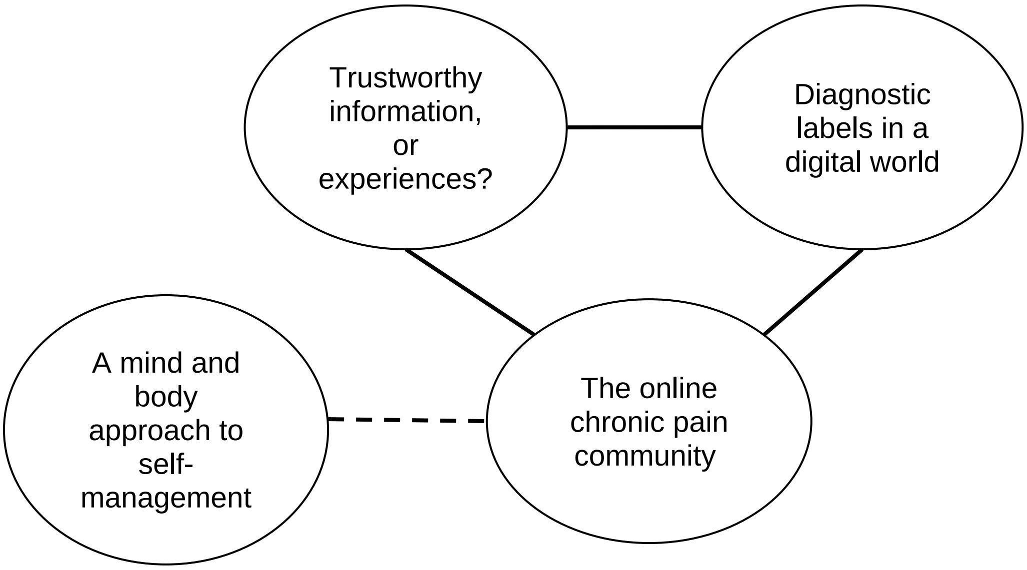

Figure 9. Thematic map.

6.3.1 Trustworthy information, or experiences?

The theme ‘Trustworthy information, or experiences?’ encompasses how adolescents and young adults use the internet to seek information about chronic pain and pain management. As might be expected within a group of young people who have grown up in a rapidly changing digital world, a variety of resources were talked about. Young people talked about using ‘trusted’ or ‘trustworthy’ health information resources, combined with information shared from an experiential viewpoint online, to shape their understanding of pain and pain management. In most cases, they turned to the internet first, before seeking advice in-person.

“The first thing I did was Google, so the NHS resources, and from there I found the Hypermobility Syndromes Association, and then I found the Facebook support groups, which have been so, so useful.” – Cameron

How individuals reached the conclusion that resources were trustworthy was a central discussion. Young people described the NHS website as trustworthy because it is tied to the UK healthcare system, and they generally trust the healthcare system. Other information resources that were trusted included (i) charity-run websites, which were often linked via the NHS, and (ii) health information websites that presented information from academic sources.

"... the only ones I really use are like the EDS [Ehlers-Danlos Syndromes] website, NHS website, just the kind of main ones that I know I can trust, because I don't want to be feeding myself false information." - Laurie

"I find the Fibromyalgia Action UK Facebook quite helpful sometimes, and they have really interesting articles about new ways of dealing with it." – Cameron

Young people also sought information about chronic pain using videos posted by 'professionals' on YouTube. Here, there was discussion about ensuring the 'professional' was credible and "*actually qualified as what they're claiming to be,"* (Eden). Young people believed they could make informed choices about who to watch and listen to.

A key reason for diverting away from the NHS website, highlighted by several interviewees, was that it was lacking in detailed information on chronic pain and that the treatment options offered were 'basic' or 'generic'. In reference to fibromyalgia, participants described the NHS website *"missing a lot out*" (Alex) and providing nothing new. Many interviewees were inclined towards seeking pain management methods that they had not tried before, rather than re-trying any options listed by the NHS.

"... in terms of treatment and stuff, I don't think it's updated very recently and it's a very one road type approach to treatment, so it just like your typical pharmaceutical approach, your physio. I mean there are alternative approaches as well." – Jamie

Beyond health information-seeking, the internet was also used to search for experientially-based advice on pain management, which was highly valued and generally trusted. Deciding who, and how much, to trust online was a complex process; this is discussed in greater depth in 'The online chronic pain community' theme (Figure 10). This trust in experience was, however, also present in relation to non-community platforms, such as blogs and forums.

"I would scroll through the pages on Google, looking for... not so much doctors or web page stuff, I wanted to see more what people had to say about it. It did take a while because I had to go through so many different pages just to find people that were relevant to what I had." – Erin

In trusting others online, participants considered factors such as online identity, accuracy of experiential accounts, as well as advertising and ‘influencing’. Pain management strategies suggested online were sometimes verified for accuracy with a healthcare professional in-person:

“Obviously, at the end of the day, these are all just strangers on the internet, so yeah, take everything they say with a pinch of salt but it’s nice to know that they’re out there and they have advice of what you could ask your own doctor.” – Harley

‘Trustworthy information, or experiences?’, is linked with ‘Diagnostic labels in a digital world’, where others’ advice seemed to be more readily trusted if they had an online identity that clearly featured chronic pain.

6.3.2 Diagnostic labels in a digital world

This theme emphasises a core message from young people with pain: relevant online information and support groups for chronic pain cannot be found without knowing what to look for.

A diagnosis of chronic pain was perceived as being crucial for ensuring accurate information about pain management strategies could be sourced online. This was typically emphasised in relation to information-seeking using internet searches (e.g., Google). Young people highlighted that once a diagnosis is made, this changes their internet search history, which becomes ‘tailored’ to the diagnosis.

“I mean my own search history has changed since I was diagnosed, because I just never knew anything, like I hadn't even heard of it.” – Alex

This focus on information-seeking around diagnosis links to a broader issue seen in young people with chronic pain, where experiences of diagnostic uncertainty are common. In synchrony with the rapidly changing digital world, this diagnostic search has become intertwined with internet use, where the diagnostic label becomes the search term.

Searching for a diagnostic label and ‘pre-diagnosis’ internet searching may fuel each other bi-directionally. Young people spoke of attempting to prompt a diagnosis from their doctor by ‘researching’ the suspected condition before appointments.

“I found obviously the NHS page and just reading all the symptoms and it was just all adding up and “could it be something like this?” because it’s not like you can get a blood test for it and the doctors could just miss it. So, I booked an appointment, and I didn’t mention the

fibromyalgia because I didn't want to put something in the doctor's head that might not be the case, but when I went to the doctor, I said about all my symptoms and the first thing he said was, "fibromyalgia"." – Dylan

Participants compared searching based on a specific diagnosis to searching symptoms. The latter resulted in anxiety-provoking, worst-case scenarios appearing in the search results. Obtaining a diagnostic label ensures appropriate information resources can be found online and prevents escalation of symptom-based internet searching.

"I think obviously it's better once you get a diagnosis because... when you're just searching like "pelvic pain", "bad periods", everything is coming up, it's like, "You have cancer" and everything and you're like, "Oh my god!" but now you actually know what it is, it's a lot better because you can like search around your diagnosis" - Frankie

Though the diagnostic label was often initially typed into internet searches to find accurate pain management information, the purpose of the search often shifted towards seeking experiential advice. Individuals were drawn towards online blogs and forums, as well as reading and listening to other young people's experiences of chronic pain on social media platforms. 'Diagnostic labels in a digital world' has a different meaning in context of seeking support from others with lived experience; the diagnostic label becomes part of an online identity. For example, the label itself may be present in an Instagram or Twitter handle or may be used as a hashtag (#) to validate the pain condition.

"I feel more valid by the fact that it's a condition, beforehand you wouldn't go on Instagram and just search like "pain" but if you follow people who have got like EDS [Ehlers-Danlos Syndrome] and people talk about that stuff." – Toni

Engaging with social media, whether liking a video or sharing your own story, requires an online identity. Participants expressed the belief that having an online identity featuring chronic pain is essential for online group membership. The structure of social media may have contributed to such beliefs, where diagnostic labels are used to identify the group and its members. One young person spoke about membership of a 'general' group for pain, but legitimised the group by referring to those members who had a diagnostic label:

"I'm part of, not one of the official groups but one that's got quite a lot of members, people that have got hypermobility syndromes, EDS and people like that. And they have been so supportive when it comes to seeking help, and they're often a lot more knowledgeable than regular people would be." – Cameron

Young people also touched on the idea that *“some people get very competitively ill”* (in vivo code – Toni), in that they may challenge others’ diagnoses online. Such challenges may increase the perceived need for a diagnostic label.

“It can be quite draining just seeing people all the time being like, “Well I’ve got this” or, “I’ve got that” or downplaying people’s pain, being like, “No, you haven’t got that, yours isn’t as bad as mine”, that can be quite, I don’t want to say “toxic” but it’s not very good.” – Jamie

6.3.3 The online chronic pain community

‘The online chronic pain community’ highlights that young people believe the online resource that has been the most helpful to them for managing chronic pain is the Instagram ‘community’ of young people with chronic pain. Interviewees talked about using Instagram to seek information to help them understand chronic pain, and to seek practical pain management and empathetic support from others with lived experience. When accessing the online chronic pain community for pain management purposes, information-seeking and support-seeking became inseparable.

Being part of an online ‘community’ came across as distinctly different from being part of a user-group. Accessing forums was centred around information-seeking, rather than interpersonal interactions between users. Whereas, in online communities, interpersonal exchanges of empathetic support and advice between individuals was central.

“I just have learned a lot, especially about pain and the different kinds of pain as well and it’s really nice because I can relate with other people, so they’ll be like “I’ll have this and this” and then you sit there and think “oh my gosh yeah, that’s how I feel as well, that’s how my body’s feeling”, that’s really amazing, that’s probably been the best thing so far, this little Instagram community I’ve found.” - Dylan

Some individuals talked about using Instagram to branch out to YouTube and blogs for the purpose of reading or listening to another young person’s lived experience of chronic pain. Sometimes this was purposed as seeking advice, however sometimes reading experiences of others from the ‘community’ was enmeshed with helping the young person feel less alone with pain.

“Mainly social media and online, like the NHS website, because you do feel so alone, you want to find if there’s anyone dealing with the same thing and then if they’re having any successful methods of relieving it.” – Laurie

Thinking about the online communities outside of Instagram, there were suggestions that a safe space for young people with chronic pain to interact is needed. These suggestions were not specific to the pain condition, with emphasis that across conditions, the experience of being a young person with pain is shared.

"... it would have been helpful to have a community of, like a safely accessible, because I was only so young, safe accessible sort of forums and sort of support group discussion type things for younger people experiencing it." – Eden

Establishing an online community as 'safe' inherently links to the theme 'Trustworthy information, or experiences?' (Figure 9). The issue of online safety prompts questions about whether the person contributing to the community can be trusted; the accuracy of their online identity, and motivations for sharing information or advice. The above quote (Eden) emphasises that online safety is especially important in younger adolescence. Nonetheless, advice based on lived experience of chronic pain is embraced by young people in online communities.

Initial formation of online communities, and subsequent trust in online communities, may be fuelled by the underlying belief that the real-world perceives *"young people shouldn't have pain"* (Cameron), which was distinctly noticeable throughout interviews. Young people conveyed that their experiences of chronic pain are misunderstood by others in their social world and 'dismissed' by healthcare professionals.

"Lots of family members have told me, "Oh, you're so young, you shouldn't have these issues, you're so youthful, this is the prime of your life, why can't you go and do this stuff?" and I'm like, "I physically can't, my body won't let me" this is a point of contention between me and my dad." – Harley

"I don't really like to talk about it with people because they don't really get it, and then I just feel really invalidated. I guess maybe a bit like alone from it? Yeah. Maybe a bit cut off from my friends." – Charlie

Family members and friends who experience pain were favoured when seeking in-person advice and support. Joining an online community may similarly help validate the experience of pain and its impact on quality of life. It is unlikely that advice based on lived experience of chronic pain will be rejected or questioned, because there is a great deal of shared empathy surrounding these experiences.

"... the fact that all of us on the community have some kind of pain, we all kind of have that basic knowledge of what that's like, and I don't think there's that many people with

EDS and I feel like, to separate people with different things, even though we all have chronic pain, I think it would just make things complicated." – Laurie

There is a clear link to diagnostic labelling here, where an online identity that includes chronic pain remains important to be embraced into the 'community'. Though, as per the quote from Laurie, and unlike 'official' groups (e.g., charity-led Facebook groups), there is less focus on specific diagnoses on Instagram. This online community is likely to continue growing as these young people act together to provide validation and support for each other.

Interestingly, some advice from members of the community drew from evidence-based information and analogies used in multimodal pain treatment, such as 'spoon theory' (used to explain fatigue) and use of Transcutaneous Electrical Nerve Stimulation (TENS) (Vance et al., 2014).

"I learn a lot off [of] other people and I know a lot of people who I follow are in pain management, and they've got, they obviously see therapists and whatnot and so yeah, I guess that's how they've learned, and they've put all their stuff on." – Dylan

However, though intending to be helpful, some suggestions encouraged pain acceptance to the point of giving-up on functional improvements. For example, 'balancing' activities included accepting full-time employment was not realistic. This misconstrues how pacing would be used in clinical practice; pacing should be a stepped-progression towards improved functioning (Rajapakse et al., 2014).

6.3.4 A mind and body approach to self-management

This theme encapsulates how young people use the internet to facilitate non-pharmacological pain self-management strategies. Specifically, young people talked about their use of the internet to improve any combination of their mood, sleep, and physical activity levels as part of a general effort to manage chronic pain.

This theme can be indirectly connected to 'The online chronic pain community', as interviewees that were heavily engaged with social media talked about self-management in terms of what they had learnt from online communities.

"... especially fibro and IBS, I've recently learned they're so, so interlinked with one another and even how both of those are interlinked with how stressed you are, how much sleep you get, how active you are..." – Dylan

Resources used to target mood and sleep that were mentioned frequently included mindfulness apps, Calm (https://www.calm.com/) and Headspace (https://www.headspace.com/), and YouTube. Young people identified that commercial apps can be expensive. Once the free components of commercial apps had been exhausted, YouTube was generally favoured for mindfulness, meditations, and other relaxation resources.

Young people also used YouTube to participate in online yoga. YouTube yoga was talked about noticeably more than any other exercise technique. Aside from these classes being free and doubling as relaxation, an important context for the current study was the COVID-19 pandemic. It is likely that YouTube yoga became the most practical low-impact exercise choice for many people under 'stay at home' guidance.

"I tried to do some yoga during lockdown and then walking my dog, if it's not been too much, on days where the pain in my legs is more prevalent, my parents have taken my dog out for a walk instead of me, so I've tried to opt for a more easy form of yoga, just to kind of stretch and still do some exercise that isn't too strenuous. - Skye

One individual pointed out that exercising at home, using online resources, avoids feeling embarrassed about one's exercise ability. This links to the belief discussed in 'The online chronic pain community', that *"young people shouldn't have pain"* (Cameron). In this case the experience being misunderstood by others' is the impact of chronic pain on exercise participation.

"... everyone talks about things like do some strengthening activities like yoga or Pilates but when you're in pain, you don't feel like doing that so if there's particular key aspects you could just do at home, or try to build up to without having the pressure of anyone else looking at you." – Billie

6.4 Discussion

This qualitative interview study explored internet and social media use by 24 older adolescents with chronic pain. Objectives included exploring information-seeking surrounding chronic pain, resources that have helped facilitate pain management, which resources have been the most helpful, and why. Three closely interlinked themes were generated: 'Trustworthy information, or experiences?', 'Diagnostic labels in a digital world', and 'The online chronic pain community'. A fourth theme 'A mind and body approach to self-management' was also identified and linked indirectly to the community theme (Figure 9).

The theme ‘Trustworthy information, or experiences?’ revealed that non-professional advice on pain management was sought out frequently. There was a strong sense of trust in others’ lived experience of chronic pain, which was expanded upon in the online community theme. Trusting advice given online is a complex issue, given that 16 to 24-year-olds are more likely than the average adult to agree that people should be able to post on social media anonymously, hiding their identity (Ofcom, 2020). This indicates young people are likely to take advice given by others online, regardless of legitimacy. Further, coining a diagnostic label for chronic pain seemed to increase trust. These are ‘strangers on the internet’, therefore advice should always be checked with a healthcare professional. Relaying this message to young people can be difficult, as the tendency to believe online health misinformation is dependent on the individual and the context (Scherer & Pennycook, 2020). Clinicians working in primary care may be best positioned to prompt young people to be cautious about taking advice found online. This may serve as a protective measure at the peak of internet searching; when pain is first labelled as chronic, and when patients are placed on waiting-lists for multimodal or psychological therapies.

Within the theme ‘Diagnostic labels in a digital world’, young people portrayed a high focus on obtaining a diagnosis, and this was intertwined with internet use. Often the diagnostic label becomes the internet search term, handle, or hashtag, and can shape the young person’s online identity. This extends findings from other qualitative research exploring diagnostic uncertainty in young people with chronic pain. Diagnostic uncertainty was experienced by nearly one third of adolescents in one study, and a diagnosis of idiopathic chronic pain is often not accepted (Neville et al., 2019; Neville et al., 2020). Adolescents often embark on a search for the ‘right’ diagnosis that continues for several years, despite physicians’ attempts to cease further diagnostic testing (Neville, Noel, et al., 2021). A key question for future research is to what extent social media, which requires labels inherently in its structure, is fuelling young people’s search for a diagnosis with chronic pain.

The current study found that young people with pain turn to ‘The online chronic pain community’ partly because they feel misunderstood by others in their social world. This mirrors findings from previous research, that adolescents with chronic pain are likely to interpret non-supportive social interactions with close friends as more distressing, and that they tend to endorse, and expect, social support from friends (Forgeron et al., 2011). Similarly, a qualitative synthesis of interpersonal relationships in adolescent chronic pain found discrepancies between adolescent’s and other’s perception of the impact of pain on daily life (Jordan et al., 2017). Young people in this study talked about feeling ‘dismissed’ by healthcare professionals, and this may further contribute to their search for validation and empathy through the online ‘community’. An interpretative case study, which investigated the appropriation of Instagram for adults with chronic illness (Isika et al., 2020), similarly highlighted that emotional support exchanges and validation contribute to the appropriation of Instagram for illness management. However, content moderation on social media remains a pressing issue (Harris, 2021; Scherer & Pennycook, 2020); it is important to remind young people to remain vigilant of health misinformation and not to endorse online advice solely based on shared empathy.

Internet use represents an important context for engagement with digital interventions; understanding context from users' point of view can impact intervention success (O'Cathain et al., 2019; Yardley et al., 2016; Yardley et al., 2015). Findings from the current study illuminate three points that should be considered by developers of online interventions for 16 to-24-year-olds with chronic pain. First, young people emphasise the importance of online communities to support everyday pain management, hence adding a community platform or message board within interventions may improve engagement. Second, it is important that novel online interventions and resources are linked via a trusted source such as the NHS website. Third, young people are open to all types of chronic pain being addressed within the same platform; they identify that the overall experience of chronic pain requires addressing, rather than specific conditions.

Limitations include that the sample did not represent young people with cancer-related or neuropathic pain, and disproportionality represented participants of female sex (only one male was interviewed). Nonetheless, a range of chronic pain conditions were represented. Two individuals who did not identify with a male or female gender were interviewed in this study; it is important the experiences of LGBTQA+ young people are included in chronic pain research, especially where intervention is intended for use across genders.

6.4.1 Conclusions

This study is the first qualitative exploration of internet use in UK-based young people with chronic pain; this is an important topic given the rapid expansion of digital healthcare over the past few years. This study highlights the importance of considering internet use in context of developing new online interventions for young people with chronic pain, and the importance of considering young people's internet use in clinical practice. Findings showed that young people tend to trust advice from others whom they consider to be part of their online community. Clinicians working with young people with chronic pain should advise them to check pain management strategies others suggest online with their doctor. Findings also revealed that having a diagnostic label helps young people find relevant support networks and appropriate pain management online. Lastly, young people acknowledge the link between pain and mood; they use a variety of online resources for mindfulness, and yoga. Clinicians should empower young people in the safe use of available resources to facilitate chronic pain self-management, as appropriate.

Chapter 7 General discussion

7.1 Summary of findings

Findings from the three papers presented in this thesis are summarised in numerical order, starting with the review and content analysis of online interventions for paediatric chronic pain (Chapter 4/ Paper 1), followed by the needs-assessment survey targeting adolescents (Chapter 5/ Paper 2), and then the thematic analysis exploring internet use in older adolescents (Chapter 6/ Paper 3).

Interdisciplinary content included in existing online interventions for paediatric chronic pain management was evaluated with reference to UK evidence-based guidelines in Paper 1 (Hurley-Wallace et al., 2021). The content analysis identified 13 interdisciplinary online interventions that have been developed internationally, revealing a lack of interventions covering all aspects of pain management in-line with an interdisciplinary, biopsychosocial approach. Existing online interventions that focus on a specific pain condition, or therapeutic technique (such as CBT), have potential to be further developed to include a broader range of content. This may include content such as videos of basic physiotherapy exercises. Further development of existing online interventions is warranted in the context of the COVID-19 pandemic, to ensure interdisciplinary pain management content can be accessed from home. None of the interdisciplinary interventions for chronic pain identified in the review had been developed in the UK or evaluated in UK paediatric samples.

Many of the interventions included in the content analysis were targeted at adolescents, including an exemplary intervention for JIA which encompassed all nine of the target chronic pain management strategies identified by the research team (‘Teens Taking Charge’ (Connelly et al., 2019; Stinson et al., 2010a)). Adolescents represent an important target group for online pain self-management interventions, as they are heavy internet users and self-management may support their developmental transition to independence. It is important that new interventions being developed reflect current best practice guidelines for patient-centred, interdisciplinary pain management (World Health Organization, 2020). New interventions should seek to incorporate insights from children and adolescents with chronic pain, and their families, using a robust development approach such as the PBA (Yardley et al., 2015). Process evaluations of interventions should be pre-planned to allow investigation of which intervention components are effective for which users and in which contexts (Moore et al., 2015).

The survey presented in Paper 2 (Hurley-Wallace et al., 2020) conducted a needs-assessment for a new, UK-based, online intervention for adolescents with chronic pain. Ninety-five participants completed the online survey (54 adolescents and 41 parents), where 16 to 18-year-olds self-reported and parents reported on behalf of 12 to 15-year-olds (parent proxy). Findings highlighted adolescents aged 16 to 18-years commonly use online resources and social media for managing chronic pain; many adolescents turn to Instagram and YouTube for content and support. A suggested solution to avoid potentially harmful online content was to create a freely available, NHS-linked, resource for adolescents with chronic pain. Quantitative findings additionally indicated that online access to a range of interdisciplinary pain management techniques is desired. Some barriers and facilitators to using a new intervention for chronic pain management were also identified. Barriers included levels of pain and fatigue determining engagement with an online program, as well as the program having too much text, or taking too long to work through. Parent comments emphasised the need to ensure the program was not condescending, which was echoed in comments from adolescents.

A content analysis was conducted on written responses to the survey question, '*What are your initial thoughts about creating a new online resource that could help young people/ you manage chronic pain?*'. Responses indicated a new online resource for chronic pain would be endorsed by adolescents and parents. Needs for online connectedness and age-specific content were emphasised. Research exploring how adolescents use social media to seek pain management support was recommended.

Paper 3 presented a thematic analysis of semi-structured interviews conducted with 24 young people (16 to 24-year-olds, UK-based) with chronic pain. Findings highlighted the importance of considering internet and social media use as integral in the long-term management of pain. Four themes were generated using an inductive approach to reflexive thematic analysis (Braun & Clarke, 2006, 2019a): 'Trustworthy information, or experiences?', 'Diagnostic labels in a digital world', 'The online chronic pain community', and 'A mind and body approach to self-management'. The first three themes were interlinked, conveying that young people are likely to trust advice from others whom they consider to be part of their online community. Obtaining a clear diagnostic label helps them find relevant online communities, as labels are an inherent structure of social media. In reference to the self-management theme, young people acknowledge the bi-directional relationship between pain and mood and should be empowered in the safe use of mindfulness, meditation, and other similar relaxation apps.

The thematic analysis also highlighted three key points for intervention developers to consider when designing an intervention for chronic pain management for 16 to 24-year-olds. First, young people turn to online communities to support everyday pain management, hence adding a community element to interventions may improve engagement. Second, novel online interventions and resources should be linked to a trusted source such as the NHS website. Third, young people identify that the experience of being a young person with chronic pain is shared, regardless of specific diagnoses. Hence, they are open to all types of chronic pain being addressed within one platform.

7.2 Considering context: internet use

The recommendations made in subsequent sections of this discussion must be considered in relation to findings from previous research. There has been relatively little research on internet use in young people with chronic pain. In general, usage statistics are presented by commercial companies (Ofcom, 2019, 2020). However, reports that provide usage statistics do not clarify why certain groups use certain platforms, and for which purposes. Each of the papers presented in thesis has been introduced by acknowledging that young people of the current generation are native internet users (Bolton et al., 2013). Although they are experts in the digital world, until this point, research has not thought to directly ask young people with chronic pain what they are using and why. Echoing the PBA (Yardley et al., 2015), internet use for chronic condition management is an important psychosocial context that must be considered when developing online interventions for young people. Researching this topic can improve our understanding of what is engaging for young people and provide insights into how novel interventions might fit with resources that are already being used. Only one other study has investigated social media use in this population (Forgeron et al., 2019).

The point that online chronic communities are important for emotional support and validation of chronic pain (Paper 3) builds on findings from a scoping review which investigated YouTube as a platform for social support (Forgeron et al., 2019). Adolescents with chronic pain were found to be engaging in interpersonal, supportive interactions with other adolescents with chronic pain in video comments sections. A strong sense of shared empathy was emphasised with the overarching message ‘you are not alone!’. The review investigating how adolescents with chronic pain use YouTube searched for relevant videos using the terms ‘youth’ and ‘teens’, hence there is no certainty of the age range these findings are relevant to. It may be that young people’s preference of online platform for seeking and providing social support varies with age, or that preferred platforms for seeking social support simply vary with the everchanging digital landscape. Considering the latter, the way that young people interact online is likely dependent on which platform is most popular at the time. Research in the area of internet use must keep pace with the changing digital world, and the temporal context of individual studies be considered, especially when developing novel online interventions.

7.3 Recommendations for intervention developers

The following subsections outline: (i) guiding principles that may be used by intervention development teams seeking to create (or adapt) interventions for adolescents with chronic pain, (ii) how relevant theories could be integrated into a novel intervention for adolescents with chronic pain, with suggestions for specific theories that could be integrated, and (iii) how behaviour change techniques could be integrated in the design of a novel intervention.

7.3.1 Guiding principles

As discussed in Chapter 1, the PBA stipulates that the planning stage of development should lend to the formation of guiding principles that can be utilised by intervention development teams going forward (Yardley et al., 2015). Guiding principles specify design objectives, which are mapped to suggested key features of an intervention that will help meet these objectives. The design objectives outline what the intervention must achieve in order to address target users' needs and improve overall engagement with the intervention (Morrison et al., 2018). Alongside gaining qualitative insights, the planning stage of complex intervention development may also include examination of relevant theory and evidence from other trials (Yardley et al., 2015). Therefore, the following guiding principles (Table 6) are outlined based on insights illuminated by this thesis. These principles relate to the identified target user-group of 16 to 24-year-olds with chronic pain (all types), who are eligible for NHS (UK-based) healthcare.

Table 6. Guiding principles for an online intervention for young people with chronic pain.

Intervention design objectives	**Key features**	**Relevant paper(s) or findings principles are inferred from**
To help young people to independently manage chronic pain into adulthood.	Intervention should develop skills that facilitate self-management of chronic pain. Examples may include goal-setting (SMART goals), activity pacing, cognitive skills to address catastrophizing, mindfulness, and relaxation strategies.	Paper 1: Identified that parent-integrated interventions are not as successful for older adolescents. Paper 1: Highlighted key components that have been included in successful interventions (e.g., CBT components). Paper 2: Content analysis Category 2, ‘Helpful’; Sub-category: ‘Improving accessibility’. Thesis introduction/ narrative review: CQC guidance on provision of transitional services for young people with complex physical needs (up to age 24).
To reassure young people that the resource they are using is evidence-based and trustworthy.	Ensure the intervention in is clearly linked or endorsed by a trusted body, such as the NHS. Ensure information provided within the intervention is clearly referenced.	Paper 1: It is important to ensure multimodal, interdisciplinary resources can be mapped to the evidence-base (which can be done using guidance for best practice). Paper 2: Linking an online resource to a service/ clinic was ‘moderately’ important. Paper 3: ‘Trustworthy information, or experiences?’ theme. Young people trust the NHS website but feel it is too ‘basic.’
To enable young people to share their experiences of chronic pain in a safe online space.	Add a community platform to the intervention, such as a community feed, forum, or message board, which is accessible by all participants.	Paper 2: Instagram highlighted as a key resource (42% used this for pain management). The content analysis highlighted the need for ‘connectedness.’ Monitoring of potentially harmful

	A healthcare professional trained in chronic pain management should monitor the community platform. Establishment of community rules to ensure online safety. This should include a function that enables young people to report or flag content and comments that they believe breach these rules.	content also highlighted in discussion. Paper 3: 'The online chronic pain community' theme. Ensuring online safety also links with 'Trustworthy information, or experiences?'
To acknowledge the impact of chronic pain on the daily lives of young people.	Provision of examples and vignettes that are representative of young people's daily experiences with pain. Focus on improving areas of functioning that are specifically relevant to young people, such as education and work, and interpersonal relationships. Provision of content that acknowledges and addresses the emotional impact of living with chronic pain. This could include psychological components from, for example, CBT and ACT.	Paper 2: Most wanted content in a new resource was 'advice on explaining chronic pain to others' (interpersonal relationships). Paper 3: 'The online chronic pain community' theme. Experiences of chronic pain as a young person asserted as being different to older people. Young people turn to online because in-person interpersonal relationships are often poor. Paper 3: 'A mind and body approach to self-management.' Young people acknowledge the need for psychological components in pain management. Thesis introduction/ narrative review: CBT and ACT are recommended in the most recent guidance for managing chronic pain in over 16's (NICE).

Barriers and facilitators to using a new program were also briefly explored in Paper 2. Barriers included levels of pain and fatigue interrupting engagement, and the program having too much text, taking too long, or being condescending. These barriers and facilitators can be considered in the full intervention design through integration of behavioural analysis. Indeed, guiding principles are not intended to replace the underpinning theoretical model of how intervention components map onto behaviour change techniques (see Behaviour Change, section 7.3.3) (Yardley et al., 2015).

Guiding principles are outlined to summarise key features that are central to achieving the intervention objectives, which can be easily referred back to throughout the intervention development process. The target group for which the intervention should be designed has been clearly identified as: 16 to 24-year-olds with chronic pain (all types), who are eligible for NHS (UK-based) healthcare. In designing the first draft of an intervention for chronic pain self-management, it is also important to also consider how theoretical models (and which ones) could be integrated. This would represent a combination approach (person-based and theory-based) to intervention development (O'Cathain et al., 2019).

7.3.2 Integrating theory

The planning stage of the PBA focuses on understanding the user-group and the psychosocial context in which users will engage with the intervention (Yardley et al., 2015). However, research teams in other areas of health (e.g., reducing transmission of cold and flu (see Yardley et al., 2010)) have integrated health psychology theories such as the Theory of Planned Behaviour (Ajzen, 1991) into intervention design and development alongside initial qualitative insights from the target population.

Thinking about the findings from the papers presented in this thesis, there is potential to integrate health psychology theories relevant to managing chronic pain in young people. As stated in Paper 1 (Hurley-Wallace et al., 2020), it is important that new interventions being developed encompass interdisciplinary pain management. Therefore, the biopsychosocial approach, which underpins interdisciplinary pain management, is an essential integration for any chronic pain management intervention. In addition, the thematic analysis presented in Paper 3 can be interpreted through the lens of The Common-Sense Model (CSM) (Leventhal et al., 2003), and may be considered as a suitable theory for integration in a novel chronic pain intervention (see section 7.3.2.2).

The IFAM (Goubert & Simons, 2013), which was presented in section 3.1.2, is not suggested for integration within a self-management program for transitional adolescents. This is because the guiding principles presented are relevant to young people aged 16-years and over. This population are considered adults with regards to their healthcare; therefore, a new intervention would focus on self-management and promotion of independence. Additionally, findings from the review and content analysis (Paper 1) highlighted that existing parent-integrated online interventions for chronic pain, are not as effective for older adolescents aged 15-years and over (Murray, de la Vega, et al., 2019).

In the following subsections, findings from Papers 2 and 3, which pertain to the views and opinions of adolescent participants, are aligned with (i) the biopsychosocial approach, which stems from The Biopsychosocial Model (Engel, 1977), and (ii) the CSM (Leventhal et al., 2003). These two models are proposed for integration in the development of a novel intervention for the self-management of chronic pain in young people.

7.3.2.1 The biopsychosocial approach

Looking first at insights from young people that took part in the interview study (Paper 3), findings indicated that they understand pain management as a ‘mind-body’ approach, and that they often turn to social media for advice and support for chronic pain management. This maps to the biopsychosocial approach, where use of the internet represents an important psychosocial context for pain management. The ‘mind-body’ view of long-term pain management indicates an awareness of needing to engage in both physical and psychological pain management techniques to reduce the impact of chronic pain. Young people’s engagement with mindfulness resources, and their awareness of the relationship between pain and mood, is indicative that psychological techniques are likely to be viewed as acceptable within an interdisciplinary intervention.

Whilst the online chronic pain community was important to many of the young people interviewed in Paper 3, they generally emphasised the importance of having a social support network both online and offline. The online world and the offline world are not separate entities; the two things knit together, and this is also evident within the diagnostic labels theme from the thematic analysis. From the survey (Paper 2), the most desired strategy in a new online resource was ‘advice on explaining chronic pain to others.’ The qualitative content analysis also indicated a clear need for resources which allow adolescents to connect in a similar way to social media. Again, this emphasises that social support in an online intervention is very important to adolescents, however, this does not replace the need for stronger interpersonal relationships in-person.

Findings from the survey also pointed towards adolescents wanting a resource similar to a ‘pain management toolbox’, where they can access a variety of resources and choose which they want to use. Overall, an intervention that incorporates biological, psychological, and social pain management techniques is likely to be endorsed by young people over the age of 16, as it fits with their needs and can be conveniently accessed.

7.3.2.2 The Common-Sense Model

Findings from the interview study (Paper 3) can be interpreted through the lens of the CSM of self-regulation of health and illness (Leventhal et al., 2003). The following paragraphs explain this interpretation using the CSM and propose the CSM as a relevant model that could be integrated in the design of an intervention for young people with chronic pain.

The first three themes presented in the thematic analysis were strongly interlinked: 'Trustworthy information, or experiences?' and 'Diagnostic labels in a digital world' and 'The online chronic pain community'. The diagnostic labelling theme, and particularly the question of why identity and labelling are so important to young people with chronic pain, resonates particularly strongly with the CSM.

The CSM proposes a parallel system of coping with illness threat using both active cognitive processing and emotional control. According to the CSM, the first step in dealing with chronic illness involves developing illness representations, or 'lay' beliefs about the condition (Hale et al., 2007; Nerenz & Leventhal, 1983). Five domains of illness representations are described: identity, timeline, cause, consequences, and control. As novel information is integrated with existing schemas, illness representations can broaden from being encompassed by one or two domains to all five (Leventhal et al., 2003). It has been argued, with regard to identity, that people like to have a label for their symptoms, and in this case a label for chronic pain, to legitimize their symptoms (Hale et al., 2007). As per the thematic analysis from Paper 3, engaging with social media requires an online identity, and young people indeed felt more 'valid' coining their diagnostic label when seeking support online. This may branch from diagnostic uncertainty experienced by adolescents in real life (see section 1.2.2.1) (Neville et al., 2019; Neville et al., 2020).

The importance placed on the diagnostic label may also relate to the control domain of the CSM. Beliefs about whether pain can be kept under control and the extent to which the individual plays a role in this are an inherent to self-management. Indeed, young people relayed the belief that they have more control over their pain management through identifying what the condition is, as this enables them to find accurate treatment information when searching online. Nonetheless, when turning to social media resources, diagnostic labels appear to shift purpose towards legitimization of the pain condition.

Illness representations (i.e., identity and control) are expected to influence subsequent coping efforts (Hale, 2007). Clarifying illness representations, and subsequent treatment representations are essential in developing successful action plans for illness management (Leventhal et al., 2016); in this case chronic pain management. For example, interventions targeting adolescents with chronic pain could consider clarifying the characteristics of the condition (managing illness representations), before then clarifying how the impact of pain can be monitored to understand if treatment modalities are working (managing treatment representations). However, treatment representations are influenced by a number of other interrelated factors beyond illness representations alone.

The original CSM (Leventhal et al., 2003) emphasises that coping efforts (e.g., pain management strategies) are constantly appraised and modified. The dynamic model of treatment perceptions (Yardley et al., 2001) proposed that concrete treatment representations are influenced by four dimensions of appraisal: past experiences of treatment (including cost and convenience), perceived changes in symptoms, perceived competence of the healthcare professional, and past experiences with the healthcare professional in question (Yardley et al., 2001; Bishop et al., 2008). Indeed, as discussed under the chronic pain community theme in the qualitative study presented (Paper 3), young people felt generally dismissed by healthcare professionals, and in the interviews overall there was a sense that past experiences of treatment were negative, where young people seemed to constantly search for new pain management strategies on the internet. These young people have negative treatment expectations relating to primary care in particular, where trial-and-error action plans for pain management are perceived as unsystematic guess work. This process of trial-and-error seems to be continued by young people using treatment information they find online, which is arguably more convenient and less emotionally taxing than contacting their GP. This links back to the previous point: that interventions for young people chronic pain should endeavour to manage treatment expectations and help them create realistic action plans for long-term pain management. This involves also understanding and accepting that chronic pain will not go away i.e., managing illness representations especially around timeline and control. Once treatment outcomes are appraised positively by young people, this will halt the cycle of treatment-seeking, which many young people seem to be stuck in. Some further treatment modification is likely over time; however, treatment expectations must be reframed to encourage acceptance of pain chronicity.

Overall, the convenience of online intervention maps well to the CSM, and it also makes sense to include a section of pain education that addresses how chronic pain can be labelled (or remain labelled as simply ‘chronic pain’). Drawing from the CSM, interventions may also include content that encourages acceptance that pain is going to remain chronic (ACT component), and a component that helps young people create realistic action plans for pain management (e.g., SMART goals). Indeed, ACT is a core recommendation within recent guidance for chronic pain management in over 16’s (NICE, 2021). Thus, the CSM can be considered a suitable theoretical framework for an online intervention that would need to sit in a broader biopsychosocial framework, in order to align with clinical practice.

7.3.2.2.1 The CSM and mind-body pain management

The CSM can also be used to understand the endorsement of mind-body self-management, such as yoga, which was identified in the thematic analysis (Paper 3). This can be helpful in considering how better engagement with recommended pain management strategies can be facilitated in the population of young people with chronic pain (both in-person and online). The aforementioned dimensions of treatment representations can be integrated into a dynamic extended CSM (Bishop et al., 2008). This model has been applied to the use of CAM, finding that treatment appraisals (perceptions of therapist and difficulties travelling to appointments) were associated with ongoing CAM use. It is likely that yoga is appraised positively by young people, and thus continued, because it is: (a) practical with regard to ability to practice from home, (b) perceived to have the dual positive effect on improving pain, as well as mood, (c) perceived that the teacher/ therapist is competent. The dynamic extended CSM could be tested in future research in relation to yoga participation.

7.3.3 Behaviour Change

As an intervention for chronic pain management will require young people to make long-term changes to their behaviour, integration of specific Behaviour Change Techniques (BCTs) (Michie et al., 2013) will be essential to intervention design. The guiding principles presented (which may change with further qualitative research) provide design objectives and suggested features. However, in order to ensure the intervention addresses relevant areas of behaviour change, identified features (components) can be mapped to relevant BCTs and outcomes, using a logic model (Morrison et al., 2018). Table 7 provides a simple example drawing from the key features suggested in Table 6.

Table 7. Basic integration of identified intervention component with Behaviour Change Techniques (BCTs).

Intervention component	BCTs	Processes	Outcomes
Skill development: goal -setting (SMART goals).	1.1: Goal setting (behaviour) 1.4: Action planning 1.5: Review behaviour goal(s)	Setting physical activity goals that are specific, measurable, achievable, realistic, and timed (SMART).	Improved physical functioning. Improved mood. Increased confidence in self-management

	Reviewing SMART goals.

Hypothesised mediators could also be added between process and outcomes. In practice, when drawing a logic model for all of the intervention components, they will likely overlap on several BCTs and outcomes. Behaviour Change Theory is psychology-based, and hence the integration of BCTs would also be useful in terms of clarifying exactly which psychological (cognitive and behavioural) techniques are going to be utilised in the intervention. This is important because it is apparent that CBT-based online interventions for chronic pain have been largely successful with adolescents (Hurley-Wallace, Schoth, et al., 2018). Complete logic models usually have a complex web of BCTs and processes, which map onto a smaller number of outcomes. The guiding principles are there to be referred back to at any point to ensure the core objectives of the intervention are not getting lost in the design process.

7.3.4 Vision for a novel intervention

At the end-stage of intervention planning, a set of guiding principles have been developed, although, it is also important to have a vision of what a self-management intervention for 16 to 24-year-olds would look like, and how it would be delivered. To halt the cycle of trial-and-error treatment, as conceptualised in relation to the CSM, an intervention for young people with chronic pain would best be delivered via primary care, at the point of referral to a wait-list for specialist chronic pain services. Ideally, given young people's aptitude for digital technology, this would look something like an interdisciplinary pain toolbox, with a community messaging platform built in. Interestingly, the concept of a 'pain toolbox' was identified in the discussion section of Paper 1 of this thesis. Nonetheless, this remains a valid idea to enable young people to develop better self-management skills for chronic pain, whilst being able to talk about their experiences with similar others. It is imperative that the scenarios and examples within such an intervention address issues faced by young people in particular, in-line with the guiding principles that have been presented (Table 6).

7.4 Expansion of existing resources: the NHS website

Findings from Paper 3 of this thesis clearly showed that the NHS website is a highly trusted resource and is well-known to young people in the UK. However, the study also highlighted the need for the NHS website to include more detailed information on chronic pain in general, and particularly on fibromyalgia. Young people wanted more information on available treatment options, including CAM therapies and how they could access psychological treatments that deal specifically with chronic pain conditions (see Appendix G: coding manual). The subsequent paragraphs discuss (i) barriers that may prevent implementation of some of the changes desired by young people, and (ii) changes and additions to the NHS website that could address the need for more detailed information.

7.4.1 Barriers to changing NHS resources

There are barriers that make implementing some of the changes to NHS resources, desired by young people, difficult. In the UK, individual Clinical Commissioning Groups (CCGs) are responsible for the design of local health services, and each local service for adult chronic pain may be structured differently, depending on the expertise available. For example, within Improving Access to Psychological Therapies (IAPT), some services have expanded to offer tailored treatment for patients with medically unexplained symptoms (Geraghty & Scott, 2020), such as primary chronic pain (Nicholas et al., 2019), via self-referral. Recent research has indicated that the evidence-base for treatment of conditions such as chronic pain under IAPT services is mixed, and services remain heavily focussed on mental health outcomes (Geraghty & Scott, 2020). Hence, as well as access to psychological services for pain varying across areas of the UK, there is also an ongoing discussion surrounding appropriation of these services for conditions such as chronic pain – even if young people say they want to engage with pain-specific psychological therapies.

Within clinical guidance for the management of chronic pain, it remains that not all treatments are suitable for everyone; a person-centred approach is recommended for both children and adults (NICE, 2021; World Health Organization, 2020). Part of the reason that the NHS website may seem vague is because most healthcare advice should be discussed with a healthcare professional before implementation. Young people recognised this in interviews, however many of those interviewed in study 3 seemed to prefer to solely use the internet to seek help and guidance with chronic pain. The issue of treatment suitability is especially pertinent with regards to advice on medications and non-pharmacological physical treatments. Indeed, recent guidance on the pharmacological management of chronic pain has reversed to state that only antidepressants should be used in the management of chronic primary pain, and that specialist advice needs to be sought for young people aged 16 and 17-years (NICE, 2021). The guidance provided by NICE justifies this by explaining that the licenced alternatives (including paracetamol and NSAIDs) for chronic pain have shown limited effectiveness for chronic pain. The British Pain Society have disputed this guidance on pharmacological management as not reflecting clinical practices or current evidence (Kmietowicz, 2021). Thus, individualised multimodal treatment plans require discussion with a healthcare professional, as opposed to blanket guidance being provided on all modalities of treatment that are available.

7.4.2 Suggested changes and additions

Despite barriers to adjusting the information on chronic pain provided on the NHS website, there remains a general lack of information available on chronic pain. This requires addressing to help young people recognise when pain is becoming chronic, and moreover provide them with multimodal, evidence-based advice on chronic pain management. This issue could be partially addressed by creating, and providing links to, trustworthy pain education and pain management resources. These links could be provided under a separate header of ‘pain management for young people’. A new, comprehensive pain management intervention for young people in the UK could be linked via the NHS here. Nonetheless, correspondence with a trained healthcare professional remains important. One solution to ensure clinical advice is sought first may be to provide a self-management resource that young people can sign-up to via their GP. This ensures that any necessary referrals can be made, that medication use can be discussed, and confirms that a self-management program is appropriate for the individual. In addition, open links to more detailed resources on pain education could be provided, so that young people can freely explore and understand more about chronic pain in the knowledge that they are not feeding themselves false information (Paper 3). Notably, a content analysis of pain neuroscience education on YouTube only found one video that adequately addressed all of the pain neuroscience target concepts that had been developed by experts (Heathcote et al., 2019). Further, only 10% of videos they found were linked to a reputable source. Adding reputable, linked resources for pain management and pain education may reduce young people’s need to information-seek using unvalidated resources. This is an important insight from Paper 3, which found the main reason young people with chronic pain turn away from the NHS site is because the information is ‘basic’.

7.5 Clinical recommendations

It is likely that young people with chronic pain will be seen by a range of healthcare professionals of different specialties, different levels, and in different types of services (Kaiser et al., 2017; NICE, 2021). The main aim of this thesis was to provide guidance to intervention development teams seeking to develop an online intervention for chronic pain in adolescence. However, the qualitative interview study (Paper 3) provided rich data on how young people experience chronic pain and pain management, both online and offline. The study highlighted the clear importance of internet use for pain self-management and support in 16 to 24-year-olds.

The following recommendations are made in relation to internet use and are intended for consideration by healthcare professionals of any level, who may find themselves working with a young person who is experiencing chronic pain of any aetiology:

- The internet is a core part of young people’s daily lives, and they are highly likely to be using a combination of health-information resources and/or social media as part of their pain self-management. Social media-based communities of young people with chronic pain must be recognised as a psychosocial factor in the assessment and management of chronic pain and should be asked about when creating a young person’s pain management plan.

- It is important to encourage young people with chronic pain to check any treatment advice they find, or are offered, online with a registered healthcare professional.

- Facilitation of pain self-management using ‘mind-body’ online resources, including mindfulness, meditation, yoga, and others, should be empowered in safe use.

- Young people with chronic pain often feel dismissed by healthcare professionals. It remains important to reassure them that their pain is valid, and that some modality of treatment or advice can be offered (whether medication, psychological therapies, physical therapies, or otherwise (NICE, 2021)).

7.6 Future research

The overarching aim of the current thesis was to lay the groundwork for developing a novel online intervention for the management of adolescent chronic pain. The guiding principles presented earlier in this discussion provide clear objectives for intervention development teams seeking to design an intervention for 16 to 24-year-olds with chronic pain. Further research could usefully qualitatively explore barriers and facilitators that may impact the intended behavioural changes being targeted by an intervention for chronic pain management. The guiding principles may be adjusted based on any new research insights about barriers and facilitators to behaviour change, as relevant to the target group. The PBA is an iterative approach to intervention development, which outlines how stakeholder feedback can be integrated throughout planning, optimisation, and evaluation (Yardley et al., 2015; Morrison et al., 2018). Hence, once the initial design of an intervention has been drafted (which could potentially also involve co-design), further research will be needed to test out components of the intervention, investigate acceptability and usability, explore the overall user experience, and evaluate outcomes, as well as behaviour change processes.

Whilst the groundwork for developing an online intervention for chronic pain self-management in 16 to 24-year-olds has been laid out, more qualitative research is needed to further explore the psychosocial context of younger adolescents (12 to 15-year-olds) with chronic pain prior to designing a UK-based online intervention for this group. Such an intervention is likely to include components intended for both young people and their parents, as has been exemplified by the US-based intervention WebMAP (Palermo et al., 2020; Palermo et al., 2016). In particular, use of the internet and online resources, and how this relates to pain management, requires exploration to ensure the success of a novel intervention for this paediatric population.

As well as exploring internet use, the interviews conducted in the qualitative study (Paper 3) asked young people about their experiences of chronic pain management in general. This was part of the warm-up section, and to help contextualise internet use within the interview topic guide. Whilst the thematic analysis presented in Paper 3 focused on the overarching aim of exploring internet use, the interview data could also be analysed with a view to explore young people’s experiences of healthcare for chronic pain management in general. Indeed, experiences of pain management appear not to have been explored in academic research with young people aged 16 to 24-years-old in the UK. However, there have been several qualitative studies conducted with adults with chronic pain that specifically relate to self-management (Devan et al., 2018). This older adolescent age group is of particular interest given that this is a stage of transition to independence, in healthcare (CQC, 2014), as well as other social contexts (Rosenbloom et al., 2017; Sawyer et al., 2018).

Also related to Paper 3, many references to the COVID-19 pandemic were made in the interviews conducted, though this was not the focus of the thematic analysis. Similarly, the interview data could be re-analysed with a view to understanding the impact of the COVID-19 pandemic on young people with chronic pain. A few codes were identified and labelled with COVID-19 in the coding manual (Appendix G). There were also codes generated such as ‘You can’t replace seeing a doctor in-person’ and ‘Online physiotherapy’, which link to healthcare service adaptions made during COVID-19 and the impact of these adaptions (positive and negative) on people with chronic pain.

Paper 2 and Paper 3 presented within the current thesis highlighted an ongoing problem in the area of paediatric chronic pain: the underrepresentation of boys with chronic pain in research. Ninety-four percent of the adolescent survey sample were girls, and only one young male participant was interviewed in the qualitative study of internet use. Whilst it is true that chronic pain is more prevalent in girls and women (Keogh, 2013; King et al., 2011), this is not as drastic as the 95% versus 5% split seen in the current thesis. This is an important issue that requires addressing in future research, and especially within qualitative research. Reflecting on the interview with the one male participant (Paper 3), underlying beliefs about pain and use of healthcare services provided a different context from which to explore internet use, compared to participants of female sex at birth.

The qualitative study presented in this thesis could also be adapted to target a male-only sample, as the findings of the study presented did not capture young men’s experiences. Researchers may consider that young men may prefer to be interviewed by someone they feel they can relate to, or is similar to them, particularly on sensitive topics such as chronic pain. A male interviewer may be preferred, though the low recruitment of young men may have been due to any number of other factors, such as the way the study is framed in advertising. It would be potentially useful for PPI teams to include male patient representatives when conducting research with young people with chronic pain.

7.7 Strengths and limitations

This thesis has several strengths. The three papers presented have encompassed several methods, including reviewing, surveying, and conducting qualitative interviews. Reviewing and primary data collection adhere to the selected intervention development approaches i.e., the PBA and the MRC guidance (Yardley et al., 2015; Craig et al., 2008; MRC, 2008). Moreover, the papers presented in this thesis work together in coherent sequence to meet the overarching aim of the thesis: to lay the groundwork for developing a novel online intervention for the management of adolescent chronic pain. The sequence of papers shows an iterative and flexible approach to intervention planning (O'Cathain et al., 2019), where each research study is informed by findings from the previous. Further, a combination of data analysis techniques was used, including a variety of descriptive quantitative analyses in Paper 1 and Paper 2, as well as qualitative content and thematic analyses in Paper 2 and Paper 3. Two of the papers presented are peer-reviewed, published works. The interview study was re-designed following the impact of COVID-19 and was successful in exploring internet and social media use in young people with chronic pain. The interview study also utilised a PPI group, which was integral to its success. Insights from all three papers represent valuable and novel contributions to the field of adolescent chronic pain management, which are especially important as the digital world continues to advance.

Limitations of each individual paper are presented in their relevant chapters. However, the thesis as a whole has two main limitations. First, adjusting the sample age upwards iteratively to focus on self-management of chronic pain resulted in turning focus away from the paediatric adolescent group (12 to 15-year-olds). This group remain an important group to study in future research, however, are notoriously difficult to access. Healthcare professionals working with these younger adolescents would be best placed to conduct research with them. Second, the guiding principles developed are based on the interpretation of an individual researcher. As such, these principles will need refining with input from a multidisciplinary team of researchers and healthcare professionals.

7.8 Conclusions

The findings from this thesis lead to the following conclusions, which include research and clinical practice implications:

1. Intervention developers should consider the guiding principles presented in this thesis as a base from which to develop novel interventions. A multimodal, interdisciplinary chronic pain management intervention for young people is yet to be developed for use in the UK.
2. It is imperative that interventions developed for young people with chronic pain draw from the biopsychosocial approach (or a biopsychosocial model) for chronic pain management. Another theory that may be useful in guiding intervention design is the Common-Sense Model (Leventhal et al., 2003). In particular, managing illness representations about chronic pain (using pain education and/or ACT components), and managing treatment representations (using action planning such as SMART goals) may help to halt and reframe the cycle of trial-and-error treatment that many young people find themselves in.
3. The internet is an important psychosocial context in the assessment and management of chronic pain. Internet use should be considered and actively asked about when creating treatment plans for young people with pain. This may be relevant to clinicians working with adolescents in paediatric clinics, as well as clinicians working with young people under adult healthcare.

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Appendix A Sample size calculation (Paper 2)

A target sample size was calculated to estimate how many participants would be required to produce results that accurately represent the UK-based adolescents with chronic pain. Primary aims of the study were to find out which online resources adolescents and parents currently use to manage chronic pain and mental health issues, and what content and features adolescents and parents would like to see in a new online intervention. As these were categorical selections, a sample size calculation for categorical data was used:

$$n = \frac{p(1-p)z^2}{e^2}$$

n = required sample size, p = population variance, *e* = percentage maximum error, *z* = value corresponding to level of confidence

With a confidence level set at 95% (z = 1.96), margin of error (e) set at 5%, and variance (p) maximised at .50, a representative sample size was calculated as 385 complete responses in total (Qualtrics, 2019; Taherdoost, 2017).

This calculation assumes parent responses are representative of adolescents aged 12 to 15 years, and those aged 16 to 18 years would answer the survey themselves. Mathematical correction was not needed, as the required sample size of 385 does not exceed 5% of the UK population of adolescents with chronic pain (Gobina et al., 2019; Cochran, 1977; Kotrlik & Higgins, 2001).

Appendix B Details of questionnaires administered (Paper 2)

B.1 Pain characteristics

Pain condition was classified as per ICD-11 diagnostic categories (Treede et al., 2015) i.e., chronic primary pain, chronic cancer pain, chronic postsurgical and posttraumatic pain, chronic neuropathic pain, chronic headache and orofacial pain, chronic visceral pain, and chronic musculoskeletal pain. Multiple selections were allowed as some patients' chronic pain overlaps two or more categories, where one of the categories will be defined as the 'primary parent' diagnosis.

Participants were asked who diagnosed their chronic pain (options: GP, Consultant, Nurse, or 'Someone else'). If they selected 'Someone else' they were asked to specify whom, using a text input box.

The next question related to pain duration. Duration could be selected from ≥ 3-months, ≥ 6-months, ≥ 1-year, ≥ 3-years, or ≥ 5-years. There were also options to select < 3-months or < 4-weeks. However, participants that selected these options were politely advised to exit the survey, as a pain duration of < 3-months does not match the criteria for chronic pain outlined for the ICD-11 (Treede et al., 2015).

Pain intensity was then assessed using the numerical rating scales from the Brief Pain Inventory (BPI) (Cleeland & Ryan, 1991) which ask patients to rate their pain at its worst in the last 24 hours, at its least in the last 24 hours, and 'on average' (0 = no pain to 10 = pain as bad as you can imagine). The BPI, although was initially developed to assess cancer related pain it has been validated, and used widely, in non-malignant chronic pain samples (Tan et al., 2004; Keller et al., 2004). An acceptable level of internal consistency was achieved for adolescent BPI scores ($\alpha = .784$), and parent-proxy scores ($\alpha = .793$).

B.2 Health-related quality of life

Health-related quality of life (HRQL) was measured using the Pediatric Quality of Life Inventory (PedsQL™ 4.0) (Varni et al., 2003; Varni et al., 2001), which is a validated scale that measures HRQL in children and young people in different age bands, as developmentally appropriate. The Child Self-Report is available for ages 5 to 7, 8 to 12, and

13 to 18 years, and the Parent Proxy-Report is available for ages 2 to 4, 5 to 7, 8 to 12, and 13 to 18 years. The version used in the current study targeted adolescents aged 13 to 18 years, and the parent proxy-report was used for the parent branch of the survey. The adolescent PedsQL™ contains 23 items and four subscales (physical, emotional, social, and school functioning). HRQL total scores were computed as per guidance from the PedsQL™ 4.0. A psychosocial summary score can be computed using the emotional, social, and school functioning subscales, and the physical summary is comprised of scores from the physical subscale only. Transformed HRQL scores range from zero to 100, with a higher score indicating better HRQL. The PedsQL™ is widely used to assess HRQL in healthy (Motamed-Gorji et al., 2019; Bazzano et al., 2018; Lam et al., 2013) and clinical populations of children and adolescents; for example in ADHD (Al-Habib et al., 2019; Erbilgin Gün & Kilincaslan, 2018; Yürümez & Kiliç, 2013) and chronic fatigue (Roma et al., 2019; Winger et al., 2015), as well as specifically in paediatric chronic pain research (Slater et al., 2012; Kalapurakkel et al., 2015; Yetwin et al., 2018; Tran et al., 2015; Simons et al., 2008; Varni et al., 2015). Adolescent and parent proxy reports from the present sample had high internal consistency (α = .895 and α = .908, respectively).

B.3 Healthcare use

Adolescents and parents were asked if they/ their child currently (at the time of taking the survey) attended an ‘NHS-based pain management service or program’ (‘Yes’ or ‘No’). Participants that selected ‘Yes’ were additionally asked ‘which healthcare professionals have been helping you to manage chronic pain?’ They could select multiple options for this, which included: GP, consultant, nurse, occupational therapist, physiotherapist, and psychologist. Participants that answered ‘No’ to the first question were re-directed to the subsequent section.

B.4 Online resource use

The next section asked about which resources adolescents used to manage chronic pain and mental health. Adolescents and parents could select from a range of options or input something different. There were 10 different resources available to select for chronic pain, and 12 resources available to select in the mental health management; these included a variety of apps and websites, as well as social media platforms. For both chronic pain management, and mental health management, options were presented in a randomised order. An adolescent volunteer (female, 15 years old) was asked for her input about the resources available to select for mental health management before they were finalised.

B.5 Parental information-seeking

Parents were additionally asked ‘As a parent/ guardian, do you use any online resources to help you understand or manage your teenager’s chronic pain?’ Nine options were available to select, including the option to state: ‘I do not use online resources to understand/ manage my teenager’s chronic pain’ or ‘I use a different online resource’. The other options included apps, websites, and social media resources. Options were presented in a randomised order and multiple options could be selected.

B.6 Most used pain management techniques

Following this, adolescents and parents were asked to rank their/ their child’s top three most useful pain management techniques in general (as opposed to online management only). There were 19 techniques available from which participants were asked to rank their top three (1 = most helpful, 2 = 2nd most helpful, 3 = 3rd most helpful). A range of pain management techniques from medicine, nursing, occupational therapy, psychology, and complimentary alternative medicine (CAM) were included in this selection. The following options were presented in a randomised order:

Medication/ pain-killers	Getting good night’s sleep
Getting help and support with school work	Improving my understanding of chronic pain
Improving other people’s understanding of chronic pain	Physiotherapy exercises
Keeping active	Pacing myself
Relaxation and breathing	Mindfulness and/ or meditation
Other physical pain management methods (e.g., using TENS, thermal analgesia, desensitisation)	Psychological therapy - Cognitive Behavioural Therapy (CBT)
Hypnosis	Massage
Biofeedback (increasing awareness and modifying physiological processes e.g., heart rate)	Psychological therapy - Exposure therapy
Art therapy	Guided imagery and/or visualization
Rest	

B.7 Needs assessment

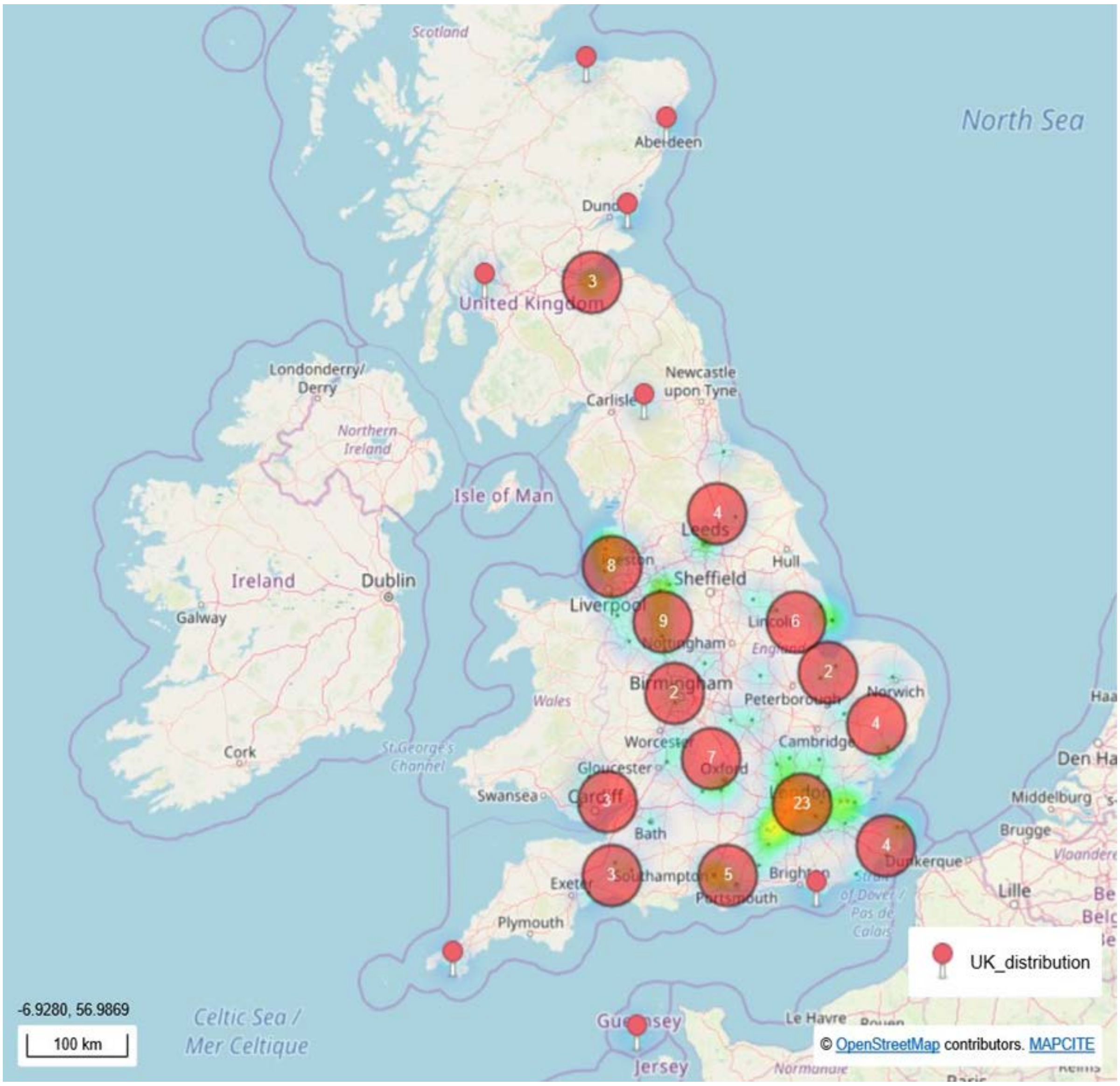
This section begun with the question ‘What are your initial thoughts about creating a new online resource that could help young people/ you manage chronic pain?’ which was a text input response question (qualitative). The main section then comprised of a series of questions about preferred techniques to be included in online chronic pain management (resource content), followed by questions about features and design.

Participants first selected which techniques they believed would be helpful to include in an online pain management resource for teenagers from a randomised selection of 19 techniques. These included techniques from multiple disciplines, for which multiple options could be selected from the following list:

Advice/ guidance on pain medications	Methods to improve sleep
Support for returning to school	Advice on explaining chronic pain to others (e.g., friends and family)
An explanation of what chronic pain is ('pain education')	Physiotherapy examples
Advice on how to pace yourself in daily activities	Advice on how to pace yourself for exercise/ sport
Relaxation and breathing techniques	Mindfulness and/ or meditation techniques
Advice on transitioning from 'paediatric' (child) to adult healthcare	Examples of other physical pain management methods (e.g., using TENS, thermal analgesia, desensitisation)
Challenging and restructuring negative thoughts	Hypnosis
Massage techniques	Biofeedback (increasing awareness and modifying physiological processes e.g., heart rate)
Exposure therapy techniques (i.e., gradually exposing yourself to situations that you would usually avoid)	Art therapy
Guided imagery and/or visualization	

Participants were then asked if there was any technique or therapy (not yet mentioned) that would be especially useful to have access to at home (text input response). Further questions addressed resource structure and design. Participants were asked what sort of structure they would like and could select from (i) a flexible structure (can chose what sections they want to use), (ii) set structure (to be completed over a number of days/ weeks), (iii) ‘I do not mind how the resource is structured’, (iv) ‘I would like something else’ (this contained a text input field). They were then asked if they would like professional adjunctive support whilst they/ their teenager was accessing the intervention. Questions were asked separately for telephone and online support, and scored as follows: 1 = definitely yes, 2 = probably yes, 3 = might or might not, 4 = probably not, 5 = definitely not. They were then asked if it would be appealing for the program to have a theme (for example, a travel theme), where response options were ‘yes’, ‘maybe’ and ‘no’. Subsequent questions asked how important the design of an online resource directed at teenagers is, whether it was important that the new program was associated with a hospital or clinic, and whether pictures and videos are important for online pain management in teenagers (1 = extremely important, 2 = very important, 3 = moderately important, 4 = slightly important, 5 = not at all important). Participants were also asked about who should feature in video content (a healthcare professional, a (teenage) patient, or ‘no preference’), and whether the person in videos should be of a particular gender (male, female or ‘no preference’) or ethnicity (White, Mixed/ multiple ethnicities, Asian/ Asian British, Black/ African/ Caribbean/ Black British, or ‘no preference’). Comments on facilitators and barriers to using an online resource to manage chronic pain were collected in the penultimate question, which asked ‘Is there anything that could motivate or prevent you/ your teenager from using an online pain programme on a regular basis?’, with options to answer, ‘not that I know of’ or ‘yes (please state)’, which contained a text response box to specify. The final question was also a text entry question, which asked for any additional comments about online chronic pain management for young people.

Appendix C UK Distribution Map (Paper 2)



Appendix D Chronic pain screening tool (Paper 3)

Non-diagnostic screening tool for chronic pain research

Participant ID: Click or tap here to enter text.

PAIN DURATION

☐ < 3-months

☐ ≥ 3-months

☐ ≥ 6-months

☐ ≥ 1-year

☐ ≥ 3-years

☐ ≥ 5-years

PAIN CONDITION*

☐ Primary pain including area-specific chronic pain of unknown aetiology (e.g., back pain, chronic widespread pain, fibromyalgia, IBS)

a. Primary pain is only appropriate where pain cannot be better explained by categories 2-7 and is associated with significant emotional distress or functional disability.

☐ Cancer pain - pain caused by cancer itself or by cancer treatments

☐ Post-surgical or post-traumatic pain - pain that persists beyond normal healing time following a surgical procedure or tissue injury

☐ Neuropathic pain - damage to the somatosensory nervous system.

a. Demonstration using imaging, biopsy, neurophysiological, or laboratory tests, in addition to negative or positive sensory signs, must be present for definitive identification as neuropathic.

☐ Headache or orofacial pain including primary and secondary headaches, and TMD/TMJ.

a. Pain must be present on at least 50% of days to be classified as chronic within this category.

☐ Visceral pain - pain originating from internal organs of the head and neck region and the thoracic, abdominal, and pelvic cavities

☐ Musculoskeletal pain - pain arising as part of a disease process that affects the bones, joints, muscles, or related soft tissues. This includes conditions of persistent inflammation, such as arthritis, as well as pain resulting from structural osteoarticular changes, such as EDS and joint hypermobility syndromes.

*Tick as many as apply

DIAGNOSIS

☐ GP

☐ Consultant (a medical doctor, e.g., paediatrician, rheumatologist)

☐ Nurse (clinical nurse specialist or advanced nurse practitioner)

☐ Physiotherapist/ physical therapist (e.g., occupational therapist)

☐ Somebody else Click or tap here to enter text.

☐ Self-diagnosed

DECISION

☐ Screening PASSED

☐ Screening FAILED

Appendix E Demographic form (Paper 3)

Participant ID: Click or tap here to enter text.

1. How old are you (in years)?

   Click or tap here to enter text.

2. What sex were you assigned at birth, on your original birth certificate?

☐ Male

☐ Female

3. What is your gender?

☐ Male

☐ Female

☐ Transgender Male

☐ Transgender Female

☐ Gender variant/ non-conforming

☐ Other Click or tap here to enter text.

☐ Prefer not to say

4. What is your ethnicity?

☐ White

☐ Mixed/ Multiple ethnic groups

☐ Asian/ Asian British

☐ Black / African / Caribbean / Black British

☐ Other ethnic group

5. What is your postcode?

Appendices

Click or tap here to enter text.

Appendix F Semi-structured interview topic guide (Paper 3)

Question number	Questions and prompts
1	Can you tell me a bit about your experience of persistent/ chronic pain? • What type of chronic pain have you experienced? • How old were you when you first started getting pain? • Can you tell me about what it was like when it first started? • Can you tell me about what it has been like more recently? • How does pain affect your school/ work/ university life? • How does pain affect your physical abilities? • How does pain affect your mood and emotions? • How does pain affect your social life?
2	Can you tell me about any advice from doctors, nurses, psychologists, or physiotherapists that you have had about your pain? • Can you tell me about advice you have had for your pain from any other alternative therapists or specialists? • Can you tell me about your experience of treatments for pain? • In the past, when you have been trying to find out how to deal with pain, who or where have you turned to first? • Can you tell me about advice you have had about it from your friends and family?
3	What kinds of things do you do yourself to cope with persistent/ chronic pain/ your pain condition? (medication/ exercise/ relaxation/ mindfulness)

- What has that been like?
- Have you used any online resources to help you cope with pain by yourself? (websites/apps/media channels)
- Have you had any problems with the coping strategies you have used to help manage your pain?
- If so, how do you overcome these problems?

4 Can you tell me [more] about any internet resources you have used to find information about persistent/ chronic pain/ your pain condition?

- What are you hoping to find when you search the internet?
- What are some of the things you have typed into a search to find out about pain?
- What things do you think about when you are looking for information about pain online?
- Can you tell me about any experiences you have had of using the NHS website to find out about pain?
- Have you used any other similar health advice websites (e.g., Healthline) to find out about pain, and what was this experience like?
- Can you tell me about any experiences you have had of looking for information about pain on social media (Facebook/ YouTube/ Instagram)?
- How has your use of internet resources and/or social media changed from when you were first diagnosed/ first started getting pain, compared to more recently?
- Which internet resources have you found the most helpful, and why?
- Which internet resources have you found were unhelpful, and why?

5	Thinking about online resources, is there anything else you think would be helpful, or would have been helpful in the past, for managing persistent/ chronic pain/ your pain condition?

Appendix G Coding manual (Paper 3)

Name	Description	Files	References
1 good doctor can make all the difference	References to a particular doctor or healthcare professional being very important in making a difference to how pain is assessed and managed. Includes references to select GPs, physios and other types of practitioners.	7	14
Academic sources - information-seeking	Information-seeking using academic sources such as Google Scholar or online journals. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel.	5	7
Accepting pain	Talking about being able to accept pain, in particular accepting the chronicity of the pain condition, and accepting some of the associated physical limitations. Some describe a sense of grief or loss associated with this, others have accepted it will always be there.	7	16
Accessing healthcare during COVID-19	References to not being able to access a variety of healthcare options during COVID-19, including face-to-face appointments, physical therapies, CAM.	9	19
Accessing NHS psychological therapies	Discussion of problems encountered when trying to access NHS psychological therapies/ talking therapies.	3	7

Name	Description	Files	References
Accessing physiotherapy	Encountering problems with access or referral to physiotherapy for pain condition. Some discussion of being sent generic physiotherapy worksheets, which have not been helpful.	3	5
Advice from friends + family with pain	References to advice sought from or given by friends/family members who have experienced similar types of pain.	6	17
Alternative health services	Use of healthcare services outside of primary/ secondary care, however not CAM or mental health. Examples: massage therapist, pharmacist, family planning, music therapy.	4	5
Anxiety-provoking content + worst-case scenarios	Anxiety-provoking content on the internet or an individual website. Includes extreme diagnoses popping up at the top of an internet search, and websites that relay worst-case scenarios for a condition. Examples of 'this could be cancer' or 'you are going to die of this illness' etc. Often associated with typing in symptoms rather than the pain condition itself.	10	21
Apps - distraction	Reference to specific apps that are used to facilitate distraction techniques.	2	4
Apps - exercise and stretching	Use of specific apps for exercising and stretching.	1	2

Name	Description	Files	References
Apps - mental health - other	References to use of other mental health apps, coded separately to the meditation and mindfulness apps (Calm, Headspace).	2	7
Apps - organisation and reminders	References to use/ desire to use organisation and reminder apps to help with pain management.	2	6
Apps - relaxation, meditation, mindfulness	Use of apps such as Calm and Headspace for relaxation, meditation and mindfulness. To help with pain or pain-related issues such as sleep.	10	29
Apps - symptom-tracking	Reference to using an unnamed pain symptom-tracking app.	1	1
Arranging pain management to reduce impact on exams	References to taking steps to ensure that pain management is up to date/ pain is minimised as much as possible in the run-up to academic exams.	2	2
Asking someone to help	References to having had to ask someone else for help, because the young person has been unable to complete a task themselves, due to pain.	4	4
Avoiding American websites because the health system is different to England	Reference to sticking to the NHS website as a primary source of information. Reasoned as the health systems are different in UK versus America and the	1	1

Name	Description	Files	References
	treatment offered might be different, plus they trust NHS sources.		
Avoiding medication where possible	References to avoiding taking medication where possible, or only taking medication when pain is severe. Usually related to worries over dependence/ tolerance or long-term impact of paracetamol/ NSAIDs.	12	17
Avoiding online groups for pain	Actively avoiding online groups for pain-related issues for a variety of reasons.	4	8
Avoiding social activities due to physical consequences	Talking about avoiding social activities, such as going out shopping, or travelling far, because of the anticipated physical consequences of increased pain. Advance planning of avoidance, as opposed to cancelling last minute.	6	7
Bad posture makes pain worse	Statement/ acknowledgement that bad posture can make pain worse.	3	3
Balancing your lifestyle at uni can be difficult	Talking about how balancing your lifestyle at university can be difficult and the impact that has on pain levels and pain management.	2	4
Becoming dependent on medication	Talking about being currently dependent or heavily reliant on medications/tablets.	3	5

Name	Description	Files	References
Before I had pain, I just didn't take people seriously	Reference specifically to not understanding others with pain or taking pain seriously, until they started experiencing pain themselves. Relates to 'lack of education and understanding of invisible illnesses'	2	3
Being aware of an injury during recovery	Reference to being 'aware' of a specific injury whilst recovering, however still keeping active.	1	2
Blogs - information-seeking	Information-seeking using online blogs. This could be information-seeking about the cause, symptoms, or treatment for a painful condition. Information sought is from the personal, experiential perspective of the writer.	2	3
Blogs - reading about others' experiences	Reading about other's personal experiences with pain via personal online blogs. These are not interactive.	1	2
Books + leaflets - information-seeking	Information-seeking using traditional paper resources such as books and leaflets. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel.	2	2

Name	Description	Files	References
Catching COVID-19 would affect me more than others	Reference to worry that catching COVID-19 would affect them more than other healthy young people, hence avoiding going out completely.	1	1
Charity websites - information-seeking	Information-seeking on charity websites. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel. Some charity websites are linked via the NHS website.	10	16
Charity websites - unhelpful	Reference to contacting a charity website for support and the response being unhelpful.	1	1
Choosing strategies that feel familiar	Choosing pain management strategies that feel familiar e.g. I used to dance, so I use the dance stretching app.	1	1
Complementary and alternative medicine	References to complementary and alternative medicine, either that they have tried or that they wish to try/ have been recommended.	11	18
Coping with pain	References to trying to cope/ manage or deal with pain, comparably to masking it with pain medications or trying to alleviate pain completely.	18	33

Name	Description	Files	References
Creating a safe space for young people with pain	Expressions of a need for a safe space for young people with chronic pain to interact online.	3	8
Current study prompted online exploration	Expressions that the current study has prompted them to explore more online communities and website/ app options for dealing with pain.	3	5
Describing an injury	Describing a specific injury and how it occurred.	6	12
Describing pain location	Description of the location of pain on the body.	14	18
Describing pain sensation	Describing the feeling of pain or the pain sensation e.g., burning, aching, sharp etc.	13	30
Desire to improve self-management	Expressions of a desire/want to improve their self-management of pain in general.	6	10
Diagnosis is the key to finding accurate information	References to a diagnosis of pain or a painful condition being key/ crucial to finding accurate information and relevant support groups online.	11	23
Different medications for migraine vs joint pain	Reference to using different medication strategies for chronic migraine versus joint pain. Comparing the different ways of using the 2 different medicines.	1	1

Name	Description	Files	References
Distraction techniques	Use of distraction techniques/tasks to draw attention away from the pain.	5	7
Doctors can misinterpret things	Talking about misinterpretation of symptoms or wrong diagnoses given by doctors. Some overlap with 'taking online information to the GP', however more emphasis on that symptoms have previously been misinterpreted.	4	7
Doesn't use online resources for pain	Statement that the individual does not use online resources - websites/apps - for pain management.	2	4
Dropping out or delaying school or uni	References to dropping out of school or university or delaying/deferring by a year or longer due to pain-related issues. Some overlap with 'struggling to keep up with school/uni' - these are the more extreme cases.	4	4
Dyslexia and hand pain affect my ability to do exams	Specific reference to combination of dyslexia and hand pain impacting ability to succeed in school/ university exams.	1	1
Early prevention resources for chronic pain	Expression of a need for early prevention resources for chronic pain e.g., apps/ websites.	1	4

Name	Description	Files	References
EDS website - provision of resources to help others understand	Reference to the Ehlers-Danlos website providing educational resources that can be used to help other people understand the condition.	1	2
EF - feeling alone	Emotional functioning - references to feeling alone or lonely. Relates to the code 'people around me don't understand' (feeling matches with the thought).	8	12
EF - feeling anxious or stressed	Emotional functioning - references to feeling anxious, stressed or worried. Some cases state this in reference to mental health comorbidities, however some express this as a feeling on its own.	7	9
EF - feeling low, down or upset	Emotional functioning - references to feeling low, down, upset or similar.	13	15
EF - low motivation due to pain	Specific reference to having low motivation to get up and do anything when the pain is high.	1	1
'Even though I was in pain, I could have done more'	In vivo code. Talks about wishing they had put more effort into managing pain when they were younger/ at the start.	1	3
Facebook - information-seeking	Information-seeking using Facebook. Social media information-seeking often involves seeking experiential advice from	5	11

Name	Description	Files	References
	others about symptoms and/or treatments for a painful condition.		
Facebook - mainly for older adults	Reference to Facebook/ Facebook groups being for middle aged/ older adults, which has little appeal to young people.	1	1
Facebook - reading about others' experiences	Reading about other's personal experiences with pain via Facebook (pages or groups) or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	3	7
Facebook - support groups	References to empathetic and interactive support groups on Facebook. Reading about other's experiences, rather than actively being part of a support group is coded separately.	8	24
False advertising of 'cure all' tablets	Reference to false online advertising of 'cure all' tablets.	1	2
Feeling dismissed by a consultant	Talking about a feeling of dismissal or not being taken seriously by a consultant doctor at pain-related appointments.	3	7
Feeling dismissed by a physiotherapist	Talking about a feeling of dismissal or not being taken seriously by a physiotherapist(s) at pain-related appointments.	1	3

Name	Description	Files	References
Feeling dismissed by GPs	Talking about a feeling of dismissal or not being taken seriously by GPs at pain-related appointments.	16	34
Fibro pain doesn't damage anything in the body	Statement that they know pain from fibromyalgia is not causing any physical damage in the body, and that exercise and activity is okay to participate in.	1	1
FMAUK website - outdated	Reference to Fibromyalgia UK website needing updating, more information, better layout.	1	1
Forums - information-seeking	Information-seeking using online forums or message boards. Information-seeking on forums often involves seeking experiential advice from others about symptoms and/or treatments for a painful condition (similarly to social media).	1	4
Forums - reading about other peoples' experiences	Reading about other's personal experiences with pain using online forums or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	4	11
Giving up a sport due to pain	References to giving up a specific sport or needing to switch to an alternative, lower-	8	14

Name	Description	Files	References
	impact sport because of pain/ pain-related issues.		
Google or search engines - information-seeking	Information-seeking using Google or an alternative search engine. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel.	21	52
Google or search engines - parents information-seeking	Parental information-seeking using Google or an alternative, in replacement of the adolescent information-seeking themselves, regarding the cause, symptoms, or treatment for a painful condition.	1	1
Google or search engines - reading about others' experiences	Reading about other's personal experiences with pain via a variety of websites listed on an initial Google search, or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	1	1
GOSH physiotherapy intensive course	Discussion about specific experience of the Great Ormond Street Hospital intensive physiotherapy course (paediatric).	1	2

Name	Description	Files	References
GP treating the immediate problem over chronic pain	Reference to GP treating acute diagnoses/ problems over addressing the chronic pain itself.	1	1
HCPs don't understand my condition	Reference to healthcare professionals not understanding EDS and proceeding to refer the individual around in a circle because they do not know how to treat.	1	4
High internet use at the start of the condition	References describing high/ much more internet use at the beginning/ onset of the pain condition compared to now. Some reference to that the information being sought about the pain condition has been found, hence there is no need to search further/ as often.	4	4
High pain during interview	Expressions of experiencing high severity of pain during the interview.	3	5
Hoping for a cure	References (often in vivo) to hoping to find a cure when searching online, or hoping to find someone that has had the same condition and been cured. Most are aware that this is an unrealistic expectation and describe it as an underlying hope. 1 or 2 references, however, state they still believe there will be a cure for their pain.	7	16

Name	Description	Files	References
I can join in by speaking to my friends online	Talking about feeling included in social interaction because they can speak to their friend online, WhatsApp, etc., even if they aren't able to meet in person.	1	1
'I can't concentrate as well as I could'	In vivo code. References to concentration levels being diminished by pain.	8	11
I can't do everything a normal teenager can do	States that pain is holding them back from being a normal teenager, and that they should be able to do everything.	1	1
'I can't go out as much as a normal 21-year-old would'	In vivo code. References to not being able to go out as much as other young people who do not experience chronic pain.	14	18
'I do worry about being consumed by constantly looking'	In vivo code. Expressing worries that online searching of symptoms, diagnoses etc. will become a mentally consuming, unhealthy habit.	2	2
I find the same online resources now as I did before	Reference to the online resources coming up when searching for information about pain online being unchanging over time/ still the same as when pain started.	1	1
I have a different circle of friends because of pain	Talking about having changed social groups/ circles entirely because of pain and associated disability.	1	1

Name	Description	Files	References
I have been told that this particular pain will get worse	Reference to patella alta (knee joint condition) - advised by HCP that this pain will get worse over time.	1	1
I have had to cancel plans with my friends	References to making plans with friends, which then must be cancelled at late notice due to pain.	3	5
I have met new friends online	Talking about meeting new friends via apps/websites/social media. References to meeting online friends via either pain-related and/or mental health-related issues.	3	4
I haven't been offered any pain medication	Statement that no pain medication has been offered by GP/ doctors. No medication tried.	1	2
'I just thought it was normal'	In vivo code. References to the initial belief that to experience chronic pain was normal/ a similar experience for everyone/ not abnormal.	3	9
'I just try to deal with it quietly'	In vivo code. References to not wanting other people to see that they have pain or pain-related issues. Includes using anonymous accounts or aliases.	3	4
I need stronger painkillers than what the GP can prescribe	Strong belief that UK GPs are powerless to prescribe stronger pain medication, and that they need to be taking some of the medications they have seen suggested by	1	9

Name	Description	Files	References
	people online (US etc.) to manage their pain.		
'I need to know that I'm not the only one'	In vivo code. Emphasis on searching online just to know they are not the only young person with a pain condition; that they are not alone.	1	1
I was given conflicting treatment advice	Reference to being given conflicting treatment advice, specifically about exercise (do less/ do more).	1	1
I was told it was 'stress-related', but that isn't the main trigger	Reference to someone else labelling pain as 'stress-related', and individual disagrees with this label/ believes stress is not the main trigger.	1	2
IBS-pain and period pain interacts	References to the interaction between IBS-pain and period pain e.g., period pain can worsen IBS pain and vice versa.	1	5
'If you've got more money, you can handle illnesses better'	In vivo code. References to level of monetary income being important in enabling access to good treatments and services to help with chronic pain/illness.	2	5
I'm looking for advice that improves my QOL	Talking about looking for pain management advice with the aim to improve quality of life/ overall wellbeing (as opposed alleviating or reducing pain). Often juxtaposed with 'hoping for a cure', which is used in a humorous way.	4	6

Name	Description	Files	References
Impact of COVID-19 on general wellbeing	Discussion of the impact of COVID-19 on general wellbeing, for example discussing the emotional impact of the lockdowns, lack of access to gyms/sports facilities, not being able to use public transport etc.	6	8
Implementing new techniques is challenging	References to trying a new pain management technique that they have been recommended by either a HCP or family/friend/partner, however, finding that implementation of the new technique is challenging.	5	17
Instagram - health or gym inspo	Use of Instagram to find health and fitness or gym inspiration.	1	1
Instagram - information-seeking	Information-seeking using Instagram. Social media information-seeking often involves seeking experiential advice from others about symptoms and/or treatments for a painful condition.	7	20
Instagram - mental health inspo	Use of Instagram to find mental health inspiration and motivational/ encouraging/ positive mental health/ mental wellbeing posts.	2	3
Instagram - pain positivity	Use of Instagram to follow pages that post positive quotes and images about chronic pain.	1	2

Name	Description	Files	References
Instagram - reading about others' experiences	Reading about other's personal experiences with pain via Instagram or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	6	20
Instagram - sharing information and experiences	Sharing one's own personal experiences about chronic pain via Instagram, using either a personal account or an account built specifically for sharing experiences with chronic pain/ illness.	2	6
Instagram - the chronic pain 'community'	Finding a sense of community and support with chronic pain via Instagram, Emphasis on exchange of informational and/or empathetic support. Includes specific references to 'community' and references to making new friends via Instagram.	4	22
Instagram - workout and stretching videos	Reference to using/ saving workout and stretching videos that are circulated via Instagram.	1	2
Invisible conditions can be made visible through social media	References to wanting young people's stories of pain/ invisible illness to be shared via social media, followed by wider sharing to others who do not have a pain condition, to improve their understanding.	2	2

Name	Description	Files	References
'It does affect my education, but I still get my work done'	Overlaps with 'struggling to keep up with education/studying'. However, in this case, pain has not affected attainment/ achievement.	1	2
'It’s just the curse of being a woman'	In vivo code. Others (doctors, parents) normalizing women's severe abdominal/menstrual pain as to be expected. Refusal/ apprehension to investigate/ treat the pain.	2	4
'I've lost a lot of my friends'	Talking about the loss of certain friendships or friendship groups due to the impact of pain.	3	3
'Keep the medication perfectly consistent'	In vivo code. Reference to keeping arthritis medication consistent for it to be effective.	1	1
Lack of education and understanding of invisible illnesses	Talking about a general lack of education and public understanding of invisible illnesses, such as pain conditions. Emphasis on that there needs to be more education and resources available for others who do not understand.	3	10
Lack of pain psychology services	References to a lack of availability of, or a lack of referral to, specific services for pain psychology. These individuals express that generic talking therapies are not appropriate because emotional issues	4	9

Name	Description	Files	References
	would not be there if it weren't for chronic pain.		
Lack of social interaction during COVID-19	Talking about a lack of social interaction due to COVID-19 restrictions.	4	5
Learning from personal experience	References to learning how to manage pain/ ways to reduce pain specifically from personal experience of what has worked and what has not.	3	6
Little to no impact on studying	Reference to pain having little to no impact on studying/ education.	1	1
Looking for realistic content that is also uplifting	References to looking for social media content that strikes a balance between being realistic about the impact of pain and being uplifting/ motivational.	2	3
Lots of different doctors	References to having seen lots of different doctors or specialists over the course of several months/ years.	6	13
Making adjustments	Making physical adjustments or using support equipment e.g., braces/ cane/ migraine glasses, to help increase comfort and reduce pain.	11	25

Name	Description	Files	References
Making pain resources more aesthetically pleasing	Statement that it would be nice if pain resources were more aesthetically pleasing and print-friendly, Comparison made to mental health resources being more visually appealing.	1	2
Medical professionals don't believe in my condition	Reference to not feeling believed by medical professionals, and that there is still stigma in medicine regarding chronic pain conditions.	1	1
Medication description	Describing a medication name, label, or purpose. This includes specific pain medications, antidepressants, and any other medication taken in relation to managing the pain condition.	13	20
Medication helps with engaging in physical activity	Reference to medication being helpful to complete physical activity goals. Specific reference to Duke of Edinburgh Award.	1	1
Medications reduce pain	Statements that medications do work to reduce level of pain severity (though usually do not alleviate pain entirely).	11	21
Mental health comorbidities	Talking about mental health comorbidities that have been treated independently/ diagnosed independently by a healthcare professional. Includes anxiety, depression, stress disorders, OCD, panic attacks, and many more.	8	20

Name	Description	Files	References
Mental health support online	References to websites (sometimes in combination with apps/ social media) that are used specifically for mental health support e.g., Mind. Specific mentions of mental health apps are also coded under mental health apps - other.	4	11
Mindfulness - very difficult when pain is high	Reference to mindfulness being difficult to engage in when pain intensity is high.	1	1
Mindfulness hasn't helped me	References to have tried mindfulness and not liked it, found it a struggle to 'be mindful'. Found that mindfulness did not help them/ would not try it again.	6	9
More free mindfulness and relaxation resources	Expression of need for more free/ cheaper meditation and mindfulness resources.	1	2
More information for young people specifically	Expressions of a need for information tailoring (online) towards young people. Several references to the NHS website needing to address this issue.	5	9
More online information and support for patella alta	More online information and support is needed specifically surrounding the condition patella alta (a knee joint condition that causes pain).	1	2

Name	Description	Files	References
'My own search history has changed'	In vivo code. References to internet search history changing as pain changes, or as more information is gained about the pain condition and how to manage it.	6	7
My parent(s) panicked about potential diagnoses	Parental panic about a potential diagnosis of chronic illness (reference to chronic fatigue), having known someone else who has a diagnosis.	1	1
My school was not supportive	Reference to the school being non-supportive and seeing young person's pain as an 'excuse' not to attend.	1	1
My teacher was supportive	References to an individual teacher being supportive and helpful with pain issues. Provision of tangible and empathetic support.	2	3
My university supports me	References to the young person's university providing support with pain including access to support services, and extra time in exams.	5	5
My workplace are understanding	Reference to the workplace being understanding of physical pain condition and making adaptions for employee.	1	1
NHS waiting times	Discussion of NHS waiting times with the emphasis that there are long waiting times for appointments with primary or secondary care services. Discussion of	4	6

Name	Description	Files	References
	waiting times for psychological therapies is coded separately under 'accessing psychological therapies'.		
NHS website - COVID-19 banners are off-putting	Reference to COVID-19 banners (yellow headers) on the NHS website being off-putting when searching surrounding different condition.	1	1
NHS website - directing friends to read information	Reference to directing friends to read information on the NHS website, which is easy for them to do.	1	1
NHS website - information-seeking	Information-seeking on the NHS website. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel.	21	55
NHS website - accessible, easy to use	References to the NHS website being easy to use/ navigate, accessible for everyone, clear to read, and easy to understand.	8	10
NHS website - basic or vague	References to the NHS website, being basic, vague, too simplistic or not providing enough information about the specified condition.	13	20
No support with the emotional impact of a pain diagnosis	Discussion about the lack of support with the emotional impact of a chronic pain diagnosis. A lack of any signposting,	1	4

Name	Description	Files	References
	information or reassurance given from the diagnosing doctor. No help with accepting pain chronicity.		
No symptoms at the Drs appt.	Reference to the irony of not showing any symptoms at the time of the medical consultation/ doctor’s appointment.	1	3
No 'unhelpful' resources	No unhelpful resources if you use common sense/ avoid irrelevant websites	9	10
Normalised GP visits due to a different condition	GP visits are normalised due to attending regularly for another separate condition (heart condition).	1	1
Online GP	Using/ describing use of an online, private GP.	1	2
Online health information is readily accessible	Talking about online health information being readily accessible in instances where a face-to-face GP appoint is not available or is not immediately necessary.	2	2
Online healthcare should be freely available to everyone	Discussion that good online healthcare should be freely available to everyone, or at least discounted. References to online GPs and advanced activity tracking such as Fitbit.	1	3

Name	Description	Files	References
Online meditation classes	Taking online meditation classes that have been adapted from in-person due to COVID-19.	1	1
Online physiotherapy	Engaging with online physiotherapy, usually adapted from face-to-face physiotherapy due to COVID-19.	3	5
Online predators taking advantage of pain diagnoses	Specific references to predatory behaviour online via social media such as offering to give a massage to help pain etc.	1	2
Online psychological therapy	Engaging in online psychological therapies (talking therapy).	1	2
Other health websites - information-seeking	Information-seeking using other mentioned health websites. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel.	6	11
Other people normalise my pain	References to other people normalising the young persons' pain e.g., 'everybody experiences this' or 'I have that as well, it's normal'.	4	5
Other symptoms	Additional symptoms that relate to the pain condition - descriptions. Much of the content coded relates to Ehlers-Danlos Syndrome (a connective tissue disorder) and hypermobility, as well as the	13	36

Name	Description	Files	References
	additional symptoms of fibromyalgia, secondary headaches etc.		
Pain and fatigue	Talking about the relationship between pain or the pain condition and levels of fatigue/ energy.	11	19
Pain and sleep	References to having trouble getting to sleep or staying asleep because of physical pain. Some individuals in the fibromyalgia group talk about how they have been given medication to improve sleep, which has helped with overall pain and fatigue levels.	9	17
Pain changing over time	Long-term changes over the course of the persons' pain condition/ pain experience. The difference between pain then and pain now.	18	32
Pain is still the same	Stating that pain has stayed the same over time.	2	2
Pain sensation - allodynia	Reference to experiencing allodynia (hypersensitive pain sensation that occurs when touching the skin).	1	1
Pain-related worry	References to specific pain-related worries, which are described as worries or thoughts, usually 'what will happen if/when'.	8	9

Name	Description	Files	References
Parents go to the GP with me	Statement that parents go to the GP with young person.	1	2
Parents have a 'traditional' view of pain management	Reference to parents having a traditional view of pain management, and discouraging meditation/ mindfulness/ psychological strategies.	1	1
Parents relay online health information to me	Statement that parents look online and relay health information to the young person, rather than the young person directly accessing resources themselves.	1	3
People around me don't understand	Perceived lack of understanding that people in the young persons' life do not understand their pain and the impact it has on their life. This could be friends, family members, colleagues etc. Links with code 'select family and friends are supportive.'	10	26
People can be nasty online	References to coming across people in online forums/ groups who are generally nasty towards others or make hurtful comments/ insults.	2	3
People spread misinformation online	Reference to people spreading misinformation online. Specific reference to anti-vaxxers.	1	2

Name	Description	Files	References
PF - impact on physical activity	References to the pain conditions' impact on overall physical activity. For example, reducing physical activity due to pain or pain being a problem during regular physical activity, such as walking.	18	49
PF - routine tasks and self-care	References to the pain conditions' impact on daily tasks and self-care. For example, inability to shower, or put jeans on, or carry a bag. Struggling to write/ type is coded separately.	14	24
Physio - helpful but not tailored enough	Discussion that although aspects of physiotherapy can be helpful, the individual believes their physiotherapy programme is not tailored enough for their specific needs.	2	3
Physio - very difficult when pain is high	Discussion that engaging with physiotherapy is very difficult when pain severity is high/ pain flare present.	2	5
Physio 'a godsend'	References to physiotherapy being a really important, crucial aspect of the individuals' pain management plan. 'a godsend' coded in vivo.	3	7
Physio 'I don't gel with that'	References to physiotherapy exercises/ advice that has been given, and finding that it is not helping with pain, or making a	4	9

Name	Description	Files	References
	choice to not engage with it for specific individual reasons.		
Pinterest - information-seeking	Using Pinterest to information-seek, as well as save, pain management resources.	1	2
Pinterest - relatable quotes	Use of Pinterest to look at 'relatable' pain-related quotes.	1	1
Pop culture pain inspirations	Talk about celebrities or public figures journeys as told online/ through social media. Specifically, Lady Gaga mentioned a few times in relation to Fibromyalgia.	2	7
Popping, cracking and subluxations	References to joint popping, cracking, clicking and subluxations (often referred to as dislocations). Usually present with hypermobility/ EDS.	5	7
Presenting to A&E with pain	Experiences of presenting with pain at A&E.	3	5
Prioritising other problems over pain	References to prioritising treatment/ management of other health or mental health problems over chronic pain.	2	5
Prioritising pain over other problems	Prioritising physical pain problem over addressing issues with mental health and/ or social life.	2	2

Name	Description	Files	References
Psychological therapy	References to receiving psychological therapy/ talking therapies/ CBT.	8	15
Psychological therapy - CAMHS	Reference to receiving psychological therapy under CAMHS for pain-related issue.	2	5
Reddit - an appropriate platform for younger people	Reference to Reddit being a more age-relevant platform for younger people compared to other health forums.	1	1
Reddit - information-seeking	Information-seeking using Reddit, which is similar to online forums or message boards, however, is also considered as social media. Information-seeking on Reddit often involves seeking experiential advice from others about symptoms and/or treatments for a painful condition.	2	5
Reddit - reading about others' experiences	Reading about other's personal experiences with pain via Reddit (forum-based social media) or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	1	4
Remote working, studying and pain COVID-19	Talking about exacerbation of pain-related difficulties as a result of working/studying from home during COVID-19.	2	4

Name	Description	Files	References
Resorting to private healthcare	Resorting to private healthcare for reasons including NHS waiting times, access to more tailored services than what the NHS can provide, or not meeting criteria for a certain service.	7	15
Rest is important	References to rest being important in terms of taking breaks and ensuring to allocate recovery time in relation to specific activities and/or generally balancing rest and activity.	8	16
Risking pain to achieve your goals	Talking about risking a backlash of pain to achieve a specific personal goal. Specific reference to Duke of Edinburgh Award.	1	1
Risking pain to do things you enjoy	Talking about risking a backlash of pain to take part in activities that bring enjoyment or to continue to take part in activities that the individual is passionate about.	3	8
Running out of options	References to running out of treatment options for pain management. Includes references to treatments not working fully and not being offered anything further, and statements that there are limited options available.	10	13
Saving useful resources for later	References to saving/pinning/storing pain management resources found online, so	4	4

Name	Description	Files	References
	that they can be returned to later/ when needed.		
Searching for a diagnosis	References to searching for a diagnosis either via medical services or online. Several descriptions of wanting answers, pushing for a diagnosis from HCPs, and emphasising that they want to know what the problem is so they can get the right treatment.	15	31
Seeing the school counsellor	References to seeing the school counsellor to talk about pain and related issues. Particularly issues they experience at school.	2	3
Select family and friends are supportive	References to select friends and/or family members being supportive around the pain condition. Often this is a partner or 1 or 2 members of a family. Sometimes discussed in contrast with other friends and family who normalise pain or are dismissive.	13	22
Self-blaming	Expressions of self-blame for pain experience. Thoughts that they might have done something to deserve to have pain, or that they were just being lazy in some way.	3	6
Self-inflicting pain in an attempt to desensitize	Attempting to desensitize the pain sensation via self-harming strategies to	1	3

Name	Description	Files	References
	create temporarily increased pain sensation in the painful limb/ area.		
Self-management - non-pharma physical	Use of heat and cool packs, massage, TENS for self-managing pain.	18	39
Self-management - relaxation, meditation, mindfulness	Use of relaxation, meditation or mindfulness to self-manage pain or issues related to pain, such as sleep and stress. Mindfulness apps are layered as a separate code.	20	42
Self-management - stretching, strengthening and yoga	References to self-managing pain by stretching, completing strengthening exercises, and several references to yoga (which can also be for relaxation and a combination of stretching/ strengthening).	11	20
Self-management sometimes helps, sometimes doesn't	Statement that self-management strategies are being used, but that they only help sometimes.	1	1
Social media is a 'highlight reel'	References to social media being a 'highlight reel' or not a portrayal of 'real life'	2	3
Social media is readily accessible	References to social media and the internet being readily accessible, and that they can always turn to the internet for support and advice for pain, or mental health, as needed.	3	4

Name	Description	Files	References
'Some people get very competitively ill'	Discussion of some individuals on social media turning pain severity and impact into a competition, particularly comparing their experience to others i.e., 'whose got it worse'.	4	10
Struggling to keep up with studying + attendance	References to struggles keeping up with school/college/university workloads. Includes references to reduced attendance	10	24
Struggling with work	Talking about pain-related issues with engaging with work/ employment. Several references to needing more breaks than colleagues, as well as not being able to take on a full-time role.	7	15
Struggling with writing + typing	References to struggling with completing tasks that involve writing or typing, due to hand and wrist pain.	6	10
Surgery can potentially make things worse	HCP advice given that surgery (knee surgery - patella alta) can potentially create more problems and make pain worse.	1	1
Taking nutritional advice from HCPs on board	Implementing nutritional advice given by healthcare professionals in relation to IBS and functional abdominal pain disorders.	2	4

Name	Description	Files	References
Taking nutritional advice from non-HCPs	References to taking nutritional advice from non-healthcare professionals online.	1	2
Taking online information to the GP	References to taking information from either the NHS website, or other alternative health websites, with them to the GP appointment. This may be physically printed out/ electronic document or may be that they have a list of specific symptoms they are planning to mention.	7	11
Targeted ads for pain relief products	Reference to online advertisements for pain relief products, usually with a link to the website where you can purchase the product. These adverts are often targeted based on internet search history.	1	6
The changing digital world	Talking about how the digital world has rapidly changed, and that there is much more information and more support resources that can be accessed online now compared to several years ago. Referenced frequently by those who have had pain for many years.	7	13
The relationship between mood and pain	Talking about the relationship between mood and pain, and how the two are inter-related. Some individuals discuss that they do not fully understand the relationship / see how the two are related, however, most emphasise the importance of this relationship.	13	29

Name	Description	Files	References
There is no treatment plan	References to there being no treatment plan, only management, with the emphasis that self-management is necessary because of this.	1	2
Tracking and recording pain	References to tracking or recording pain severity and pain-related symptoms, with the idea that it either is or could be helpful for pain management.	6	12
Transitioning from paediatric to adult healthcare	Discussion of 16-18 years transitional stage from paediatric to adult healthcare.	1	2
Traumatic experiences	Talking about pain-related traumatic experiences.	2	6
Treatment misinformation - dangerous to impressionable people	Stating that online misinformation regarding remedies and treatments for pain can be very dangerous to impressionable/ less educated people who might cause further problems for themselves by taking incorrect advice.	1	2
Treatments help, but only temporarily	References to pain management being frustrating because treatments only help temporarily, and the same strategies need to be repeated over and over.	3	3

Name	Description	Files	References
Trial and error treatment	Reference to treatment for the painful condition feeling as if it is 'trial and error' rather than a treatment plan.	1	4
Trustworthy information sources	References to a website or internet-based resource being trustworthy or reliable for health information either as a standalone or compared to other websites.	17	38
Trying to understand triggers	References to attempting to understand and avoid triggers that onset a pain flare. Frequently referenced by those experiencing chronic migraines or headaches. Triggers talked about mainly include light/ screens, and food and drinks.	7	14
Trying treatments suggested online	Trying out treatment advice/ management strategies from non-HCPs suggested online. Usually, suggestions found on forums and blogs.	7	8
Tumblr - light-hearted chronic pain humour	Reference to using Tumblr to follow light-hearted chronic pain humour. This is different to 'realistic content that is also uplifting' in the sense that this is only sought for the comedic value.	1	2
Turning to my partner first	Turning to a partner as the first point of support when experiencing high pain	1	1

Name	Description	Files	References
	levels or generally turning to them before anything/ anyone else (parents, internet).		
Turning to parents first	Turning to parents as a first line of support with pain, before other support sources (internet, partner).	5	6
Turning to the internet first	Turning to the internet as a first line of support with pain and pain-related issues. This is done before turning to anyone/ anywhere else (parents, partner, GP). Relates to code 'taking online information to the GP'.	11	11
Twitter - information-seeking	Information-seeking using Twitter, which is considered as social media. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, from an experiential and/or medical/scientific perspective.	1	2
Twitter - reading about others' experiences	Reading about other's personal experiences with pain via Twitter or reading conversations/ interactions between other users about their pain experiences. Emphasis on reading/ liking/ viewing rather than sharing one's own experience.	1	2
Understanding medication by searching online	Talking about attempts to better understand pain medication the individual has been prescribed by searching online.	3	7

Name	Description	Files	References
Understanding pre-disposing factors by searching online	Understanding pre-disposing factors e.g., genetic factors by searching online. Reference is specifically to lactose intolerance.	1	1
Understanding that pain disorders are interlinked	Statement of understanding that having one pain disorder makes your vulnerable to others.	1	1
Unpredictable pain	Describing pain as different on different days, ups and downs of pain on the same day, bad pain days versus good pain days	13	25
Use of disability services	References to using/accessing disability services to help with pain-related issues.	5	10
We need medical professional advocacy online	Reference to needing medical professionals to show their support and advocacy for chronic pain conditions online.	1	1
WebMD - information-seeking	Information-seeking on WebMD. This could be information-seeking about the cause, symptoms, or treatment for a painful condition, which are often sought in parallel. WebMD has a symptom checker.	10	20
WebMD - unhelpful	References to WebMD being unhelpful by being either dismissive of the impact of	3	8

Name	Description	Files	References
	hypermobility syndromes, or the symptom checker being anxiety-provoking.		
Websites downplayed my pain condition	References to websites downplaying or dismissing the impact of Ehlers Danlos/ hypermobility syndromes.	2	3
'what works for them might not work for me'	In vivo code. Recognition that treatments that work for one person may not work for another.	2	4
wikiHow - information-seeking	Information-seeking using wikiHow. This is usually in the form of 'how to treat' a specific ailment, using a step-by-step guide, with images.	1	1
Women understand women's pain	Reference to women understanding pain related to gynaecological issues better than a male doctor could.	1	2
Worries about medication dependence	Expression of worry about taking medication frequently/ becoming dependent.	3	4
You can't replace seeing a doctor in-person	Relates to accessing healthcare during COVID-19 code. Even though the NHS website is good, and telephone appointments are available, individual expresses that you can't replace a doctor getting a holistic view in-person, and that in-person interaction is also important to feel understood as a patient.	1	1

Name	Description	Files	References
'You have to learn to balance all your activities'	References to the importance of learning balance or pace all your activities, including physical activity, however also including establishing a general balance of e.g., work-life.	5	15
You need to be organised to manage pain	References to personal organisation being important to manage pain effectively. Includes keeping medication on-hand and creating reminders to do exercises such as physio or yoga etc.	6	8
'Young people shouldn't have pain'	References embodying the view from others' that 'young people shouldn't have pain'. Includes references to doctors thinking young people are 'exaggerating', as well as friends/ family members stating the young person is 'too young' for said pain condition. Sometimes this view is internalised.	11	18
Young people, weight-related issues and pain	Talking about how the population weight-related issues might reflect in more young people starting to have problems with joint pain (due to obesity/ being overweight).	1	2
YouTube - easy to search	Statement that YouTube is easier to search comparably to Instagram.	1	1
YouTube - information-seeking	Information-seeking using YouTube, which is considered as social media. This could be information-seeking about the	10	16

Name	Description	Files	References
	cause, symptoms, or treatment for a painful condition, from an experiential and/or medical/scientific perspective.		
YouTube - listening to others' experiences	Listening to other's personal experiences with pain via YouTube videos. This can overlap with information-seeking on YouTube e.g., what was someone's experience of getting a diagnosis and how did they get it?	8	13
YouTube - parent relaying advice from videos	Reference to a parent looking for informational advice on YouTube and relaying the information they find to the young person.	1	2
YouTube - relaxing soundtracks and meditation	Use of YouTube to source relaxing soundtracks and/or meditations, to facilitate self-management of pain or pain-related issues.	4	7
YouTube - yoga + stretching	Use of YouTube to source yoga and stretching videos, to facilitate self-management of pain.	5	7

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Exploring internet needs for the management of adolescent chronic pain: developing digital interventions in context

Volume 2 of 2

by

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Table of Contents

Table of Tables

List of Accompanying Materials

This is Volume 2 of 2. This volume provides the online only supplementary materials that accompany Paper 1 of the main thesis, which is presented in Volume 1.

Definitions and Abbreviations

ACT: Acceptance and Commitment Therapy

CBT: Cognitive Behavioural Therapy

Supplementary Table 1. Details of intervention content and design for each intervention included in the content analysis (n = 13).

Intervention name	Descriptive reference(s)	Link to intervention (url)	Country	Target age (or sample age)	Target pain condition/ diagnosis	Mode of delivery	General appearance/ themes	Description of content – child/ adolescent facing	Description of content – parent-facing	Structure/ completion order	Duration (time for child/ adolescent to complete)
Aim To Decrease Anxiety and Pain Treatment (ADAPT)	Cunningham, Nelson et al. (2018)	https://adapt.research.cchmc.org/Patient/Login	USA	Target range: 9 to 13 years	Functional abdominal pain disorders (FAP)	Face-to-face, plus web sessions and telephone call.	Blue and red website colours with image of a young child (female) on home screen (right) and the modules displayed (left).	All content available in English only. Face-to-face sessions In-person session 1 includes scripted content that covers gate control theory of pain (pain education), anxiety education, a mini-relaxation (mindful breathing), and guided imagery. There is also advice given to continue taking any medication and that the treatment is additional to care the child receives from a doctor. Both parent and child are present in the session, however the content itself is primarily child-directed, apart from instruction on how to use the parent guidelines. Child is also given a sticker diary to track how often they practice relaxation and imagery. Session 2 is directed at the child-only, where the parent joins for a review at the end of the session. Scripted content includes progressive muscle relaxation, calming statements and advice on activity pacing. Therapist also reviews the sticker diary given in session 1. The web content is also introduced. Web sessions Session 3: pleasant activity scheduling and problem solving; 2x tasks online - contains a problem solving guide and examples. Session 4: “Thinking like a detective: identifying and challenging automatic thoughts” – tasks emphasize focus on rationalising evidence to reduce worry and the difference between an actual event and a worry (cognitive restructuring). Session 5: fighting fears by facing fears and building social skills (how to be assertive); handout on aggression verses assertion and assertiveness quiz. Also includes stepladder handout (graded exposure) and ‘facing fears’ quiz. Session 6: Maintenance planning – emphasis on planning to practice skills learnt	The parent guideline is a video talk given by a therapist offering advice to help parents to deal with their child’s pain and worry. It includes: • Encouraging independent pain management, • Praising child for using learnt skills, • Encouraging normal activity (school and play) even when pain level is high, • Eliminate ‘status checks’ e.g. stop asking about how bad their child’s pain/ worry is, • If pain/ worries lead to activity reduction, treat as if it is an illness, e.g. do not let child play games/ watch TV/ no treatment and ensure rest. Advised do not rearrange plans around their pain episodes, • Follow doctor’s guidance RE pain medications, There is also a therapist video talk for parents for each week of the child’s (web) course. They explain the tasks the child has been given and their purpose. These are about 2 minutes long.	Children 6 sessions beginning with two in-person sessions, followed by four weekly web sessions (1-6 to be completed in order) Parents Parents participate in face-to-face session 1, followed by 5 video talks, including 1 introductory talk, and then 4 corresponding video talk overviews of the child’s web modules.	6-weeks (one session per week). Session 1 and 2 last 60-90 minutes each. Web sessions last 45 minutes followed by 15 minute telephone call with therapist.
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Lalouni, Ljótsson et al. (2017)	Not provided.	Sweden	Target range: 8 to 12 years Sample age: M = 10.7 (no SD)	Pain-related gastrointestinal disorders: FAP, irritable bowel syndrome (IBS), and functional dyspepsia (FD)	Therapist-guided internet CBT	No access to website. Images provided in Figures 1 to 4 of primary descriptive paper. Visual artwork of how the model of abdominal pain is presented to the child shown in Figure 1 is black outline with red text (this is presented as an animated film). Figures 2 to 4 are black text on a bright green background (screenshots); each screenshot has at least one image/ animation.	All online content available in Swedish only. Child modules *All modules include homework exercises (reviewed following week), and case examples.* Module 1: • Psycho-education about abdominal symptoms (including animated film); explains brief neuroscience, hypervigilance, behavioural control and about the vicious circle of behaviour. • Explanatory model of symptoms and treatment. • Mapping avoidant and controlling behaviours. • Goal-setting Module 2: • The role of thoughts • Mindfulness exercise (3-steps ‘stop-observe- let go’) • Building an exposure hierarchy; instruction for exposure therapy. Children input exercises in order of least to most difficult on their ‘ladder’. Module 3: • Functional analyses. • Psycho-education about exposure therapy. • Exposure exercises (reference back to the hierarchy they created throughout all modules where exposure exercises are present). Module 4: • Review of first exposure exercises. • Toilet habits. • Functional analyses (of avoidance and controlling behaviours). • Exposure exercises. Module 5: • Review of treatment sessions 1 to 4. • Exposure exercises. Module 6: • Functional analyses of goal-directed behaviours. • Exposure exercises; increasing the difficulty level.	Parent modules *All modules include homework exercises (reviewed following week).* *Main focus of parental modules is to support the child with exposure exercises.* Module 1: • The role of parental attention (including advice on giving privileges and how this reinforces child pain behaviours). • Validating the child’s experience and shifting focus. • Mapping parental behaviours. • Handling worry and frustration. Module 2: • “Golden moments” – a focus on spending quality time with the child that is unrelated to abdominal symptoms Module 3: • Supporting the child in the treatment. • Introduction of token game; a printed game board where child checked off completed exposures, and received small rewards for every 4th to 8th exposure). • Increasing school attendance. Module 4: • How to handle parental stress. • Plan for own recreational activities.	Children 10 modules for children and to be completed in order. Each family had a clinical psychologist that they met during an initial clinical interview. New treatment modules were provided every Friday, and the participants were instructed to complete the modules at the weekend. Each Monday, the assigned psychologist reviewed the work and provided feedback (written) via the platform. Psychologists sent additional reminders throughout the week if necessary. Parents 10 corresponding modules for parents to be completed in order and in synchrony with child modules.	10 modules over 10-weeks (1 module per week). Time taken to complete each module is unknown.

								Module 7: • Functional analyses of goal-directed behaviours. • Review of the goals. • Exposure exercises. Module 8: • Positive analyses of goal-directed behaviours. • Exposure to multiple stimuli (selected from hierarchy). Module 9: • Quizzes. • Review of achievements so far. Module 10: • Review of avoidant and controlling behaviour. • Maintenance and relapse prevention.	Module 5: • Review of treatment sessions 1 to 4. • Inventory of parental challenges. Module 6: • Solving problems together with the child. Module 7: • Functional analyses of parental behaviour with emphasis on the interaction between parent and child. • Functional analysis of goal-directed behaviours. Module 8: • Review of treatment – Part 1. • Rewarding yourself for hard work. Module 9: • Review of treatment – Part 2. • Lessons learnt • Review of parental challenges. Module 10: • Review of parental behaviours. • Maintenance and relapse prevention.		
Customized CBT for adolescents with pain and emotional distress (no specific name)	Flink, Sfyrkou & Persson (2016)	Not provided.	Sweden	Sample age range: 17 to 21 years	Reccurrent pain and emotional distress	Face-to-face combined with internet CBT.	Unknown/ no access.	All content available in Swedish only. Module 1 (face-to-face); Kick-off – includes psychoeducation, goal-setting and behavioural activation. Example: - Setting up goals in terms of activities and daily functioning Module 2; Behavioural activation - scheduling activities that are positively reinforced. Module 3; Further behavioural activation, and a behavioural experiment. Module 4; Positive psychology techniques. Examples: - 'Savouring' techniques - 'Three good things' Modules 5–8 (recommended as needed/ customized): • Sleep/ sleep hygiene • Coping with stress/ scheduling activities for recovering from stress • Dealing with pain/ self-exposure • Techniques for targeting worry/ 'concreteness' training Module 9 (face-to-face); Ending - relapse prevention; identifying potential problems and maintaining improvement Daily ratings (items used) How much pain did you experience today? How stressed or tense have you felt today? To what extent have you experienced low mood today? How well did you sleep last night? To what extent have you been worried or dwelt on things today?	N/A	9 modules. Modules 1 to 4 and 9 compulsory, and to be completed in order. Modules 5 to 8 optional. Optional modules recommended to adolescents based on their daily ratings of symptoms after the initial four modules. Adolescents scoring above 5 on any symptom recommended to complete the corresponding module. Adolescents could contact a psychologist throughout the program via text message or email to request help with tasks or ask questions. Phone calls and additional face-to-face sessions arranged if necessary. Psychologists reviewed assignments each week and sent feedback (written) via the platform. Psychologists sent reminders via text or email if necessary.	Modules intended to be completed 1 per week (log on to the site at least once per week). In the study by Flink, Sfyrkou & Persson (2016), participants took between 4 to 13 weeks to complete the program.
DARWeb	Nieto, Hernández et al. (2015) Nieto, Boixados et al. (2019) *[artwork/ visuals]*	https://darweb.uoc.es	Spain	Target range: 9 to 15 years	Reccurrent abdominal pain	Web-based self-management	Green/ blue text on white background. Logo is red/orange with green. Home page shows all the modules (numbered) and the top tab can be used to navigate to the message board. Programme has child, adolescent and parent animated characters.	All online content available in Spanish only. Units are composed of text, graphics, and multimedia. Each unit is divided into 5 sections: objectives, introduction, training, exercises, and a summary. Introduction sections give a theoretical overview of the topic, and the training section instructs on how to apply the skills taught in that unit. In the 'exercises' sections, small tasks are given to help consolidate the taught skills, and the units end with a short summary of the unit contents. Children's units A comic booklet was created to guide the children's program. The character in the comic is a child with functional abdominal pain (FAP), and the situations he experiences are used to introduce the topics on the web program. Unit 1. Information about FAP including 'what is FAP?' Characteristics, Impact and treatment.	Parent units Each week the parents also receive a brief explanation of the topic their child is going to work on that week, and they receive a file with the contents of the children's unit (pdf) by email. Unit 1: Information about FAP including 'what is FAP?' Characteristics, Impact and treatment. Unit 2. Pain and triggers, including pain mechanisms and managing triggers. Unit 3. Goal setting – SMART goals (Specific Measurable Achievable Realistic Timed).	Children/ adolescents 7 modules for children to be completed in order. Parents 7 corresponding modules for parents, to be completed in synchrony with child/ adolescent program.	7 modules over 7-weeks (1 unit per week). Units are 30-45minutes each.

								Unit 2. Pain and triggers, including pain mechanisms and managing triggers. Unit 3. Goal setting – SMART goals (Specific Measurable Achievable Realistic Timed). Unit 4. Progressive muscle relaxation and breathing. Unit 5. Communication styles including training in assertiveness. Unit 6. Thought management; how negative thoughts can affect pain and how to change them. Unit 7. Distraction techniques – content on pain and attention, plus a variety of distraction techniques offered (imagination, mental games).	Unit 4. Parental responses to children's pain – how responses affect FAP and strategies to promote positive behaviours and reduce pain behaviours. Unit 5. Communication styles including training in assertiveness. Unit 6. Parental responses to their own pain – the importance of being a positive role model. Unit 7. Thought management; how negative thoughts can affect pain and how to change them. *Note that units 1-3 and 5 directly mirror the child units, and 4, 6 and 7 have a different order and slightly different content.*		
Rheumates@Work	Armbrust, Bos et al. (2015)	Not provided	The Netherlands	Target range: 8 to 13 years	Juvenile Idiopathic Arthritis (JIA)	Internet-based, interactive, educational and CBT program.	No access to website. Primary descriptive paper provides visual 'skeleton' image of the status of joint damage in each joint (as reviewed by a physician before starting the program) (Figure 2). Joints coloured red/ orange/ green to indicate damage/ limitations. There is a cartoon figure (Buddy) to guide the program (no visual available).	All online content available in Dutch only. *Two to four weeks prior to the start of the internet program, children and teenagers undergo a rheumatologic evaluation, fittest, and physical activity is measured by filling in a daily diary and wearing an accelerometer.* Weekly content contains a mixture of film, animation, puzzles, spoken text, 'brain twisters', and assignments. <u>Internet programme - themes</u> Week 0; The cartoon character (Buddy) is introduced (role model) Week 1; What is JIA and what is wrong with the immune system? Education about the immune system by means of animations. How it works in normal situations, and in case of an auto-immune disease. Week 2; How to tackle disease-related participation problems. The schedules problematic situation, thoughts, feelings, and action are introduced. Child learns to cope with set-backs. Week 3; Energy and condition. The child learns to cope with fatigue and learns to manage his or her energy level during the day and throughout the week. Week 4; How to be active in a healthy way. The child learns to manage activities and to be active, and to stay active during times of active disease and during remission. Week 5; Pain. How to differentiate between JIA and pain any child could experience, like muscle ache. Week 6; Setting goals. The child looks at his or her own goal that was set in the first group session and is helped to formulate two SMART goals. Week 7; How to increase motivation by rewarding yourself. The child learns that when you achieve a goal it is good to reward yourself. Week 8; Taking responsibility. Barriers and benefits. The child learns about the barriers and benefits one meets when wanting to change activity-related behaviour. The child is made aware of the benefits of being active. Week 9; Activities and chatting. Every child has to fill out an activity diary for one day. All the children will then join in a chat session led by a supervisor to discuss their experiences. Week 10; Doing things together and asking for help. Being active with friends is more fun. The child learns what he or she can do with friends. And the child is stimulated to ask for help when it is difficult to do something because of JIA. Week 11; Talking about JIA. Being open about JIA can be beneficial to the child. Week 12; Setbacks. The child learns that JIA is a disease that can fluctuate. The child learns how to adjust his or her goal when the arthritis becomes active again. Week 13; Motivation. The child learns that it is important to persevere/to 'keep it up'. One can keep up by developing motivation. The child is made aware that motivation is like a reward: when you reach your goals you have achieved something worthwhile.	Children could choose whether they participated in the programme by themselves or together with their parents.	14 weeks to be completed in order. Four group sessions additional over the 14-weeks (weeks 1, 4/5, 10 and 14). Program starts with the first group session. On the following Monday, the first internet week was released, and new content was released each week thereafter. An email notification was sent each time a new week was released. Assignment reminders were sent each week on Wednesdays, and anyone that had not completed that week was sent an additional reminder on Friday. Participants also had the option to email therapists/ clinicians if they wanted to request help or clarify anything.	14-weeks. Estimated module completion time is not provided.

								Week 14; Summary. Group sessions – themes 1 – What is JIA and what is wrong with the immune system? (beginning) 2 – ‘Excuses’ (week 4/5) 3 – Doing things together (week 10) 4 – What we have learnt and how to persevere (week 14) *Two-weeks after finishing program, all physiological tests/ evaluations are re-done.* *Example assignments for each week are also described in Table 1.*			
Move It Now - guided interactive internet CBT for adolescents with chronic pain	Voerman, Remerie et al. (2015)	Not provided	The Netherlands	Target range: 12 to 17 years	Chronic pain (mixed)	Guided, interactive, CBT internet intervention.	Unknown/ no access.	All online content available in Dutch only. Adolescents are led through the online chapters by an animated female guide using a voice-over. Several interactive elements were developed to help tailor the material to their responses. 1. Background and goals. - Psychoeducation about pain and its consequences - Goal setting 2. Pain killers and breathing. - Pain management strategies - Information about medication use - Deep breathing exercise 3. Relaxation. - Education about relaxation - Two relaxation exercises 4. Thinking and feeling. - ABCDE method for challenging maladaptive thoughts 5. Helpful thinking. - Challenging cognitive distortions - Thought stopping exercise - Distraction exercise 6. Staying active. - Behavioural activation - Brief relaxation exercise 7. Making a plan: relapse prevention *At the end of each module, the adolescents are instructed to practice their skills every day, using the audio files provided on the website.*	There are two online modules for parents, and they have contact with a therapist at the beginning, in the middle and at the end of the intervention (three times). Parent content includes: • Information about how parents should handle the child’s pain • Advice to encourage child to complete the ‘Move It Now’ intervention.	Adolescents 7 online modules in a fixed order (adolescents only have access to next module once current module is complete). Adolescent participants are also contacted by a therapist each week via e-mail and every other week by telephone. Therapists provide emotional support, check understanding, and answer questions. E-mails and phone calls use a standardized protocol. Parents 2 modules to be completed at any point during adolescent course. Unclear if these are in a set order.	7-modules intended to be completed once a week (7-weeks). Each module takes approximately 30 minutes to complete.
iCanCope with Pain™	Stinson, Lalloo et al. (2014) Lalloo, Hundert et al. (2019) *[artwork/ visuals]*	Not provided - currently only available to the researchers in the development team.	Canada	Target range: 14 to 18 years	Chronic pain (mixed)	Smartphone app and website combination.	No access to website. Visual material (screenshots) for the mobile app symptom tracking element available in Lalloo et al. (2019), Figures 1 & 2. Features a blue animated character, with animations reflecting the tracking element that is displayed (for example, physical activity tracker displays the character with small hand weights). Visuals are colourful (pink, blue).	All online content available in English only. The primary descriptive reference presents a proposed intervention architecture. Smartphone App The smartphone app has four parts including i) symptom trackers for pain, sleep, mood, physical activity and social activity, ii) SMART goals, iii) coping skills training (CBT techniques including relaxation, guided imagery, mindfulness and breathing), and iv) social support, which features monitored discussion boards, group-based challenges, goal sharing and ‘Ask An Expert’. Website The website contains detailed pain education and coping strategies to compliment the app content. There are seven proposed sections for the website: pain (types of pain, diagnosis and management strategies), sleep hygiene, mood (anxiety, stress and emotions), physical activity (exercise and healthy eating), social activity (communication, relationships and sexuality), health (transitional care, self-advocacy skills), and self-guided quizzes.	N/A	11 web and smartphone components in total. It is unclear if the app and website modules are to be completed in specific order.	Not specified in primary descriptive reference. Lalloo et al. (2019) used a 55-day study period to investigate the feasibility of the symptom tracking element. One check-in per day was required.
Interactive website for dysmenorrhea (no specific name)	Yeh, Hung, Chen, Lin & Wang (2013)	Not provided.	Taiwan	Internet intervention group: M = 16.94 years (SD 1.02). Acupressure only group: M = 17.94 years (SD 0.84)	Dysmenorrhea	Non-pharmalogical physical therapy (auricular acupressure), combined with interactive website.	Unknown/ no access.	Language of content unspecified. The interactive website is intended to compliment auricular acupressure treatment for dysmenorrhea. The website provides patients with nursing care instruction, as well as counselling. Website units Unit 1: Hot News; provided information on dysmenorrhea prevalence, legal rights and the health-care concerns of adolescents. Unit 2: Red Magic Book; included an online survey and menstrual e-diary. Unit 3: Understanding of Dysmenorrhea; computer-animated videos were used to describe the menstrual cycle and hormone fluctuations	N/A	8 modules/ units. It is unclear if the online modules are to be completed in specific order.	Not specified

								that occur throughout. Information on the differences between primary and secondary dysmenorrhea was provided, and physical and psychological symptoms of dysmenorrhea were explained in interactive format. Unit 4: Caring; incorporated the viewpoint of Chinese medicine, as well as self-care approaches (e.g. hot pack) and daily menstrual care and hygiene. Unit 5: Auricular Acupressure; photographs with word descriptions were used to introduce acupoint techniques and the theory, rationale, efficacy, advantages, and precautions associated with these techniques were explained using photographs. Unit 6: Professional Counselling; HCPs responded to posted questions through this webpage or email. Unit 7: Diet and Food Properties; content related to daily diet requirements to improve health, including the rationale of Chinese medicine, as well as general information on food properties and dietetics. Unit 8: Chat Room; a peer support chat room for dysmenorrhea. Unit 9: Linked Websites; hyperlinks to representative and authoritative websites on dysmenorrhea were provided should further learning be desired. <u>Auricular acupressure treatment</u> Auricular acupressure is a traditional, non-invasive, Chinese medicine treatment. This technique involves stimulating specific sites on the body (acupoints), and is thought to modulate physiological reactions by causing a release of neurotransmitters, which interrupts afferent signals in the central nervous system. Six auricular acupoints were used in this intervention; shenmen, kidney, liver, internal genitals, central rim, and endocrine. Researchers placed adhesive plasters containing seeds on each acupoint at the start of the menstrual cycle and removed it after 48 hours. Participants were instructed to press each acupoint for at least one minute, four times per day until experiencing pain relief.			
Prototype website for web-based skills training for adolescents with migraine (no specific name)	Donovan, Mehringer & Zeltzer (2013)	Website decommissioned.	USA	Target range: 12-17 years	Chronic migraines	CBT-based self-management website (plus additional mobile application for adolescents).	Unknown/ no access.	All online content available in English only. *A prototype website was developed based on Concept Mapping from a preceding interview study.* Content includes quizzes (focus on improving self-efficacy), motivational feedback and audio/ visual tools; including relaxation podcasts and video learning. Also includes social networking/ peer support features, as well as 'ask an expert' function. Adolescent version has a 'pain toolbox' of coping strategies, as well an additional mobile application which functions as both a headache diary and provides access to the pain toolbox. <u>Adolescent program topics</u> 1. Basics (diagnosis, aetiology, prognosis, etc.) 2. Taking Control (emphasizing empowerment to participate fully in treatment) 3. Causes 4. Lifestyle (practical prevention strategies) 5. Treatment (pharmaceutical and nonpharmaceutical; practical strategies for coping with a migraine) 6. Communication (friends, school, health care providers, and family)	<u>Parent/ caregiver program topics</u> 1. Education 2. Parenting a child who has migraines (encouraging independent self-management; self-care for parents 3. Causes 4. Lifestyle Management 5. Treatment 6. Communication	<u>Adolescents</u> 6 topics; it is unclear if these are to be completed in a specific order. It is also unclear whether each topic represents a separate module in the program. <u>Parents</u> 6 topics to be completed concurrently with adolescent program.	Not specified.

Teens taking charge: managing arthritis online	Stinson, McGrath et al. (2010)	https://teens.aboutkidshealth.ca/jiateenhub	Canada	Sample age: M = 15.7 years (SD 1.5)	Juvenile Idiopathic Arthritis (JIA)	Internet self-management program.	Visuals are colourful (pink, blue) with SickKids logo (blue) displayed on homepage and 'Teens' highlighted in bold pink. Top banner is a photograph of a happy teenager running with an adult outside. Modules are centre of display and drop-down arrows can expand the modules so smaller section of content can be seen.	All online content available in either English or French. Teens taking charge has 310 content pages, including animations, images, videos, forums, surveys, and interactive forms (e.g. quizzes). 1. Getting started – includes introduction section, which provides an overview of program coverage, and goal setting section (SMART goals). 2. Overview of what JIA is – contains sections relating to specific types of JIA, as well as general education about JIA and its causes, including explanations of inflammation. This section also goes through common symptoms and how it will affect teens as they grow up. Possible complications, such as eye problems are also explained. 3. Diagnosis of JIA, which explains diagnostic tests, as well as how to cope with a diagnosis –five strategies outlined including having confidence, positive thinking, knowing your limits, perusing new activities, and expressing feelings. 4. Symptom management; individual sections on managing pain, fatigue, stiffness, and stress. Pain section includes 'what is pain?' explains the medications available for pain (Non-steroidal anti-inflammatory drugs (NSAIDs), anti-rheumatic drugs (DMARDs), steroids, biologic drugs), physical methods of treating pain (heat, cold, exercise), and coping strategies. The section for fatigue has the same structure, then the stiffness section covers 'what is stiffness?' The stress section covers 'what is stress? And explains causes, symptoms and how to manage. Section finishes with a symptom management plan including symptom monitoring and reference back to SMART goals. 5. Coping strategies – relaxation with links to video-audio guides, distraction and managing thoughts (including restructuring). 6. JIA-specific medications (note: advice given in module 5 not to change medications recommended by doctor). Includes Non-NSAIDs corticosteroids, injections and DMARDs in more depth. 7. Other types of care: Physiotherapy, Transcutaneous electrical nerve stimulation (TENs), exercise and yoga (including written examples), and occupational therapy. Section also includes advice on nutrition for JIA, how to access psychological therapy and explains some different types of Complementary Alternative Medicine (CAM). 8. Therapies, self-monitoring and supports. Includes how to self-monitor, how to talk to your doctor about JIA. Section also includes how to talk to your teacher and deal with bullying. 9. General lifestyle. Sections on how to stay active, eat healthily and get enough sleep. Includes some general sleep advice and sleep hygiene tips. Section on puberty and relationships is also included – links provided to other sources on this topic. Final section provides an overview of potential issues with self-esteem, body image, depression, and some points on how to overcome these issues. 10. 'Looking ahead' – advice on transitioning through the healthcare system from paediatric rheumatologist to adult health care. More on birth control, higher education and working, and a final overview of how to cope with symptoms, stress and flare-ups moving forwards.	N/A	Descriptive article states 12 modules however current online version displays 10 core modules on the homepage. Structure of online 'hub' suggests it can be completed in order however can be flexible to move back and forward between sections.	Not specified.
In-person CBT followed by 6-week online skill review for IBD (no specific name)	McCormick, Reed-Knight, Lewis, Gold & Blount (2010)	Not provided	USA	Sample age range: treatment group; 12-17 years, wait-list control; 11-17 years (note: all female sample)	Inflammatory bowel diseases (IBDs): Crohn's disease and ulcerative colitis (UC)	In-person intervention followed by 6-week web-based skill review.	Unknown/ no access.	All content available in English only. *The modules are all presented on the treatment day, in-person by a therapist, using a detailed treatment manual. This is then followed by 6-weeks of web-based skill review.* **Parents and adolescents met in separate groups.** Each intervention module follows a similar format; introduction of a new skill, examples, discussion about the skill, and practicing the skill (if appropriate). Child modules Module 1: Overview of treatment and rationale and goal-setting. Module 2 Introduction to cognitive-behavioural model, using model to change emotions and physical symptoms, restructuring catastrophic/ maladaptive thoughts, and changing avoidant behaviour.	Parent modules Module 1: Overview of treatment and rationale and goal-setting. Module 2 Introduction to cognitive-behavioural model, using model to change emotions and physical symptoms, restructuring catastrophic/ maladaptive thoughts, and changing avoidant behaviour. Module 3: Relaxation, progressive muscle relaxation, imagery and deep-breathing. Module 4: Effectively coping with physical symptoms (e.g., distraction), verses ineffectively	Adolescents 7 modules are completed in order in the 1-day intensive training. Homework assignments and the online chat are completed once a week thereafter. Homework assignments were designed to reinforce the skills learned during the full-day intervention. Parents 7 corresponding modules to be completed in	1-day intensive in-person intervention (approximately 6 hours), followed by 6-week web-based skill review (brief assignment followed by 30-minute online chat with trained research assistants).

								Module 3: Relaxation, progressive muscle relaxation, imagery and deep-breathing. Module 4: Effectively coping with physical symptoms (e.g., distraction), verses ineffectively coping with physical symptoms (e.g., focusing on the symptom). Module 5: Distraction-based pain management techniques. Module 6: Communication skills (e.g., nonverbal skills, active listening, ‘‘I Feel’’ statements) Module 7: Application of communication skills for increasing familial cooperation and reducing stress. Web-based components Component 1: Weekly homework assignments Component 2: Weekly chat sessions – discussion of homework assignments	coping with physical symptoms (e.g., focusing on the symptom). Module 5: Setting appropriate limits and expectations, helpful verses unhelpful responses to children’s physical symptoms (e.g., encouraging regular activities verses providing extra attention and removal of responsibilities) Module 6: Communication skills (e.g., nonverbal skills, active listening, ‘‘I Feel’’ statements). Module 7: Application of communication skills for increasing familial cooperation and reducing stress. Web-based components Component 1: Weekly homework assignments Component 2: Weekly chat sessions – discussion of homework assignments	synchrony with the adolescent program.	
Internet-based self-help for paediatric recurrent headache (no specific name)	Trautmann & Kröner-Herwig (2010)	Not provided	Germany	Target range: 10 to 18 years	Recurrent primary headache: migraine, tension type headache (TTH) or combined headache.	Internet-based self-help.	Unknown/ no access.	All online content available in German only. Module topics: 1. Headache education: mechanisms, symptoms and types of headache and the role of stress as a trigger of attacks. 2. Stress management: perception of own stress symptoms, coping with stress. 3. Progressive relaxation techniques. * 4. Cognitive restructuring: identification of dysfunctional cognitions regarding headache and stress, and identification of functional cognitions. 5. Self-assurance strategies: being pro-active and sensitive to one’s own needs. 6. Problem solving. ** CD with relaxation instructions provided. Includes a full relaxation protocol involving tensing and relaxing of major muscle groups, beginning with the upper body and proceeding to the lower body (body scan). Alternatively, the relaxation instructions are downloadable from the website.*	N/A	6 modules to be completed in order. There are additional homework exercises and e-mail contact with therapists (graduate students) can be used to discuss the week’s module topics. Two booster emails were sent at week 4 and 8 after the end of training program, to remind children/ teenagers to continue practicing coping strategies in their daily lives.	6 modules over 6-weeks (1 module weekly). Estimated module completion time is not provided.
Web-MAP (Web-based Management of Adolescent Pain)/ Web-MAP2	Palermo, Wilson, Peters, Lewandowski & Somhegyi (2009)	https://webmap2.com	USA	Sample age: M = 14.8 (SD 2.0) Target range: 11-17 years	Chronic pain (mixed)	Web-based self-management intervention.	Travel-themed website. Home screen displays a passport and a world map with one introduction module plus seven ‘countries’ (modules) to travel to. Navigation to profile page, reminders and message centre tabs are displayed on the right. Background colour is brown, and modules each have a different colour (colourful/ brights). Areas that users have visited change to red once the module has been completed.	All online content available in English only. *The website has three main sections – the passport page (home page), treatment modules and a daily diary. This is the same for adolescent and parent versions.* *Children and parents interacted with the web program through completing forms, which then tailored the instructions and assignments. Website uses animations, videos, and audio files for deep breathing and muscle relaxation. ** Child Modules (main content) 1. Introduction. Includes introductory video by a specialist psychologist and structure outline for the child version. Pain education explains pain types, duration, the difference between acute and chronic pain, and some example stories from teenagers. Includes animation of the pain response. Module moves onto explaining how pain can be managed using CBT, and some examples and an explanation of goal setting. 2. Stress and bad feelings. Explains what stress is and gives some examples of daily stressors. Fight-flight response explanation of stress and explains the role of ‘worry’ in stress. Moves on to cover the relationship between stress and pain 3. Relaxation and distraction. Four techniques – abdominal breathing, muscle relaxation, guided imagery, and activity participation. Explains that relaxation is a skill that can help reduce pain and anxiety. Examples of success of relaxation with teenagers, followed by the four techniques, including visual/ audio guides. 4. School. Explains how pain interferes with school and that relaxation and distraction techniques can be used to help this.	**General information in child content column for WebMAP2 also relates to the parent version.* Parent modules (main content) 1. Introduction. Includes introductory video by a specialist psychologist and structure outline for the parent version. Pain education explains pain types, duration, the difference between acute and chronic pain. Includes animation of the pain response. Provides example stories of teen chronic pain. Module moves onto explaining how pain can be managed using CBT, and some examples and an explanation of goal setting. Outlines the role of the parent in helping teen self-manage. 2. Stress and bad feelings. Explains what stress is and gives some examples of daily stressors. Fight-flight response explanation of stress and explains the role of ‘worry’ in stress. Moves on to cover the relationship between stress and pain 3. Behaviour (i). Explains how to use parental attention to praise positive coping behaviours, how to use strategies to reduce child’s unhelpful behaviours and how to help child get	Children/ adolescents Eight modules to be completed in order (cannot move onto the next module without completing the previous module assignment). Users can click on the passport on the homepage to see progress. *Module structure (all modules) included a summary of what will be learned and why this information is important, fun facts about the destination (note: not included in content description), main content, and a question-and-answer game to test retention.* *An assignment screen then showed instructions for carrying out a specific skill over the coming week. ‘Postcards’ are also used as practice reminders from previous weeks.*	8 modules are to be completed over 8 weeks (one per week). Each module (including assignment) takes approximately 30 minutes.

	Additionally, explains how to seek support from the school/ teachers, peers and parents. Gives an example of planning for reaching school goals. 5. Cognitive skills. Explains automatic thoughts and how to identify negative and positive thoughts. Explains and gives an example of catastrophizing. Skill tasks to practice challenging negative thoughts by replacing thoughts or thought stopping. 6. Sleeping and lifestyle. Explains how lifestyle factors impact chronic pain. Followed by an explanation of pacing and how this can be used to balance activity. Some advice given on eating and keeping hydrated. Explains the importance of sleep and how this relates to pain, then moves through sleep hygiene advice (7 tips). Calculator provided to work out sleep-wake cycle times. Covers insomnia and further sleep hygiene advice given, plus reference back to using relaxation to aid sleep. 7. Staying active. Learning how to pace and schedule activities. Emphasis on planning to meet goals (goal setting example provided). Advice on what to do during the rest periods and some examples of pleasant activities are provided. 8. Maintenance and prevention. Success review and overview of the 'pain management toolbox'. Review of barriers to successful pain management and making plans for the future. Emphasis on that tools for managing pain need to be flexible, and to look out for pain triggers. Refers to making a plan for school and stress management strategies. Finishes with 'how you can keep practicing'.	support from friends. Explains teen relaxation content. Explains how to use positive reinforcement and provides examples of praise. Also gives guidelines to not give excessive attention, encourage normal activity, and think about the consequences on days when child's activities are interrupted by pain. Also advises to encourage independent pain management, remove pain 'focus' and try to reduce medicine dependence. Explains how to help teens get help from friends. 4. Behaviour (ii). Includes supporting child to make a school plan and how to create consistent activity programs. Advises how to involve other family members and school in supporting the child. Explains the child content on school. Sections describe how to create a rewards system for teens using a points system to encourage activity/ school participation. Emphasises that consistency is key. 5. Modelling. Explains teen content on positive thinking. Explains how to be a positive model with examples. Advice to monitor one's own distress and coping displays. Provides examples of some positive coping strategies and explains what catastrophizing is. Skill tasks to practice challenging negative thoughts by replacing thoughts or thought stopping. 6. Sleeping and Lifestyle. The importance of sleep and how to support good lifestyle choices. Explains how lifestyle factors impact pain. Advises on physical activity levels, eating habits and gives an example of the sleep-pain connection. Gives same 7 tips for sleep hygiene as in child module, plus adds scheduling sleep as tip 8. Covers insomnia with reference back to relaxation. Advises against sleep medications. 7. Communication. Emphasises importance of teen independence and how communication impacts this. Explains teen content on pacing. Advice given on supporting teens to become independent. Highlights communication barriers and gives examples of good communication. Advises on how to increase opportunities to communicate with teen, and finishes with how to communicate with teachers/ schools. 8. Maintenance and prevention. Identifies challenges that might remain and reasons for ongoing difficulties. Provides parent strategy toolbox. Encourages using strategies in flexible way and to practice good communication with teen. Advises parent to also ensure own self-care.	*A PhD post-doctoral therapist responded via the Centre to each assignment to review progress, encourage continued skills practice, and to assist with problem solving application.* Parents 8 modules designed to be completed in synchrony with the child program.

Supplementary Table 2. Details of development processes and evaluations of efficacy for each intervention included in the content analysis (n = 35).

Study details							Intervention development details				Evaluations of efficacy		
Intervention name	**Study reference**	**Country**	**Participant details [a]**	**Sample pain condition/ diagnosis**	**Study design**	**Method**	**Theoretical framework(s)**	**Development approach**	**Healthcare professional (HCP) input**	**Qualitative insights based on adolescent/ parent feedback**	**Pain outcomes**	**Functional outcomes – Physical/ Social/ Emotional/ School**	**Additional outcomes**
Aim To Decrease Anxiety and Pain Treatment (ADAPT)	Cunningham et al. (2018)	USA	$N = 9$ Age range: 9 to 13 years Age (M) = 11.6 (SD 1.42) Male: $n = 2$ Female: $n = 7$	Functional abdominal pain disorders (FAP)	Mixed-methods (iterative)	Participants were approached by a physician for recruitment onto the study. Demographic information, and assessments of pain intensity (visual analogue scale (0-10 VAS)), screening for Child Anxiety Related Disorders (SCARED) (Birmaher et al., 1997), functional disability (FDI-C) (Walker & Greene, 1991) and the Anxiety Disorder Interview Schedule-Child Version (Silverman et al., 2001) were taken at baseline (producing a clinician severity rating for anxiety). Participants completed 2 in-person, and 4 web sessions of the ADAPT intervention, and all outcomes were re-assessed, with the addition of adherence data and qualitative feedback. Interviews (semi-structured) Feedback on treatment content, format, ease of use, and whether they would recommend the intervention.	ADAPT was developed from an established Cognitive Behavioural Therapy (CBT) protocol for pain management and 'Cool Kids' intervention (Hudson et al., 2009). The intervention also integrates mindfulness.	Not specified	Not specified for web session development. The in-person sessions are delivered by a licensed clinical psychologist, and web sessions followed up by a therapist.	Feedback from semi-structured interviews highlighted three domains: 1. Feasibility: participants were able to use specific skills to manage pain and anxiety indicating high perceived usability. The program integrated easily into their daily schedules, however barriers included practicing skills in front of peers. Parents mentioned that demanding schedules can be challenging for children to remember. 2. Acceptability: positive feedback on content and structure overall, as well as pace and progression. Participants commented that the format was accommodating and that phone call support was particularly beneficial to reinforce skills learnt online. Least favourite content varied by participant. 3. Outcomes: Perceived overall confidence and self-efficacy improved throughout the program. Children commented that the skills they learnt led to more effective pain management. Overall improvements in school functioning and management of pain and anxiety were seen by parents.	Pain intensity - VAS (score range: 0-10) Overall decrease. Pre-post reduction (M) = 1.72 points, Z =-1,93, $p = 0.05$	Functional disability (FDI-C) (score range 0-60) 56% of patients experienced improved functioning. Pre-post improvement for responders = an average 10 point reduction, improvement overall (M) = 2.22 points, Z = 0.048, $p = 0.64$ *4 participants (44%) experienced reductions across all three primary outcomes (pain, disability, anxiety).*	Anxiety (score range 0-82) 78% of patients decreased in anxiety symptoms. Pre-post symptom reduction (M) = 16.78 points, Z = -2.20, $p < .05$ Clinician severity ratings of anxiety 89% of participants had reductions in clinician-assessed anxiety. Pre-post reduction (M) = 2.33, Z = -2.539, $p < .05$ 3 out of 9 (33%) were considered free of an anxiety disorder at posttest.
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Bonnert et al. (2014)	Sweden	$N = 29$ Age range: 13 to 17 years Male: $n = 7$ (24%) Female: $n = 22$ (76%) Two cohorts: April 2012 ($n = 12$), and September 2012 ($n = 17$)	Functional gastrointestinal disorders (FGID)	Pre-post	Adolescents in the trial received internet-based CBT (ICBT) with therapist support over 8 weeks. A parent of each adolescent also completed a parallel parent-training program. Adolescents completed online measures at baseline, post-treatment and 6-month follow-up. Primary measure was the Gastrointestinal Symptom	All content in the adolescent-directed intervention was based off a protocol for a successful ICBT program for adults (Ljótsson, Andréewitch, et al., 2010; Ljótsson, Falk, et al., 2010). Frameworks mentioned in the content description (Bonnert et al., 2014) included: - CBT - Exposure therapy techniques - Antecedent–Behaviour-Consequence	Not specified	Participants could send online messages to therapists via the program, as necessary. A phone call with a therapist was conducted in the fifth and sixth weeks of treatment to provide encouragement and discuss the exposure exercises.	N/A	PRS (range 0-30) Pre (M) = 16.21 (7.26) Post (M) = 10.99 (6.83) 6-month follow-up (M) = 9.35 (5.48) Pre-post, effect size (d) = 0.74 [CIs: 0.39, 1.09] Pre- 6-month follow-up; d = 1.05 [CIs: 0.59, 1.59] PII (range 0-36) Pre (M) = 13.97 (8.91) Post (M) = 10.77 (8.90) 6-month follow-up (M) = 7.48 (7.92) Pre-post, effect size (d) = 0.36 [CIs: 0.11, 0.61] Pre- 6-month follow-up; d = 0.76 [CIs: 0.41, 1.12]	FDI (range 15-75) Pre (M) = 23.59 (7.30) Post (M) = 21.32 (5.69) 6-month follow-up (M) = 19.99 (4.90) Pre-post, effect size (d) = 0.34 [CIs: −0.06, 0.74] Pre- 6-month follow-up; d = 0.57 [CIs: 0.10, 1.04]	GSRS-IBS (range 13–91) Pre (M) = 33.72 (13.62) Post (M) = 27.25 (12.00) 6-month follow-up (M) = 25.90 (10.47) Pre-post, effect size (d) = 0.50 [CIs: 0.16, 0.84] Pre- 6-month follow-up; d = 0.63 [CIs: 0.24, 1.02] CASI (range 18-54) Pre (M) = 32.24 (7.23) Post (M) = 30.88 (6.34) 6-month follow-up (M) = 29.18 (6.50) Pre-post, effect size (d) = 0.20 [CIs: −0.07, 0.47]

						Rating Scale-IBS version (GSRS-IBS) (Wiklund et al., 2003). Secondary outcomes included the Pain Reactivity Scale (PRS) and Pain Interference Index (PII) (Wicksell et al., 2011), functional disability (FDI), Childhood Anxiety Sensitivity Index (CASI) (Silverman et al., 1991), Child Depression Inventory (CDI) (Kovacs, 1992), and the Perceived Stress Scale (PSS 4) (Cohen et al., 1983).	model (ABC model) - Acceptance and commitment therapy (ACT) - Mindfulness						Pre- 6-month follow-up; d = 0.44 [CIs: 0.08, 0.81] CDI (range 0-54) Pre (M) = 9.00 (5.57) Post (M) = 8.44 (6.28) 6-month follow-up (M) = 8.00 (6.68) Pre-post, effect size (d) = 0.09 [CIs: −0.15, 0.33] Pre- 6-month follow-up; d = 0.16 [CIs: −0.14, 0.46] PSS 4 (range 0-16) Pre (M) = 6.28 (3.14) Post (M) = 5.18 (3.19) 6-month follow-up (M) = 5.25 (3.42) Pre-post, effect size (d) = 0.35 [CIs: 0.02, 0.69] Pre- 6-month follow-up; d = 0.31 [CIs: −0.10, 0.73] Completion rates 76% of adolescents completed the main part f the ICBT program (4 to 6 modules)
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Bonnert et al. (2016)	Sweden	*N* = 101 Age range: 13 to 17 years Age (M) = 15.54 (SD 1.56) Male: 39 (39%) Female: 62 (61%)	Irritable Bowel Syndrome (IBS)	Randomised controlled trial (RCT)	Adolescents were randomized to either ICBT (*n* = 47) or a wait-list control group (*n* = 54). The ICBT intervention was 10-weeks duration in this trial, and all measures were taken at baseline, post-treatment and 6-month follow-up. The primary outcome was completed on a weekly basis (GRSR-IBS). Other measures included: pain intensity (pain faces – revised), frequency (Hicks et al., 2001), quality of life/ functioning (PedsQL; child and parent-proxy) (Varni et al., 2003), medication use, school absence, avoidance behaviour (IBS-BRQ) (Reme et al., 2010), fear and worry (Visceral Sensitivity index (VSI) (Labus et al., 2004), PSS, Anxiety, SCAS-C/P (Spence Children's Anxiety Scale) (Spence et al., 2003), and a client satisfaction questionnaire (CSQ) (Nguyen et al., 1983). Parents also completed PedsQL-gastro (Varni et al., 2014), and Children's somatization	- CBT - Exposure therapy techniques No other frameworks were mentioned in this paper. ICBT in this study was adapted for children and tested as a face-to-face treatment prior to trialling.	Not specified	Clinical psychologists provided online support to those in the ICBT group and had weekly contact with the same psychologist throughout. Text message and phone call reminders were also sent to participants by therapists.	N/A		Pain intensity (pain faces scale – revised) ICBT – pre (M) = 5.85 ICBT – post (M) = 4.53 ICBT follow-up (M) = 4.41 control – pre (M) = 5.72 control – post (M) = 5.53 pre-post between-group effect size (d) = 0.46, *p* = .011* Pain frequency ICBT – pre (M) = 4.25 ICBT – post (M) = 3.19 ICBT follow-up (M) = 2.59 control – pre (M) = 4.04 control – post (M) = 3.66 pre-post between-group effect size (d) = 0.34, *p* = .009** * p <.05 ** p <.01	PedsQL (child) ICBT – pre (M) = 71.28 ICBT – post (M) = 76.92 ICBT follow-up (M) = 81.63 control – pre (M) = 74.90 control – post (M) = 74.89 pre-post between-group effect size (d) = 0.40, *p* = .005** PedsQL (parent-proxy) ICBT – pre (M) = 74.11 ICBT – post (M) = 77.55 ICBT follow-up (M) = 77.79 control – pre (M) = 79.42 control – post (M) = 78.15 pre-post between-group effect size (d) = 0.34, *p* = .009** PedsQL Gastro (parent only) ICBT – pre (M) = 54.43 ICBT – post (M) = 63.17 ICBT follow-up (M) = 64.11 control – pre (M) = 53.06 control – post (M) = 57.28 pre-post between-group effect size (d) = 0.32, *p* = .032* * p <.05 ** p <.01	GRSR- IBS ICBT – pre (M) = 43.19 ICBT – post (M) = 32.05 ICBT follow-up (M) = 30.87 control – pre (M) = 42.40 control – post (M) = 37.67 pre-post between-group effect size (d) = 0.45, *p* = .006** School absence ICBT – pre (M) = 1.55 ICBT – post (M) = 1.04 ICBT follow-up (M) = 0.82 control – pre (M) = 1.43 control – post (M) = 1.31 pre-post between-group effect size (d) =0.37, *p* = .021* School absence (parent rating) ICBT – pre (M) = 1.73 ICBT – post (M) = 1.22 ICBT follow-up (M) = 0.99 control – pre (M) = 1.58 control – post (M) = 1.45 pre-post between-group effect size (d) = 0.36, *p* = .015* Medication use ICBT – pre (M) = 0.77 ICBT – post (M) = 0.41 ICBT follow-up (M) = 0.34 control – pre (M) = 0.67 control – post (M) = 0.75 pre-post between-group effect size (d) = 0.41, *p* = .008** Medication use (parent rating) ICBT – pre (M) = 0.73 ICBT – post (M) = 0.49 ICBT follow-up (M) = 0.47 control – pre (M) = 0.54 control – post (M) = 0.72

						Inventory (CSI-24) (Walker et al., 2008). The wait-list control group were free to use any treatment but not initiate psychological treatment throughout the trial (cross-over results not reported in this paper).							pre-post between-group effect size (d) = 0.51, *p* = .003** IBS-BRQ ICBT – pre (M) = 79.80 ICBT – post (M) = 58.70 ICBT follow-up (M) = 54.50 control – pre (M) = 73.55 control – post (M) = 65.27 pre-post between-group effect size (d) = 0.54, *p* = .003** VSI ICBT – pre (M) = 32.28 ICBT – post (M) = 22.72 ICBT follow-up (M) = 16.63 control – pre (M) = 28.30 control – post (M) = 27.49 pre-post between-group effect size (d) = 0.50, *p* = .001*** SCAS-C ICBT – pre (M) = 28.45 ICBT – post (M) = 25.23 ICBT follow-up (M) = 21.05 control – pre (M) = 22.87 control – post (M) = 22.62 pre-post between-group effect size (d) = 0.19, *p* = .081 SCAS-P (parent rating) ICBT – pre (M) = 17.87 ICBT – post (M) = 13.75 ICBT follow-up (M) = 13.80 control – pre (M) = 14.21 control – post (M) = 12.27 between-group effect size (d) = 0.21, *p* = .033* PSS ICBT – pre (M) = 16.23 ICBT – post (M) = 13.68 ICBT follow-up (M) = 12.91 control – pre (M) = 16.11 control – post (M) = 13.14 pre-post between-group effect size (d) = 0.06, *p* = .724 CSI-24 (parent only) ICBT – pre (M) = 17.78 ICBT – post (M) = 12.42 ICBT follow-up (M) = 13.47 control – pre (M) = 17.08 control – post (M) = 16.36 pre-post between-group effect size (d) = 0.49, *p* = .001*** ** p <.05* *** p <.01* **** p < .001*
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Lalouni et al. (2017)	Sweden	*N* = 31 Age range: 8 to 12 years M = 10.7 years (no SD)	Pain-related FGID	Pre-post	The treatment consisted of ten modules for children and ten modules for parents. Duration: 10-weeks.	All content in the child-directed intervention was based off a protocol for a successful ICBT program for adults and adolescents.	Not specified	There was ongoing communication with therapists via the program.	N/A	Pain intensity - child (pain faces scale – revised) Pre (M) = 6.87 Post (M) = 5.09 Follow-up (M) = 3.74 Pre-post effect size (d) = 0.74, *p* <.001	PedsQL (child) Pre (M) = 72.48 Post (M) = 85.75 Follow-up (M) = 87.56 Pre-post effect size (d) = 1.26 , *p* <.001	CDI-S Pre (M) = 2.90 Post (M) = 1.92 Follow-up (M) = 1.86 Pre-post effect size (d) = 0.43, *p* = .006

	Male: *n* = 12 (39%) Female: *n* = 19 (61%)	New treatment modules were provided every Friday to be completed over the weekend. All measures were completed online pre-treatment, post-treatment and at 6-month follow-up. The PedsQL-gastro, pain faces - revised, pain frequency and IBS-BRQ were taken weekly. Other measures included the CDI (short version) (Allgaier et al., 2012), SCAS (unpublished short version – 18 items), VSI, CSI-24, catastrophizing response scale of the pain response inventory (Walker et al., 1997), Insomnia Severity (ISI-C) (Kanstrup et al., 2014), Pressure Activation Stress (PAS) (Lindblad et al., 2008), school absence, client satisfaction questionnaire (CSQ-8) (Larsen et al., 1979), and a subjective assessment questionnaire (SAQ) (Gonsalkorale et al., 2003). Additional parent outcomes were work absence, adult responses to child symptoms (ARCS) (Van Slyke & Walker, 2006), patient health questionnaire (PHQ-9) (Kroenke et al., 2001), generalized anxiety disorder assessment (GAD-7) (Spitzer et al., 2006), and adverse events (AE).	ICBT in this study was adapted for children and tested as a face-to-face treatment prior to trialling. Frameworks mentioned in the content description (Lalouni et al., 2017) included: • CBT • Exposure therapy techniques • Mindfulness		Pre- 6 month follow-up; d = 1.30, *p* <.001 Pain intensity - parent (pain faces scale – revised) Pre (M) = 6.19 Post (M) = 3.91 Follow-up (M) = 3.03 Pre-post effect size (d) = 0.93, *p* <.001 Pre- 6 month follow-up; d = 1.29, *p* <.001 Pain frequency - child (no. pain free days/ week) Pre (M) = 2.45 Post (M) = 3.84 Follow-up (M) = 4.35 Pre-post effect size (d) = 0.70, *p* = .002 Pre- 6 month follow-up; d = 0.95, *p* <.001 Pain frequency - parent (no. pain free days/ week) Pre (M) = 2.32 Post (M) = 3.71 Follow-up (M) = 5.20 Pre-post effect size (d) = 0.67, *p* <.001 Pre- 6 month follow-up; d = 1.38, *p* <.001 Catastrophizing (pain response inventory – child report) Pre (M) = 6.81 Post (M) = 4.61 Follow-up (M) = 2.04 Pre-post effect size (d) = 0.59, *p* = .002 Pre- 6 month follow-up; d = 1.29, *p* <.001	Pre- 6 month follow-up; d = 1.43, *p* <.001 PedsQL Gastro (child) Pre (M) = 60.30 Post (M) = 75.63 Follow-up (M) = 79.08 Pre-post effect size (d) = 1.14, *p* <.001 Pre- 6 month follow-up; d = 1.40, *p* <.001 PedsQL (parent-proxy) Pre (M) = 69.57 Post (M) = 82.79 Follow-up (M) = 85.95 Pre-post effect size (d) = 1.16, *p* <.001 Pre- 6 month follow-up; d = 1.44, *p* <.001 PedsQL Gastro (parent-proxy) Pre (M) = 57.62 Post (M) = 74.54 Follow-up (M) = 77.46 Pre-post effect size (d) = 1.37 , *p* <.001 Pre- 6 month follow-up; d = 1.60, *p* <.001	Pre- 6 month follow-up; d = 0.45, *p* = .005 SCAS (short) Pre (M) = 12.45 Post (M) = 10.27 Follow-up (M) = 9.13 Pre-post effect size (d) = 0.29, *p* = .04 Pre- 6 month follow-up; d = 0.44, *p* = .002 VSI Pre (M) = 10.74 Post (M) = 5.33 Follow-up (M) = 3.45 Pre-post effect size (d) = 0.92, *p* <.001 Pre- 6 month follow-up; d =1.24, *p* <.001 IBS-BRQ Pre (M) = 29.87 Post (M) = 18.91 Follow-up (M) = 17.96 Pre-post effect size (d) = 1.18, *p* <.001 Pre- 6 month follow-up; d = 1.28, *p* <.001. CSI-24 (child) Pre (M) = 15.48 Post (M) = 11.78 Follow-up (M) = 9.17 Pre-post effect size (d) = 0.41 , *p* = .005 Pre- 6 month follow-up; d = 0.69, *p* <.001 CSI-24 – Gastro (child) Pre (M) = 7.74 Post (M) = 4.88 Follow-up (M) = 3.50 Pre-post effect size (d) = 0.82 , *p* < .001 Pre- 6 month follow-up; d = 1.22, *p* <.001 CSI-24 (parent) Pre (M) = 13.97 Post (M) = 8.46 Follow-up (M) = 6.95 Pre-post effect size (d) = 0.92, *p* <.001 Pre- 6 month follow-up; d = 1.17, *p* <.001 CSI-24 – Gastro (parent) Pre (M) = 8.55 Post (M) = 5.29 Follow-up (M) = 3.55 Pre-post effect size (d) = 1.02, *p* <.001. Pre- 6 month follow-up; d = 1.56, *p* <.001 ISI-C Pre (M) = 6.03 Post (M) = 5.19

			Follow-up (M) = 3.97 Pre-post effect size (d) = 0.18, *p* = .31 Pre- 6 month follow-up; d = 0.44, *p* = .01 PAS Pre (M) = 11.65 Post (M) = 10.28 Follow-up (M) = 6.48 Pre-post effect size (d) = 0.20, *p* = .31 Pre- 6 month follow-up; d = 0.77, *p* <.001 School absence (child report) Pre (M) = 1.45 Post (M) = 0.81 Follow-up (M) = 0.59 Pre-post effect size (d) = 0.62, *p* <.001 Pre- 6 month follow-up; d = 0.84, *p* <.001 School absence (parent report) Pre (M) = 1.58 Post (M) = 1.01 Follow-up (M) = 0.55 Pre-post effect size (d) = 0.55, *p* <.001 Pre- 6 month follow-up; d = 0.99, *p* <.001 Parental work absence (days home/month) Pre (M) = 0.65 Post (M) = 0.34 Follow-up (M) = 0.05 Pre-post effect size (d) = 0.55, *p* = .01 Pre- 6 month follow-up; d = 1.07, *p* <.001 ARCS – protective behaviour (parents) Pre (M) = 11.35 Post (M) = 5.16 Follow-up (M) = 4.41 Pre-post effect size (d) = 1.26, *p* <.001 Pre- 6 month follow-up; d = 1.41, *p* <.001 ARCS – monitoring behaviour (parents) Pre (M) = 10.10 Post (M) = 4.82 Follow-up (M) = 3.99 Pre-post effect size (d) = 1.65, *p* <.001 Pre- 6 month follow-up; d = 1.91, *p* <.001 PHQ-9 (parental mental health) Pre (M) = 4.29 Post (M) = 3.45 Follow-up (M) = 2.40

													Pre-post effect size (d) = 0.21, *p* = .16 Pre- 6 month follow-up; d = 0.46, *p* = .002 <u>GAD-7 (parental mental health)</u> Pre (M) = 3.26 Post (M) = 1.90 Follow-up (M) = 1.83 Pre-post effect size (d) = 0.50, *p* = .004 Pre- 6 month follow-up; d = 0.52, *p* = .003
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Sampaio et al. (2019)	Sweden	*N* = 101 Age range: 13 to 17 years	IBS	RCT [Secondary data analysis (Bonnert et al., 2016)]	Secondary analysis of a web-based therapist- supported intervention for reducing symptoms of IBS and improving quality of life. Treatment lasted 10-weeks (weekly modules for adolescents, 5 modules for parents), with a focus on exposure exercises. Participants were randomised to internet CBT ((n = 47) or waitlist (n = 54). The aim of this paper was to analyse cost-effectiveness of the intervention described. The main outcome for this study was 'quality adjusted life-year' (QALY), which is created by mapping PedsQL scores onto EQ-5D-3L (Khan et al., 2014) utilities using an algorithm to convert 'level of problems' into health state dimensions. QALYs were calculated over 10-weeks using the area under the curve methods. Scores were adjusted for baseline utility. A cost-utilities analysis was conducted using QALYs, and a cost-effectiveness analysis using point improvement in the PedsQL was analysed as a secondary outcome. Willingness to pay (WTP) 700000 SEK (US$80000) was used an anchor for cost-effectiveness. Costs were comprised using information about	Not specified in this paper. See Lalouni et al (2017).	Not specified	Not specified	N/A	N/A	<u>PedsQL</u> Adolescents in the CBT group showed an average improvement of 5.647 points compared with the waitlist. There was a significant time X group interaction (M = 5.647, SE = 1.972, *t* = 2.864, *p* = .005). *<u>PedsQL: cost-effectiveness</u>* Incremental cost-effectiveness ratio estimated at US$85 .29 per one point improvement on the PedsQL. At a WTP value of approximately US$50 and above for one point improvement on the PedsQL, CBT has a greater probability of being a cost-effective option, compared to waitlist. The probability of CBT being cost-effective was approaching 100% at a WTP value of US$175 for one point improvement on the PedsQL.	<u>Resource use and costs</u> Average cost per participant to deliver the intervention = US$178.36 (SD=US$46.70). Significant incremental mean difference (CBT vs. waitlist) in total mean societal costs = US$163.81 (95% CI 48.85 to 332.55, *p* = .002). Bootstrapped estimate was US$170.24 (95% CI 63.14 to 315.04). *Full breakdown of costs between groups available in Table 3 of original paper.* *<u>Frequency of resource use by adolescents and parents in the trial</u>* **CBT group (pre, post)** Healthcare visits (n), by: General practitioner; 20, 9 Nurse; 4, 4.5 Counsellor; 5.5, 2 Physiotherapist; 9, 8 Specialist (gastroenterology); 21, 1 Other medical practitioner; 6, 2 Complementary alternative medicine (CAM); 1, 2.5 Psychologist (community); 1, 0 Psychologist (CAMHS); 4, 3 Dietitian; 3, 2 Medication (units) (n): 1207, 391 Productivity losses at school (n): School absence (days); 163, 84 Reduced efficiency at school (days; 268, 166 Productivity losses at work (n): Absence from paid work (hrs); 0, 0 Reduced efficiency at work (hrs); 298.96, 106.28 Productivity losses from unpaid housework (parents) (n): Absence from unpaid housework (hrs); 6.43, 1.14 reduced efficiency unpaid housework (hrs); 57.54, 10.69 *<u>Frequency of resource use by adolescents and parents in the trial</u>* **Waitlist (pre, post)** Healthcare visits (n), by: General practitioner; 24, 7 General practitioner (telephone consult); - , 1 Nurse; 10, 4 Counsellor; 5, 2 Physiotherapist; 2, 4 Specialist (gastroenterology); 14, 6

						direct medical costs (intervention costs; including therapist salary and platform maintenance, healthcare resources and medication use *[services by unit, see Table 1 in original paper]*), and indirect costs accrued to adolescents and parents (productivity losses due to absenteeism, including school absenteeism, and reduced efficiency in performance for paid and unpaid work. Data were collected at baseline and at post-treatment using Trimbos and Institute of Medical Technology Assessment Cost Questionnaire for Psychiatry (TIC-P) (Bouwmans et al., 2013). Only one parent per child was included in the analysis (mother as default).							Other medical practitioner; 1, 0 Complementary alternative medicine (CAM); 0, 0 Psychologist (community); 1, 0 Psychologist (CAMHS); 4, 1 Dietitian; 7, 1 Medication (units) (n): 1265, 694.50 Productivity losses at school (n): School absence (days); 145, 102 Reduced efficiency at school (days); 208, 115 Productivity losses at work (n): Absence from paid work (hrs); 46.60, 24.00 Reduced efficiency at work (hrs); 291.76, 251.65 Productivity losses from unpaid housework (parents) (n): Absence from unpaid housework (hrs); 14.00, 14.29 reduced efficiency unpaid housework (hrs); 33.26, 12.46 Health outcomes *QALYs* Significant gain in QALYs (0.0032 QALYs) for adolescents in the CBT group (95% CI 0.0001 to 0.0063, *p* = .043) over the treatment period compared with waitlist. Bootstrapped estimate was 0.0031 QALYs (95% CI 0.0003 to 0.0061). Cost-effectiveness analysis *QALYs* The probability of CBT being cost-effective was approximated at 74% given the Swedish WTP threshold of approximately US$80 000 per additional QALY. Incremental cost-effectiveness ratio (ICER): 54916 *See Figures 1 & 2 in original paper for visualisations.* *Sensitivity analysis* *Includes participants with complete cost and QALY data, compared to base-case intention-to-treat analysis.* Higher QALY gains and lower costs of CBT in 'complete' cases analysis. Higher probability of cost-effectiveness: 81% (ICER: 42945) Probability of cost-effectiveness was also increased by taking a health perspective: 81% (ICER: 48384) Increasing intervention-related costs by 20% decreased likelihood of cost-effectiveness: 68% (ICER: 62703)
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Bonnert et al. (2019)	Sweden	*N* = 31[adolescent-parent dyads] [a] Age, M (SD) = 15.2 (1.3) Age range: 13 to 17 years	FAP and Functional Dyspepsia (FD)	Pre-post	This study was an open feasibility trial. 10 weekly online exposure-based CBT-based modules completed by 31 adolescents with FAP or FD, who were not currently receiving ongoing psychological or	See Lalouni et al (2017).	Not specified	Authors of this study adapted the intervention described in detail in Lalouni et al. (2017), based on clinical experience. Adaptions made include that examples and	N/A	Pain intensity (Faces Pain Rating Scale – Revised) (range: 0-10, 0 = no pain, 10 = worst pain) Pre, M (SE): 7.03 (0.40) Post, M (SE): 4.56 (0.55) 6-month FU, M (SE): 3.56 (0.57) Pre-post effect size (d) [95%CI] = 1.20*** [0.49, 2.01]	PedsQL (range: 0-100) Pre, M (SE): 68.65 (2.60) Post, M (SE): 80.81 (2.67) 6-month FU, M (SE): 83.58 (2.73) Pre-post effect size (d) [95%CI] = 0.84*** [0.55, 1.18] Post-FU effect size (d) [95%CI] = 0.19 [–0.07, 0.46]	CSI-24 (Gastro) (somatic symptoms, 0-4) – child report Pre, M (SE): 9.06 (0.72) Post, M (SE): 5.25 (0.76) 6-month FU, M (SE): 3.19 (0.79) Pre-post effect size (d) [95%CI] = 0.84*** [0.48, 1.25] Post-FU effect size (d) [95%CI] = 0.45* [0.16, 0.80]

Male, n = 11 (35%) Female, n = 20 (65%)	psychiatric treatment. Parents participated in 5 modules (1 every other week alongside adolescent program). All participants underwent online screening prior to enrolment. This was followed by an assessment interview by a clinical psychologist to assess psychosocial and psychiatric problems before starting the intervention. Outcome measures included acceptability of treatment (credibility rating scale (Borkovec & Nau, 1972)), Working Alliance Inventory (WAI) (Falkenström et al., 2015), client satisfaction questionnaire (CSQ-8), Faces Pain Rating Scale, quality of life (PedsQL and PedsQL-GI), CSI-24, GI-specific avoidant behaviour (IBS-BRQ), and VSI. Parent-rated outcomes were collected for the PedsQL, CSI-24, and parents rated their perceptions of child's symptoms and quality of life on the SCAS, and their own behaviour on the ARCS.	exposure exercises in this version were based on adolescents with FAP/ FD, and symptom 'labelling' was added. Psychoeducation was delivered by video instead of text. 2 optional modules with additional vignettes were added. Parents were both educated and instructed on reinforcement methods. Participants received weekly feedback from therapists (written). This included feedback on questions and homework reports and providing support and guidance. Suggestions on individual exercises were given if needed. Automated SMS reminders were sent once a week to prompt login, and customised SMS messages could be created if necessary.	Post-FU effect size (d) [95%CI] = 0.48 [–0.15, 1.23] Pre-FU effect size (d) [95%CI] = 1.69*** [0.78, 2.53] *Clinically significant change (≥ 30% improvement on pain intensity) in 17 (55%) of the participants at posttreatment and at 6- month follow-up after treatment completion.* **p < .05, ** p <.01, *** p < .001.*	Pre-FU effect size (d) [95%CI] = 1.03*** [0.61, 1.46] PedsQL – parent-proxy Pre, M (SE): 72.01 (11.25) Post, M (SE): 83.22 (10.58) 6-month FU, M (SE): 84.94 (11.65) Pre-post effect size (d) [95%CI] = 0.96*** [-0.79, 1.33] Post-FU effect size (d) [95%CI] = 0.18 [-0.11, 0.46] Pre-FU effect size (d) [95%CI] = 1.14**' [0.89, 1.60] PedsQL- GI - child *Pain-related symptoms* Pre, M (SE): 49.60 (3.13) Post, M (SE): 67.64 (3.27) 6-month FU, M (SE): 77.86 (3.43) Pre-post effect size (d) [95%CI] = 1.60*** [0.88, 2.59] Post-FU effect size (d) [95%CI] = 0.91** [0.13, 1.57] Pre-FU effect size (d) [95%CI] = 2.51*** [1.57, 3.59] *Nausea* Pre, M (SE): 85.28 (2.88) Post, M (SE): 85.87 (2.98) 6-month FU, M (SE) : 94.03 (3.08) Pre-post effect size (d) [95%CI] = = 0.04 [-0.04 0.42] Post-FU effect size (d) [95%CI] = 0.54** [0.21, 0.92] Pre-FU effect size (d) [95%CI] = 0.58** [0.32, 0.89] *Eating-induced symptoms* Pre, M (SE): 82.32 (3.58) Post, M (SE): 74.68 (3.48) 6-month FU, M (SE): 88.82 (3.68) Pre-post effect size (d) [95%CI] = -0.43* [-0.11, -0.85] Post-FU effect size (d) [95%CI] = 0.79*** [0.39, 1.28] Pre-FU effect size (d) [95%CI] = 0.36* [0.03, 0.72] **p < .05, ** p .01, *** p < .001.*	Pre-FU effect size (d) [95%CI] = 1.29*** [0.90, 1.73] CSI-24 (Gastro) (somatic symptoms, 0-4) – parent report Pre, M (SE): 7.48 (0.73) Post, M (SE): 3.83 (0.43) 6-month FU, M (SE): 3.82 (0.46) Pre-post effect size (d) [95%CI] = 0.87*** [0.58, 1.04] Post-FU effect size (d) [95%CI] = 0.00 [-0.29, 0.26] Pre-FU effect size (d) [95%CI] = 0.87*** [0.54, 1.04] VSI (11-items, answer range: 0-5) Pre, M (SE): 20.23 (1.48) Post, M (SE): 9.66 (1.55) 6-month FU, M (SE): 6.98 (1.59) Pre-post effect size (d) [95%CI] = 1.09*** [0.79, 1.43] Post-FU effect size (d) [95%CI] = 0.28 [0.02, 0.64] Pre-FU effect size (d) [95%CI] = 1.37*** [0.90, 1.80] IBS-BRQ: avoidance (answer range: 1-7) Pre, M (SE): 43.39 (1.87) Post, M (SE): 30.32 (1.96) 6-month FU, M (SE) : 27.16 (2.02) Pre-post effect size (d) [95%CI] = 1.08*** [0.63, 1.61] Post-FU effect size (d) [95%CI] = 0.26 [0.06, 0.58] Pre-FU effect size (d) [95%CI] = .34*** [0.87, 1.87] Adherence *≥ 70% for feasibility* Average 72% of total treatment completed (7.2 modules out of 10) Acceptability (Credibility Rating Scale) (6 items, range: 0-10, 0 = not at all, 10 = very) M, (SD) = 30.97 (10.04) WAI (36 items, scored 1-7; 1 = never, 7 = always) Overall, M (SD) = 32.6 (10.0) Trusted therapist to help, M (SD) = 5.7 (1.8) Feel valued by therapist, M (SD) = 5.6 (1.8) CSQ-8 (1-4; very bad – very good) Overall, M (SD) = 25.4 (4.7) Adolescents helped to deal more effectively with their problems, M (SD) = 3.4 (0.6) Adolescents only helped with a few or none of their needs, M (SD) = 2.7 (0.9)

													Satisfied overall with intervention, M (SD) = 3.3 (0.8) ARCS – monitoring Pre, M (SE): 9.82 (0.52) Post, M (SE): 6.17 (0.52) 6-month FU, M (SE): 6.36 (0.56) Pre-post effect size (d) [95%CI] = 1.11*** [0.71, 1.35] Post-FU effect size (d) [95%CI] = -0.06 [-0.37, 0.24] Pre-FU effect size (d) [95%CI] = 1.05*** [0.56, 1.33] ARCS - protective Pre, M (SE): 6.49 (0.57) Post, M (SE): 3.69 (0.57) 6-month FU, M (SE): 3.20 (0.61) Pre-post effect size (d) [95%CI] = 0.72*** [0.40, 1.12] Post-FU effect size (d) [95%CI] = 0.13 [-0.19, 0.42] Pre-FU effect size (d) [95%CI] = 0.84*** [0.30, 1.33] SCAS: anxiety Pre, M (SE): 14.05 (1.79) Post, M (SE): 11.16 (1.45) 6-month FU, M (SE): 10.06 (1.50) Pre-post effect size (d) [95%CI] = 0.26* [0.11, 0.42] Post-FU effect size (d) [95%CI] = 0.10 [-0.08, 0.29] Pre-FU effect size (d) [95%CI] = = 0.36** [0.17,0.56] **p* < .05, ** *p* < .01, *** *p* < .001.*
Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	Lalouni et al. (2019)	Sweden	*N* = 90 Age, M (SD) = 10.2 (1.4) Age range: 8 to 12 years Male, n: 28 (31%) Female, n: 62 (69%)	FAP	RCT	Trial assessing the efficacy and cost-effectiveness of CBT doe FAP, delivered online. Group randomisation was to either therapist-guided internet-CBT (n = 46) (10-weeks) or treatment as usual (n = 44). Treatment protocol was adapted from Bonnert et al. (2016). Detailed description of the intervention is available in Lalouni et al. (2017). Adaptions included appropriation for all FAPDs and age. Assessments were collected at baseline, posttest and at 36-week follow-up. The primary outcome for this study was quality of life assessed using the PedsQL – GI. Secondary outcomes included quality of life (core scales), GI-anxiety	See Lalouni et al (2017).	Not specified.	Ongoing therapist support (licensed psychologists) via the program. Messages were sent as reminders or to answer questions. If the participants' answers indicated that they had misunderstood some crucial aspect of the treatment or if they did not log-in on a regular basis, therapists provided additional support via telephone (to parents) The therapists opened new modules on Fridays for those who had completed the previous module. The children and parents were instructed to log-in to the new modules over the weekend. Automatic SMS were sent to parents	N/A	*Pain faces scale (FACES) and pain-free days were collected; no data reported.*	PedsQL- GI - child *CBT group* Pre, M (SE): 60.62 (2.16) Post, M (SE): 75.99 (2.20) 36-week FU, M (SE): 77.87 (2.13) Pre-post effect size (d) [95%CI] = 1.11 [0.82–1.42] Post-FU effect size (d) [95%CI] = 0.17 [-0.17 to 0.56] Pre-FU effect size (d) [95%CI] = 1.38 [1.00–1.77] *Control group* Pre, M (SE): 54.86 (2.18) Post, M (SE): 63.80 (2.21) Pre-post effect size (d) [95%CI] = 0.64 [0.35–0.96] Between-groups effect size pre-post: (d) [95%CI] =0.46 [0.05–0.88] Mean difference = 6.43, *p* = .022 Mean difference post-FU = 2.10, *p* =.28 PedsQL- GI - parent *CBT group* Pre, M (SE): 59.90 (2.06) Post, M (SE): 75.11 (2.09)	Adherance At 36-week follow-up, 87% of children and parents in the treatment group had completed the assessments. IBS-BRQ: avoidance (child) (range: 1-7) *CBT group* Pre, M (SE): 32.44 (1.72) Post, M (SE): 16.73 (1.75) 36-week FU, M (SE): 17.99 (1.54) Pre-post effect size (d) [95%CI] = 1.23 [0.95–1.51] Post-FU effect size (d) [95%CI] = -0.10 [-0.25 to 0.08] Pre-FU effect size (d) [95%CI] = 1.09 [0.82–1.38] *Control group* Pre, M (SE): 30.48 (1.74) Post, M (SE): 25.05 (1.76) Pre-post effect size (d) [95%CI] = 0.43 [0.25–0.60] Between-groups effect size pre-post: (d) [95%CI] = 0.81 [0.48–1.14] Mean difference = -10.28, *p* < .001 Mean difference post-FU = 1.26, *p* =.452

	(VSI), avoidance (IBS-BRQ), and parental responses to child symptoms (ARCS). An assessment overview is included, however not all outcomes are reported on for efficacy. The cost analysis is conducted in US dollars, based on 2016 pricing. GLMs were used to calculate cumulative costs between-groups over the treatment period. Linear mixed-models were used to calculate mean differences in QALYs Incremental cost effectiveness ratio (ICER) was calculated using the difference in costs divided by the difference in QALYs		to as reminders. The children and parents were instructed to log-in to the new modules during the weekend.	36-week FU, M (SE): 79.85 (1.81) Pre-post effect size (d) [95%CI] = 1.21 [0.94–1.49] Post-FU effect size (d) [95%CI] = 0.41 [0.00–0.84] Pre-FU effect size (d) [95%CI] = 1.97 [1.50–2.46] *Control group* Pre, M (SE): 55.74 (2.11) Post, M (SE): 62.86 (2.12) Pre-post effect size (d) [95%CI] = 0.56 [0.30–0.85] Between-groups effect size pre-post: (d) [95%CI] =0.64 [0.26–1.03] Mean difference = 8.09, *p* < .001 Mean difference post-FU = 4.20, *p* =.019 *Clinical signifiance* *26 of 45 (58%) of children in the CBT group reported ≥30% improvement of their gastrointestinal symptom severity at the 10-week follow-up evaluation, verses 14 of 44 (32%) of children in the treatment-as-usual group.* RR = 1.8 (*p* = .019) NNT= 3.8, favouring CBT PedsQL (range: 0-100) *CBT group* Pre, M (SE): 76.73 (1.91) Post, M (SE): 86.39 (1.96) 36-week FU, M (SE): 87.76 (1.82) Pre-post effect size (d) [95%CI] = 0.73 [0.46–1.01] Post-FU effect size (d) [95%CI] = 0.11 [-0.10 to 0.31] Pre-FU effect size (d) [95%CI] = 0.82 [0.58–1.03] *Control group* Pre, M (SE): 73.87 (1.94) Post, M (SE): 77.04 (1.96) Pre-post effect size (d) [95%CI] = 0.24 [-0.06 to 0.46] Between-groups effect size pre-post: (d) [95%CI] = 0.49 [0.13–0.89] Mean difference = 6.49, *p* =.008 Mean difference post-FU = 1.49, *p* =.34 PedsQL – parent-proxy *CBT group* Pre, M (SE): 74.51 (2.03) Post, M (SE): 84.48 (2.05) 36-week FU, M (SE): 89.02 (1.89) Pre-post effect size (d) [95%CI] = 0.73 [0.51–0.97]	VSI-C (7-items, range: 0-35) *CBT group* Pre, M (SE): 13.93 (1.05) Post, M (SE): 4.97 (1.08) 36-week FU, M (SE): 4.55 (0.96) Pre-post effect size (d) [95%CI] = 1.14 [0.85–1.45] Post-FU effect size (d) [95%CI] = 0.05 [-0.15 to 0.27] Pre-FU effect size (d) [95%CI] = 1.16 [0.88–1.45] *Control group* Pre, M (SE): 14.55 (1.06) Post, M (SE): 9.88 (1.08) Pre-post effect size (d) [95%CI] = 0.59 [0.34–0.87] Between-groups effect size pre-post: (d) [95%CI] = 0.55 [0.15–0.92] Mean difference = -4.29, *p* =.008 Mean difference post-FU = 0.41, *p* =.711 ARCS – protective *CBT group* Pre, M (SE): 10.11 (0.93) Post, M (SE): 2.52 (0.94) 36-week FU, M (SE): 1.77 (0.78) Pre-post effect size (d) [95%CI] = 1.10 [0.87–1.33] Post-FU effect size (d) [95%CI] = 0.09 [-0.02 to 0.24] Pre-FU effect size (d) [95%CI] = 1.11 [0.80–1.42] *Control group* Pre, M (SE): 11.55 (0.95) Post, M (SE): 7.11 (0.95) Pre-post effect size (d) [95%CI] = 0.64 [0.40–0.92] Between-groups effect size pre-post: (d) [95%CI] = 0.46 [0.12–0.79] Mean difference = -3.16, *p* = .015 Mean difference post-FU = -0.66, *p* =.474 ARCS – monitoring *CBT group* Pre, M (SE): 10.83 (0.50) Post, M (SE): 3.56 (0.51) 36-week FU, M (SE): 3.85 (0.53) Pre-post effect size (d) [95%CI] = 2.13 [1.64–2.70] Post-FU effect size (d) [95%CI] = -0.07 [-0.27 to 0.14] Pre-FU effect size (d) [95%CI] = 1.80 [1.35–2.33] Mean difference post-FU = 0.27, *p* =.608 *Control group* Pre, M (SE): 12.23 (0.51) Post, M (SE): 8.58 (0.51) Pre-post effect size (d) [95%CI] = 1.07 [0.71–1.43]

												Post-FU effect size (d) [95%CI] = 0.32 [0.07–0.57] Pre-FU effect size (d) [95%CI] = 1.02 [0.76–1.32] *Control group* Pre, M (SE): 73.36 (2.07) Post, M (SE): 74.60 (2.08) Pre-post effect size (d) [95%CI] = 0.09 [-0.12 to 0.32] Between-groups effect size pre-post: (d) [95%CI] = 0.64 [0.33–0.94] Mean difference = 8.73, p <.001 Mean difference post-FU = 4.59, p =.009	Between-groups effect size pre-post: (d) [95%CI] = 1.06 [0.55–1.59] Mean difference = -3.62, p < .001 Cost effectiveness *Resource use* Significant incremental cost differences (mean differences) between-groups for: • Therapist time, M = 117.40 (99.39–135.42), p <.001 • Internet-CBT total cost, M = 183.60 (168.37–204.40), p <.001 • Health care resources, M = -118.08 (-155.24 to -37.67), p = .011 • Total healthcare consumption, M =-136.94 (-182.90 to -52.90), p = .006 *See Supplementary Table 3 in original paper for breakdown of all between-groups costs.* Receiving internet-CBT resulted in 0.0181 QALYs gained compared with decreased QALYs in the treatment-as-usual group (-0.0006 QALYs). Mean incremental health gain of 0.0187 QALYs (95% CI, 0.0102–0.0271; p ≤ .001) *See Figures 1 and 2 in original paper for visualisations.* The probability that the intervention was cost saving was 92%.
Customized CBT for adolescents with pain and emotional distress (no specific name)	Flink et al. (2016)	Sweden	N = 6 Age range: 17 to 21 years Age (M) = 18.33 Male: n = 1 Female: n = 5	Reccurrent pain and emotional distress	Pre-post	Single-case experimental with two baselines. Participants began filling in daily reports, which continued throughout the intervention and were randomized to begin the intervention on either day 11 or day 14. Daily reports contained 5 items; levels of pain, perceived stress, depressive symptoms, sleep difficulties, and worry and/or rumination. The internet-based CBT intervention consisted of 5 to 9 modules of CBT. Four optional modules were recommended based on daily symptom ratings at week 5. Adolescents were asked to log on at least once a week and complete weekly assignments; if not completed, psychologists sent	• CBT • Mention of transdiagnostic process	Not specified	Not specified	N/A	*Daily symptom ratings are given in graphs in Figure 3 of this paper and therefore could not be extracted (pain, stress, depressive symptoms, sleep difficulties and worry).* PCS-C Px.1 Pre: 31 Px 1 Post: 26 Px 1 Follow-up: 25 Px.2 Pre: 28 Px 2 Post: 28 Px 2 Follow-up: 13 Px.3 Pre: 5 Px 3 Post: 11 Px 3 Follow-up: 25 Px.4 Pre: 32 Px 4 Post: 28 Px 4 Follow-up: 30 Px.5 Pre: 21 Px 5 Post: 22 Px 5 Follow-up: 17 Px.6 Pre: 19 Px 6 Post: 7 Px 6 Follow-up: not given	FDI Px.1 Pre: 38 Px 1 Post: 38 Px 1 Follow-up: 41 Px.2 Pre: 10 Px 2 Post: 0 Px 2 Follow-up: 0 Px.3 Pre: 3 Px 3 Post: 2 Px 3 Follow-up: 0 Px.4 Pre: 20 Px 4 Post: 5 Px 4 Follow-up: 14 Px.5 Pre: 35 Px 5 Post: 30 Px 5 Follow-up: 23 Px.6 Pre: 30 Px 6 Post: 3 Px 6 Follow-up: not given	*Daily symptom ratings are given in graphs in Figure 3 of this paper and therefore could not be extracted (pain, stress, depressive symptoms, sleep difficulties and worry).* HADS - Anxiety Px.1 Pre: 10 Px 1 Post: 6 Px 1 Follow-up: 14 Px.2 Pre: 9 Px 2 Post: 10 Px 2 Follow-up: 7 Px.3 Pre: 8 Px 3 Post: 4 Px 3 Follow-up: 8 Px.4 Pre: 19 Px 4 Post: 18 Px 4 Follow-up: 21 Px.5 Pre: 8 Px 5 Post: 7 Px 5 Follow-up: 7 Px.6 Pre: 14 Px 6 Post: 4 Px 6 Follow-up: not given HADS - Depression Px.1 Pre: 6 Px 1 Post: 4 Px 1 Follow-up: 9 Px.2 Pre: 2 Px 2 Post: 2 Px 2 Follow-up: 2

						reminders via SMS or email. Participants also could contact psychologists by SMS or email as necessary (face-to-face sessions offered in some cases). Participants were paid €10 for completing each weekly questionnaire (returned by post). Assessments were also completed at pretest, posttest and 6-month follow-up. These were the Pain catastrophizing scale (children) (PCS-C) (Crombez et al., 2003), functional disability inventory (FDI), Hospital Anxiety and Depression Scale (HADS) (Lisspers et al., 1997; Zigmond & Snaith, 1983), Perseverative thinking questionnaire (PTQ) (Ehring et al., 2011) and the Insomnia Severity Index (ISI) (Yang et al., 2009).							Px.3 Pre: 7 Px 3 Post: 2 Px 3 Follow-up: 6 Px.4 Pre: 9 Px 4 Post: 8 Px 4 Follow-up: 11 Px.5 Pre: 7 Px 5 Post: 3 Px 5 Follow-up: 7 Px.6 Pre: 11 Px 6 Post: 0 Px 6 Follow-up: not given PTQ Px.1 Pre: 52 Px 1 Post: 49 Px 1 Follow-up: 45 Px.2 Pre: 32 Px 2 Post: 29 Px 2 Follow-up: 19 Px.3 Pre: 26 Px 3 Post: 25 Px 3 Follow-up: 27 Px.4 Pre: 40 Px 4 Post: 46 Px 4 Follow-up: 55 Px.5 Pre: 33 Px 5 Post: 31 Px 5 Follow-up: 34 Px.6 Pre: 34 Px 6 Post: 15 Px 6 Follow-up: not given ISI Px.1 Pre: 20 Px 1 Post: 11 Px 1 Follow-up: 12 Px.2 Pre: 5 Px 2 Post: 8 Px 2 Follow-up: 7 Px.3 Pre: 7 Px 3 Post: 4 Px 3 Follow-up: 7 Px.4 Pre: 13 Px 4 Post: 12 Px 4 Follow-up: 10 Px.5 Pre: 20 Px 5 Post: 18 Px 5 Follow-up: 21 Px.6 Pre: 11 Px 6 Post: 2 Px 6 Follow-up: not given
DARWeb	Nieto et al. (2015)	Spain	*N* = 15 Age range: 9 to 14 years Median = 11 years Male: *n* = 6 (40%) Female: *n* = 9 (60%)	Reccurrent abdominal pain	Mixed-methods (evaluation)	Parents and children completed a psychosocial online intervention (7 units), separately, over 7-weeks. Units were schedules weekly and participants could not access the next unit until the previous unit had been completed. Parents had the option to participate in the parent program as a couple or one parent could	- Psychosocial	Not specified	Not specified	Interview data was analysed using Atlas.ti 6.2, and an inductive content analysis was performed (please see main article for participant quotes). 40 codes were generated, and grouped into 5 categories: 1. Satisfaction with DARWeb. **Positives**; generally satisfied with DARWeb, recommend DARWeb,	*Pain-related information was collected at pre-test only.*	*Functional information (PedsQL) was collected at pre-test only.*	Satisfaction with DARWeb (range 0-10) Results based on the 9 families that completed the full program. Parent ratings on all aspects of all modules were 8 or higher (usefulness, interest, design, learning, satisfaction). Child ratings on all aspects of most modules were 8 or higher, with the exception of unit 1 which was rated a median of 6 for usefulness, 5 for interest, and 7 for design.

						complete the program individually. All participants were asked to complete a pre-treatment online survey which asked about demographic and pain-related information. A similar survey was completed at posttest, which included questions about overall perceptions of the program. Posttreatment interviews were also conducted in family groups; the interviews lasted approximately 30 minutes. Satisfaction and time measures were also taken electronically throughout the intervention.				DARWeb is useful, comic's vignettes and pictures, comic's stories, videos, would participate again, relaxation techniques, reiterating main ideas, feeling reflected, reassurance of positive behaviours, SMART goals. **Negatives**; difficult to understand, comic's vignettes and pictures, too much reading, not feeling reflected, not users' first language, boring and repetitive, DARWeb is not useful, SMART goals. 2. Ideas for improving DARWeb Adding exercises or games, adding forums, adding videos, adding face-to-face sessions, reducing units' lengths, reducing text for children. 3. Burden **Positives;** time established correctly **Negatives;** time supervision, lack of time 4. Pain perception and skills **Positives;** relaxation techniques, giving less importance to pain, coping strategies, distraction techniques, pain reduction, communication techniques. **Negatives;** no pain reduction. 5. General perceptions about online interventions **Positives;** advantages of technology, flexibility and comfort, online method satisfaction, **Negatives;** technology problems.			There were significant differences between parent and children's ratings on the following: - Usefulness of unit 1 (Mann-Whitney *U*: 18.50; *p* = .04) - interest of unit 1 (Mann-Whitney *U*: 17.5; *p* = .04) - Design of unit 2 (Mann-Whitney *U*: 18.5; *p* = .05). There were no significant differences found in global ratings of the program overall.
DARWeb	Nieto et al. (2019)	Spain	*N* = 37 families Age range (target) = 9 to 15 years M age (children who completed the program = 11.23 years Age range (actual) = 9-14 years Male = 36.3%	Recurrent abdominal pain/ FAP	Mixed-methods (evaluation): pre-post and interviews	Evaluation of the effects of DARWeb on a variety of outcomes. The intervention included parallel content for parents and children and includes 7-units, each broken down into 5 sections. Each takes 30mins to complete, and they must be completed in order. Families were recruited via collaborating healthcare professionals in	- CBT	Not specified	Not specified	*Authors state that the intention is to integrate qualitative findings from this paper with feasibility study findings (Nieto et al., 2015)* Inductive content analysis % = percentage of families cited *Positive aspects* Relaxation techniques (94%) Giving less importance to pain (76%) Coping Strategies (71%) Distraction techniques (65%)	API – global rating of pain severity (0 to 4) *Children, M (SD)* Pre: 1.5 (0.9) Post: 0.9(0.9) 3-month FU: 1.1 (1.1) Children's improvement on the API was statistically significant from pre-post *t*(13) =2.33, *p* =.03. Effect size (d) = .57 No significant differences in children's scores pre-FU; *t*(13) = 1.7, *p* = .12, or post-FU; *t*(13) = .53, *p* =.62 *Parents, M (SD)* Pre: 1.9 (1.1) Post: 1.2 (0.8)	PedsQL (short) (0-100) – total scores only *Children, M (SD)* Pre: 75.7 (12.9) Post: 79.9 (14.3) 3-month FU: 79.6 (19.7) No significant differences in child self-reports pre-post; *t*(16) = -.97, *p* = 0.35, post-FU; *t*(13) = .16, *p* = 0.87, or pre-FU; *t*(13) = 1.30, *p* = .21. *Parents, M (SD)* Pre: 70.5 (16.7) Post: 77.8 (12.7) 3-month FU: 79.2 (13.8) No significant differences in parent-proxy scores pre-post;	Treatment satisfaction (post-treatment only), 11-point NRS *Children, M (SD)* General satisfaction: 8.53 (2,3) Helping to cope with pain: 8.47 (2.4) Improving the overall situation: 8.41 (2.6) *Parents, M (SD)* General satisfaction: 9.24 (0.7) Helping to cope with pain: 9.06 (1.7) Improving the overall situation: 8.24 (2.4)

			Female = 64.7%			Spain and using websites. When families were referred the study was explained initially by telephone, and if interest expressed, details were given in person or by video call. Participants were given a pre-treatment, online, survey to collect demographic information and information related to study outcomes. The same survey was given 2-weeks after completing the intervention (post-treatment), and at 3-months follow-up. Children and parents were asked to complete surveys separately. Measures included the PedsQL (short; 12-item) (Huguet & Miró, 2007), pain severity, frequency and intensity (Abdominal Pain Index - API) (Walker et al., 1991), and treatment satisfaction (11-point numerical rating scale (NRS), post-treatment only). After post-treatment surveys were completed, families (parents and children together were also interviewed (semi-structured). Interviews covered 2 main topics: (1) impressions about the program and online interventions and (2) perceived effects of DARWeb on their pain situation learned skills. Out of 37 families, 15 did not complete the program, 17 completed the post-test measures and 14 completed the follow-up measures				Pain reduction (53%) Communication techniques (30%) *Negative aspects* No pain reduction (6%) Participant quotes available in original paper.	3-month FU: 1.1 (1.2) There were significant differences in parent scores of their child's abdominal pain from pre-post $t(16) = 2.56$; $p = .02$; effect size (d) = .63 There were also significant differences in parent scores on the API from pre-FU $t(13) = 2.6$; $p = .023$; effect size (d) = .68. There were no significant differences post-FU $t(13) = .77$; $p = .45$.	$t(16) = 1.86$, $p = .08$, or post-FU; $t(13) = .96$, $p = .35$ Significant difference in parent-proxy scores pre-FU, t $t(13) = 2.8$, $p = .015$. Effect size (d) = .76	
Rheumates@Work	Lelieveld et al. (2010)	The Netherlands	$N = 33$ Intervention group: Age (M) = 10.6 years (SD 1.5) Control group: Age (M) = 10.8	Juvenile Idiopathic Arthritis (JIA)	RCT	All participants were randomized into either the intervention group ($n = 17$) or wait-list control ($n = 16$). The intervention version used in this study focused on improving physical activity (PA), using a	• Elements of behaviour change theory are mentioned in introduction (modelling, social support, self-efficacy) • Health education • SMART – creating specific, measurable,	Not specified	Paediatric rheumatologist monitored disease progression and could update the personal page in the program with joint status etc.	N/A	N/A	N/A	Physical activity (M, SD) *AEE (megajoules/ day)* Control T0: 2.07, 0.59 Control T1: 2.95, 0.86 Within-group difference (t) = 0.88** Intervention T0: 2.38, 0.85 Intervention T1: 3.62, 1.27 Within group difference (t): = 1.24** *PA level*

			years (SD 1.4) Male: *n* = 4 Female: *n* = 29			17-week internet-based program, which was combined with 4 group-sessions (initial session also included parents). Elements included: 1) health education, 2) barriers to PA are identified, 3) self-efficacy and perceived effect of PA are identified and reinforced, 4) family and school influences, 5) PA options in daily life are explored and encouraged, and 6) SMART goal-setting. PA, fitness, and joint status were all measured at baseline and input into the program (individualised page). Patients received normal treatment for JIA throughout (rheumatologist intermittently) and were allowed to participate in normal sport and leisure activities. Additional CBT training focused on PA was not permitted. Reminders were sent by email if weekly assignments were not completed. Measures for this trial included a 7-day physical activity diary (pre & post); PA is shown as PA level, activity-related energy expenditure (AEE) (Bratteby et al., 1997), time spent on moderate to vigorous PA, and number of days with 1hour or more of moderate to vigorous PA. Other measures included aerobic capacity, adherence (measured by participation in weekly assignments), and disease activity (recorded by rheumatologist).	achievable, realistic and timed goals						Control T0: 1.57, 0.12 Control T1: 1.76, 0.17 Within-group difference (t) = 0.19** Intervention T0: 1.63, 0.16 Intervention T1: 1.89, 0.25 Within group difference (t): = 0.26** *Moderate to vigorous activity (hours per day)* Control T0: 1.19, 0.44 Control T1: 1.77, 0.79 Within-group difference (t) = 0.58* Intervention T0: 1.30, 0.68 Intervention T1: 2.30, 1.04 Within group difference (t): = 1.00** *No. of days with ≥1 hour moderate to vigorous activity* Control T0: 3.87, 1.51 Control T1: 4.87, 1.85 Within-group difference (t) = 1.00* Intervention T0: 3.87, 1.64 Intervention T1: 5.07, 1.22 Within group difference (t): = 1.20* Aerobic capacity (M, SD) *Resting HR (bpm)* Control T0: 89, 10 Control T1: 78, 10 Intervention T0: 90, 13 Intervention T1: 89, 10 *Max. HR (bpm)* Control T0: 200, 9 Control T1: 193, 12 Intervention T0: 201, 11 Intervention T1: 200, 8 *Max endurance (seconds)* Control T0: 608, 83 Control T1: 603, 83 Within-group difference (t) = -5 Intervention T0: 579, 74 Intervention T1: 605, 64 Within group difference (t): = 26* Adherence 14 out of 33 patients (82%) completed the full internet program 3 patients completed the majority of the program (18%) * *p* <.05 ** *p* < .01
Rheumates@Work	Armbrust et al. (2015)	The Netherlands	*N* = 64 Age (M) = 10.0 years (SD 1.4) Male: *n* = 23	JIA	RCT (acceptance results only)	All participants were divided into six groups and were randomized into either the intervention group or wait-list control. The analysis in this paper	• Health education and health promotion model • Social cognitive theory • CBT	Not specified	A physiotherapist, a paediatric rheumatologist, and a psychologist developed the program content.	Satisfaction (written suggestions) *Parents – positives* - The children experienced that they were not the only ones	Satisfaction (pain education) 84% of children that participated felt they had learnt something about pain. *See last column for additional education outcomes.*	N/A	Commitment Participants completed the weekly assignments by Monday: M = 53.0 (SD 6.5) Completed incompletely (participants per week): M = 8.3 (SD 7.6)

			Female: *n* = 41			takes into account data from all participants that received the intervention over two 2.5 years, without accounting for randomization This version of the program was 14-weeks long, with an overarching purpose to achieve health-promoting behaviour in JIA. There were an additional 4 group-sessions additional to the internet-based modules. Elements included: 1) Health education 2) Emotions and affect in JIA. 3) Barriers to and benefits of being physically active 4) Self-efficacy and perceived effect of physical activity, including fatigue and pain coping. 5) Peer support. 6) SMART goal-setting 7) Setbacks 8) 'Keep it up' (continuation and perseverance). The program was personalised based on each patient's physical activity level as measured by a 7-day activity diary and an accelerometer. Factors including gender, age, disease activity, joint damage (assessed by a rheumatologist), and functional disability were measured pre-test and used for personalisation. The main outcomes described are to evaluate acceptance of the program by monitoring commitment, technical program aspects, levels of interaction and satisfaction with the program and costs. E-mail reminders were sent by the program to prompt task completion as necessary.				with arthritis and that it helped to talk about it. - To talk about arthritis in a positive manner. - To have peer contact. - To receive education and information. - To be understood by other parents and coaches. - To share experiences, and to receive tips. *<u>Parents – areas for improvement</u>* - Classification by age (8 to 10 and 10 to 12). - More assignments for physical activities. - More involvement of the parents during the program - Make the assignments less childish for the older kids and easier for the young ones. - Create the possibility for the children to chat without the supervisors listening in. - Fewer group sessions. *<u>Children – positives</u>* - I liked it very much. - I made a new friend. - I liked Buddy very much. *<u>Children- areas for improvement</u>* - It was too childish. - Buddy was not original. - I would like more physical assignments.			Caught up and fulfilled assignments completely by Monday: M = 54.5 (SD 8.2) At the end of the program, 60 participants (93.8 %) had completely fulfilled all assignments for the 14-weeks program. <u>Technical Aspects</u> M = 1.7 (2.7 %) participants per week sent an email about technical aspects. <u>Level of interaction</u> Number of participants per week that sent an email: M = 6.9 (SD 4.6) *<u>Email topics M (SD)</u>* - Technical 1.7 (2.5) - Something not clearly understood 1.1 (1.1) - Friendly communication 2.6 (1.7) - Parents 0.5 (0.8) - Response to a reminder 1.1 (1.3) Only 26.6 % of the participants took part in the chat sessions. <u>Satisfaction</u> 81% of the participants and 99% of the parents liked the program. The level of the program and the assignments were perceived as adequate or too easy by 89 to 97% of the participants. 85% of the participants and 75 % of the parents indicated that they had learnt something, or quite a lot. 84% of participants felt they had learnt something about energy management. 87% felt they had learnt something about arthritis. Group sessions were appreciated by 97% of the parents and by 82 % of the children.
Move It Now - guided interactive internet CBT for adolescents with chronic pain	Voerman et al. (2015)	The Netherlands	*N* = 69 Age range: 12-17 years Age (M) = 14.9 years (SD 1.1)	Chronic pain (mixed)	Pre-post *Note: this study started as an RCT but the design*	Adolescents were initially randomised into a treatment group or wait-list control. Participants were asked to log-in once	• CBT – focus on coping	Not specified	Not Specified	N/A	<u>VAS – current pain (0-100)</u> T0: M = 44.22 T1: M = 44.56 T2: M = 33.86 T3: M = 39.79 *<u>Effect sizes</u>* T0-T1: .01	<u>PedMIDAS (disability) (range 0-50)</u> T0: M =26.43 T1: M = 26.36 T2: M = 18.74 T3: M = 24.05 *<u>Effect sizes</u>*	<u>Treatment satisfaction (*n* = 21)</u> *<u>Satisfaction (1 to 5)</u>* 57% satisfied *<u>Recommend (1 = yes, 2 = no)</u>* 76% of adolescents would recommend the program to other adolescents in pain.

	Male: 23% Female: *77%*	*required altering after high attrition (52%).*	a week to complete a module (7 modules). They were instructed to practice learnt skills every day using supplementary audio files. Participants were contacted by a therapist weekly by e-mail and every 2-weeks by telephone to provide support. E-mails and phone calls were standardized using a protocol. Parents also worked through 2 online modules and had contact with the therapist 3 times throughout. Measures were taken 7-weeks before the program, as well as pre & post-treatment and 3-month follow-up. This included pain location, pain intensity using a VAS (0-100) diary (averaged over 7 days: current pain, worst pain – severity & interference). An adapted version of the paediatric migraine disability assessment was used to measure disability (PedMIDAS) (Hershey et al., 2001). The study also used the Child Health Questionnaire (CHQ- CF87) (Landgraf et al., 1996) to measure quality of life, the Pain Coping Questionnaire (PCQ) (Reid et al., 1998), pain catastrophizing (PCS-C), a single item sleep question, and measured treatment satisfaction. Parental pain rewarding behaviour was also measured using the Illness Behaviour Encouragement Scale – Child (IBES-CF) (Walker & Zeman, 1992). Analysis used multilevel modelling in addition to mean values and effect sizes (see Table 3).		T1-T2: -.42 T2-T3: .23 VAS – worst pain – severity (0-100) T0: M = 58.88 T1: M = 57.36 T2: M = 46.69 T3: M = 46.98 *Effect sizes* T0-T1: -.06 T1-T2: -.43 T2-T3: .01 VAS – worst pain – interference (0-100) T0: M = 42.49 T1: M = 41.86 T2: M = 30.69 T3: M = 30.94 *Effect sizes* T0-T1: -.03 T1-T2: -.46 T2-T3: .01 PCQ (range 14-70) (coping)* *Approach* T0: M = 49.04 T1: M = 50.09 T2: M = 51.71 T3: M = 49.08 *Effect sizes* T0-T1: .09 T1-T2: .14 T2-T3: -.23 *Problem-focused avoidance* T0: M = 38.02 T1: M = 38.57 T2: M = 43.00 T3: M = 42.91 *Effect sizes* T0-T1: .06 T1-T2: .45 T2-T3: -.01 *Emotion-focused avoidance* T0: M = 21.10 T1: M = 21.46 T2: M = 20.14 T3: M = 19.30 *Effect sizes* T0-T1: .05 T1-T2: -.19 T2-T3: -.12 PCS-C (range 0-52) (catastrophizing) T0: M = 23.81 T1: M = 23.42 T2: M = 21.43 T3: M = 15.79 *Effect sizes* T0-T1: -.04 T1-T2: -.18 T2-T3: -.52 **Additional data for information seeking, problem solving, seeking social support, positive self-statements, behavioural distraction, cognitive distraction, externalizing and internalizing on the PCQ are available in Table 4 of this paper.*	T0-T1: .00 T1-T2: -.36 T2-T3: .25 CHQ- CF87 (range 0-100)* *Physical functioning* T0: M = 70.88 T1: M = 73.76 T2: M = 6.46 T3: M = 78.18 *Effect sizes* T0-T1: .14 T1-T2: .13 T2-T3: .08 *Role functioning - emotional* T0: M = 68.16 T1: M = 73.22 T2: M = 78.29 T3: M = 85.63 *Effect sizes* T0-T1: .17 T1-T2: .17 T2-T3: .25 *Role functioning behaviour* T0: M = 84.64 T1: M = 85.23 T2: M = 83.98 T3: M = 94.07 *Effect sizes* T0-T1: .03 T1-T2: -.05 T2-T3: .43 *Role functioning physical* T0: M = 63.42 T1: M = 61.76 T2: M = 72.56 T3: M = 67.56 *Effect sizes* T0-T1: -.05 T1-T2: .35 T2-T3: -.16 *Bodily pain* T0: M = 57.64 T1: M = 54.41 T2: M = 41.07 T3: M = 50.29 *Effect sizes* T0-T1: -.13 T1-T2: -.55 T2-T3: .38 Sleep problems (0 = no, 1 = yes) T0: M = .63 T1: M = .65 T2: M = .37 T3: M = .25 *Effect sizes* T0-T1: .04 T1-T2: -.60 T2-T3: -.24 **Additional data for mental health, self-esteem, health perceptions, changes in health, family activities, and family cohesion on the CHQ are available in Table 4 of this paper.*	*Goal attainment (VAS 0-100)* M = 50.1, SD = 30.0 Adolescents achieved on average half of their goals. *Improvement – dealing with problems (1 to 5)* 57% of adolescents reported improved ability to deal with problems. *Improvement – daily activities (1 to 5)* 38% improved in carrying out daily activities. IBES-CF (range 0-48) (parental rewarding pain behaviour) T0: M = 20.54 T1: M = 23.08 T2: M = 19.00 T3: M = 19.95 *Effect sizes* T0-T1: .57 T1-T2: -.91 T2-T3: .21

iCanCope with Pain™	Stinson et al. (2014)	Canada	*N* = 23 Age range: 14 to 18 years Male: *n* = 5 (21.7%) Female: *n* = 17 (73.9%)	Chronic pain (mixed)	Qualitative (exploratory & iterative)	Three focus-groups were conducted with adolescents (*n* = 16) & one focus group was conducted with HCPs (separately) (*n* = 7) A proposed architecture for iCanCope was developed based on the focus groups, as well as current theories for pain self-management. Interviews were conducted with a new sample of adolescents (*n* = 7); the proposed architecture was presented to adolescents to collect feedback on the acceptability/ perceived value of the features.	- Theory of behavioural activation - SMART framework – creating specific, measurable, achievable, realistic and timed goals - CBT; self-management strategies such as muscle relaxation, guided imagery, mindfulness and belly breathing, as well as problem-solving and communication skills training - Social Learning Theory; encouraging sharing coping strategies as a form of peer support	User-centred needs assessment	Adolescent and HCP focus group data was analysed in combination. Four major themes were identified from the focus groups (initial needs assessment): (i) pain impact (sub-themes; physical impact, role functioning, social and emotional impact, future), (ii) barriers to care (sub-themes; healthcare system, patient specific barriers, societal barriers), (iii) pain management strategies (sub-themes; support system, pharmalogical strategies, physical strategies, psychological strategies), and (iv) transition from pediatric to adult care (sub-themes; disconnect between paediatric and adult health services, skills needed to transition, parental role, fear/anxiety). Based on the identified needs (as well as practice guidelines, and theory) a core intervention architecture for iCanCope was created. Individual interviews were then conducted with newly recruited adolescents to gain feedback on the core architecture. The majority of adolescents (6 out of 7) endorsed the iCanCope with Pain™ architecture as acceptable for meeting their needs. One adolescent indicated that they were not interested in learning self-management. Feedback regarding the value of each individual feature of the intervention architecture is provided in Table 4, using participant quotes.		N/A	N/A	N/A
iCanCope with Pain™ (symptom-tracking only)	Lalloo et al. (2019)	Canada	*N* = 60 Age (M) = 16.4 years (SD 0.9) Male: *n* = 7 (12%) Female: *n* = 53 (88%)	Chronic pain (mixed)	RCT (parallel groups)	Participants were randomized allocation to one of two possible versions of the iCanCope app; version A (*n* = 27) and B (*n* = 33). Versions A and B both included a symptom reporting function; version B also included content on goal setting, pain coping, and social support. Participants were instructed to complete one symptom 'check-in' per day for a 55-day duration. Pain intensity was measured using a numerical rating scale (NRS, 0-10), and pain interference, as well as mood, physical activity, sleep quality and energy were measured using 1-5 pictorial scales.	Not specified	Not specified	N/A	N/A	Pain intensity (0-10 NRS) M = 5.5 (SD 2.4) Pain interference (1-5 pictorial Likert scale) M = 2.9 (SD 1.0)	*All functional outcomes measured using a 1-5 pictorial Likert scale.* Mood M = 2.6 (SD 1.0) Physical activity M = 2.8 (SD 1.1) Sleep quality M = 2.8 (SD 1.1) Energy M = 2.9 (1.0)	Feasibility Successful deployment of mobile app in 98% of devices. Adherence to symptom tracking Version A: check-ins (M) = 36.0 (SD 13.9) Low (adherence) (7%), low-moderate (19%), high-moderate (26%), high (48%) Version B: check-ins (M)= 33.8 (13.6) Low (adherence) (6%), low-moderate (28%), high-moderate (28%), high (38%) Participant interaction with symptom history data 83% of participants accessed their previous symptom data at least once throughout the study period.
Interactive website for dysmenorrhea (No specific name)	Yeh et al. (2013)	Taiwan	*N* = 107 (female only) Internet intervention group: Age (M) = 16.94 years (SD: 1.02)	Dysmenorrhea	Non-randomised controlled trial (NRCT)	Participants were divided into two groups, receiving either auricular acupressure only or auricular acupressure plus the internet intervention. Six acupoints were used: shenmen, kidney, liver, internal	Not specified	Not specified	All website content was assessed for validity (between objectives and content) by two experts in obstetrics and gynaecology.	N/A	There were no significant differences between the internet intervention group and the acupressure only group pre-to posttest on pain and physiological measures. Within-group pre- to posttest improvements in pain and physiological symptoms were significant.	N/A	The combination of the auricular acupressure treatment with the website elicited greater improvements in self-care in adolescent girls compared to using acupressure alone. Adolescent dysmenorrheic self-care scale (ADSCS) Internet intervention:

			Acupressure only group: Age (M) = 17.94 years (SD: 0.84)			genitals, central rim, and endocrine. Adhesive plasters containing seeds were placed on each acupoint at the start of menstrual bleeding and removed after pain relief 48 hours later. All participants were told to press each acupoint for at least one minute, four times per day until experiencing pain relief. The website contained nursing care and instruction specific to dysmenorrhea and was separated into nine units. It is unclear whether these units were completed in a specific time-frame or if they should be completed a specific order. The study flow diagram indicates the intervention was only completed for a duration of one menstrual cycle. Pre and posttest measures included the Adolescent dysmenorrheic self-care scale (ADSCS) (Ching-Hsing et al., 2004), menstrual distress questionnaire (MDQ) (Wang, 1991), pain intensity (VAS 0-10), and the McGill Pain Questionnaire (SF-MPQ, 11 items scored 0-3) (Melzack, 1987).			The overall content validity index was 0.95. Auricular acupressure: Two experts licensed in traditional Chinese medicine confirmed the accuracy and precision of the techniques.		McGill pain questionnaire (range : 0-33) Internet intervention: Improvement, M = 11.98 (SD = 8.46) Acupressure only: Improvement, M = 13.44 (SD = 8.62) Between group difference F = 0.06, p < .81 VAS (range: 0-10) Internet intervention: Improvement, M = 4.59 (SD = 1.93) Acupressure only: Improvement , M = 5.14 (SD = 2.32) Between group difference F = 0.11, p < .75		Improvement in self-care, M = 50.54 (SD = 30.16) Acupressure only: Improvement in self-care, M = 5.76 (SD = 18.80) Between group difference F = 46.92, p < .001 MDQ Internet intervention: Improvement, M = 7.42 (SD = 9.28) Acupressure only: Improvement , M = 10.72 (SD = 6.85) Between group difference F = 1.18, p < .28
Prototype website for web-based skills training for adolescents with migraine (no specific name)	Donovan et al. (2013)	USA	Group 1 Age range: 12 to 17 years M = 14 years (no SD) n = 12 Female: n = 6 Group 2 Age range: 12 to 17 years M = 15 years (no SD) n = 7 Female: n = 7	Chronic migraines	Mixed-methods (iterative)	Adolescents in Group 1, and their caregivers, were asked about barriers to self-management of adolescent migraines, using a semi-structured interview. Concept mapping was utilised to generate content topics for the planned program, along with theoretical frameworks. Adolescents and caregivers were interviewed separately (60 minutes), and clinician interviews were conducted by telephone. All participants were	References to: • CBT • Current evidence base for migraine interventions (including Trautmann & Kröner-Herwig, 2010)	Concept Mapping	12 specialist clinicians (adolescent migraines) were recruited and participated in the interviews and concept mapping. Interviews were coded using grounded theory. The most common themes were: 1. Difficulty making lifestyle changes within busy adolescent schedules, 2. Difficulties associated balancing parental involvement. In the concept mapping, clinicians rated self-management skills	Interviews Adolescents reported barriers to pain self-management, including: • Perceiving lifestyle changes as interfering with favourite activities • Difficulty communicating about migraines. Caregivers reported barriers including: • Difficulties associated with practicing self-management within the demands of the school schedule • Difficulty communicating about migraines. Concept Mapping	N/A	N/A	Acceptance testing *Adolescents* Adolescents were likely to use a range of features when: i) they felt a migraine coming on; M = 2.50, SD = 1.38 ii) they had a migraine; M = 2.50, SD = 1.62 Adolescents stated they were less likely to use the features on a pain free day; M = 3.00, SD = 1.04 Adolescents were very likely to use the 'ask an expert' feature; M = 2.17, SD = 1.19 Adolescents were open to video-based information; M = 1.33, SD = 0.49 The most popular reasons stated for returning to the program were to 'ask an expert' (91.7%), and to track headaches and learn about triggers (91.7%).

						asked to generate 10 content ideas at the end of the interview, and later asked to group them and rate their importance using an online program. Adolescents in Group 2, and their parents, completed a 30-minute acceptance testing of the prototype website by telephone. Each participant downloaded the program for free and shared their screen with the interviewer during this test stage. The acceptance test contained 18 items rated on a 1 to 5-point Likert scale (1= extremely, 5 = not at all).			training, parental self-care, and communication skill building as most important.	8 conceptual clusters were generated for both the adolescent and caregiver programs. Disagreement between adolescents and clinicians about the relative importance of the content areas, including diet and exercise, was apparent (adolescents rated as not important, whilst clinicians rated these areas as important). Managing migraines away from home (i.e. socially, at school) was rated as extremely important by both adolescents and clinicians. Disagreement between clinicians and caregivers was even greater, where caregivers perceived self-management skills training, parental self-care, and communication skill building as less important than diagnostic information and triggers.			<u>*Caregivers*</u> Caregivers reported they would be most likely to use the 'ask an expert' feature; M = 2.08, SD = 1.24 The main motivation reported for returning to the program was to help them learn more about parenting a child with migraines (58%). 50% stated that talking with other caregivers about their experiences would motivate them to return. <u>*Clinicians*</u> Clinicians were extremely interested in adopting the program for use in practice; M = 1.42, SD = 0.52 They also reported that it fit well with their treatment approach (1 to 4 point scale); M = 1.42, SD = 0.52, and that it would fit well into their practice; M = 1.17, SD = 0.39 83.3% of clinicians state they would prefer a nurse or school to deliver the program. Clinicians reported it would be extremely helpful for them to have access to symptom tracking data/ headache diary; M = 1.08, SD = 0.29
Teens taking charge: managing arthritis online	Stinson, Toomey, et al. (2008)	Canada	*N* = 36 English-speaking: Age (M) = 15.4 years (SD 1.7) French-speaking: Age (M) = 16 years (SD 1.2) Male: *n* = 12 (33.3%) Female: *n* = 24 (66.7%)	JIA	Qualitative (exploratory)	Individual interviews (*n* = 25) and focus-groups (*n* = 11) were conducted across four sites over 9-months. Individual interviews followed a semi-structured schedule, and focused on gaining insight into JIA self-management issues, as well as preferences for internet-based self-management (schedule available in Table 1 of this research paper). Focus groups were conducted to confirm insights. Some demographic information was collected immediately prior to the interviews, as well as information about computer-use. Information was also gathered from medical charts, and physicians' global assessment ratings were obtained. The interview sample was stratified for disease severity based on this rating. Whether adolescents	Not specified	Not specified in this paper (see Stinson et al. 2010a)	N/A	Adolescents explained how they developed effective JIA self-management strategies, and reported various levels of proficiency in JIA management. There were two key strategies (two key themes) used to develop self-management skills: <u>1. Acquiring knowledge and skill to manage the disease (5 subthemes)</u> • Listening to & challenging care providers; *importance of developing collaborative partnerships with HCPs.* • Acquiring skills to communicate with the doctor; *recognised need for learning skills to accurately communicate health status. Some adolescents preferred presence of a parent in consultations, whereas others preferred independence.* • Managing pain and discomfort; *leaning about more ways to manage pain*	N/A	N/A	N/A

	participated in individual interviews or a focus group was their decision. Individual interviews lasted between 20-40 minutes, and focus groups lasted 40 to 75 minutes. All interviews were audiotaped and transcribed verbatim (interviews in French were transcribed directly into English by a bilingual transcriptionist) with the addition of field notes. Qualitative analysis was done within the NUD*IST 6.0 program. Initially these were coded and organised into themes by one experienced researcher, and two team members reviewed the transcripts. Codes were identified and revised iteratively throughout data collection, where individual and focus group data were eventually triangulated together to create one set of themes (as the data was similar).		*when severe, side effects of medications. Adolescents referenced physiotherapy, exercise, and heat/ice to manage pain. Some experienced trouble with motivation to exercise.* • Managing emotions; *managing isolation and distress related to physical symptoms, as well as self-esteem related issues. Mention of distraction techniques and ‘self-talk’ (thought challenging)* • Acquiring knowledge and awareness about arthritis; *primarily learnt from doctors however some adolescents used educational resources – this learning was cited as a way of becoming more independent.* 2. Experiencing understanding through social support Including family, peer, teacher, and HCP support. Emphasis on understanding and compassion regarding obstacles faced in JIA management. Finding and communicating with other adolescents with JIA was important to alleviate feelings of isolation. Some of the adolescents mentioned peer pressure and temptation to give into risky behaviours, however they did not due to potential adverse reactions of substances with medication. Additional insight: views on web-based approach to learning and self-management. Adolescents believed having a web-based approach to learning about arthritis would be useful. This would provide easily accessible information on self-management from trustworthy sources. Emphasised enthusiasm towards a chat room or discussion board for social support.	

										Adolescents outlined 7 essential website components (specific examples listed in Table 3 of this paper): - Information about arthritis, - Treatments for JIA. - Procedures and Tests associated with JIA, - Managing symptoms, - Managing Emotions, - Lifestyle, - Social Support.			
Teens taking charge: managing arthritis online	Stinson et al. (2010a)	Canada	$N = 19$ Age (M) = 15.7 years (SD 1.5) French speaking: $n = 8$ (M age =16.0 (1.2)) English speaking: $n = 11$ (M age = 15.4 (1.7)) Male: $n = 5$ (26%) Female: $n = 14$ (74%)	JIA	Qualitative (iterative)	Semi-structured usability testing interviews were conducted with adolescents with JIA and one of their caregivers. Participants were asked demographic questions and about level of comfort with computers immediately prior to the interviews. Additional medical information was gathered from their chart, along with a rheumatologists' global assessment of disease severity (10cm VAS). Adolescents and parents participated separately and interviews lasted 30-45 minutes. A brief explanation of the program was given first, and then participants were asked to 'think-aloud' as they worked through a live version. Interviews were audio recorded and the research assistant also took observational field notes. This version had 12 modules, was available in both English and French. Content included JIA-specific education, self-management strategies (including dealing with pain and stress), and social support via monitored discussion boards and stories from There were two parent modules to promote encouragement of healthy teens behaviours.	• JIA education, self-management and social support are mentioned however no reference to specific theoretical base.	Sequential phased approach Study design based on 'hermeneutical circle' (Snodgrass & Coyne, 1992)	The program content was developed by a team of experts in JIA from across Canada. Content was written at a grade 6 to 7 reading level. Information was also developed to suit the needs identified in the initial exploratory study (Stinson et al., 2008).	User Satisfaction (5 themes) *Aesthetics (design)* Participants felt aesthetics were a critical factor in enhancing engagement. Four subthemes were identified: 1. Layout 2. Navigation 3. Visual assets 4. Visual appeal Adolescents advised the large amount of texts should be "chunked up" with additional visuals. Parents advised they wanted larger font (42%), whereas most adolescents did not see this a problem (only 15%). 16% of French-speaking participants suggested labelling medical diagrams. *Quote examples for aesthetics are available in Table 3 of this research paper.* *Content* Overall comments were positive. Four subthemes were identified: 1. Completeness 2. Understandability 3. Quality & credibility 4. Relevance Additional content was recommended by 21% of adolescents and 32% of parents. The most common suggestion was for photos or videos to show how to perform exercises (unable to implement due to budget and time constraints). Participants generally found the information, language level, and	N/A	N/A	Usability *Ease of use* All of the adolescents were able to navigate through with little to no guidance. 27% of parents required several minutes' orientation. *Learning* All participants were able to complete standardized tasks in 25 minutes or less (as predicted). *Errors* 10% of adolescents and 21% of parents experienced navigation errors. 26% of adolescents and 58% of parents experienced presentation errors (for example trouble understanding labels/ selecting desired section). These were only made on the medication module homepage, which was edited for the 2nd cycle of qualitative feedback. These presentation errors did not occur in the 2nd cycle. 42% of adolescents and 26% of parents experienced control usage errors (for example, improper field entry). Functional input fields were adjusted for the 2nd cycle of feedback. Control usage errors did not occur in the 2nd cycle.

						After completing the think-aloud procedure, additional questions on program satisfaction were asked using a semi-structured schedule. Initial interviews were conducted with English-speaking participants, iterative changes were made, and the revised interface was evaluated in the same way by French-speaking participants.				explanation of medical terminology (including a glossary) to be helpful in furthering their understanding. *Quote examples for content are available in Table 4 of this research paper.* *Functionality/ features* Refers to adaptive and interactive website features. Examples include quizzes, the symptom diary, and the 'ask an expert' feature. All participants felt that the adaptive features enabled personalisation to meet individual needs, and enhanced motivation to engage with the program. *Sociability* Adolescents commented that the peer support features within the program (i.e. discussion boards & example stories) helped with feelings of isolation/ hopelessness. 95% of adolescents indicated they would like to use the discussion board, however this was only endorsed by 42% of parents. *Future use* 84% of all participants advised they would like t use the program in the future. Additional comments that the program would have been helpful in the context of an initial diagnosis. Participants also liked the focus on self-management, improving quality of life, and the promotion of transitional care management (paediatric to adult health).			
Teens taking charge: managing arthritis online	Stinson et al. (2010b)	Canada	*N* = 46 Age range: 12 to 18 years Median age = 14.5 (SD 1.48) Male: *n* = 15 (32.6%) Female: *n* = 31 (67.4%)	JIA	RCT	Adolescents and their parents (1 parent/ caregiver per adolescent) were randomised into either an internet intervention with telephone support or a control group that received attention-control phone calls only. Both groups also continued to receive usual rheumatology care. Adolescents in the treatment group were asked to log on	• JIA education, self-management and social support are mentioned however no reference to specific theoretical base.	Not specified in this paper (see Stinson et al. 2010a)	Telephone coaches were non-HCPs with an undergraduate degree in psychology. HCP input is indicated in Stinson et al. (2010a).	N/A	Pain Intensity (RPI – weekly average – 47 items, 11-point scale) *Intervention group (M, SD)* Pre: 2.73 (1.93) Post: 2.17 (1.34) *Control group (M, SD)* Pre: 3.00 (2.00) Post: 3.47 (2.12) *F* = 5.04, *p* = .03 Effect size (d) = 0.78 *F-values given are baseline adjusted ANCOVAs.*	HRQL outcomes Gross motor function *Intervention group (M, SD)* Pre: 3.16 (1.94) Post: 2.32 (1.51) *Control group (M, SD)* Pre: 3.79 (2.08) Post: 3.02 (1.78) *F* = 0.12, *p* = .73 Effect size (d) = 0.21 Fine motor function *Intervention group (M, SD)* Pre: 1.91 (1.91) Post: 1.33 (1.48)	Stress - PSQ (30 item, 4-point scale) *Intervention group (M, SD)* Pre: 1.98 (0.39) Post: 1.98 (0.42) *Control group (M, SD)* Pre: 2.09 (0.36) Post: 2.13 (0.42) *F* = 0.20, *p* = .65 Effect size (d) = 0.20 Knowledge *Intervention group (M, SD)* Pre: 4.34 (2.17) Post: 6.98 (1.08)

	once a week to complete a module (approximately 20-30 minutes). This version of teens taking charge consisted of a 12-week internet-based self-management program; content included JIA-specific information (diagnosis, medications, and symptoms), self-management strategies (e.g. managing stress, relaxation, exercise, nutrition) and social support. Also included a module on transitional care looking ahead), and a journal to track progress based on goals. There were two separate modules for parents to help them encourage healthy teen behaviours. All content (teen and parents) was available in English or French. Telephone support consisted of coached contact once weekly using a standardized script; the purpose of this was to review progress, answer questions and provide guidance. Research assistants additional obtained demographic and disease-related data from medical charts Intervention aim was to reduce physical and emotional symptoms and improve health-related quality of life (HRQL). Measures were assessed pre and posttest, including the Juvenile Arthritis Quality of Life Questionnaire (JAQQ) (Duffy et al., 1997), the recalled pain inventory (RPI) (Stinson, Stevens, et al., 2008), and perceived stress (PSQ) (Kocalevent et al., 2007). Medical Issues, Exercise, Pain and Social Support (MEPS) (André et al., 1999), Children's arthritis self-efficacy (CASE)			*Control group (M, SD)* Pre: 2.30 (2.07) Post: 1.94 (1.64) *F* = 0.00, *p* = .97 Effect size (d) = 0.06 Psychosocial function *Intervention group (M, SD)* Pre: 1.82 (1.28) Post: 1.88 (1.81) *Control group (M, SD)* Pre: 2.14 (1.62) Post: 1.95 (1.32) *F* = 0.41, *p* = .53 Effect size (d) = 0.22 General symptoms *Intervention group (M, SD)* Pre: 2.53 (1.77) Post: 2.26 (1.45) *Control group (M, SD)* Pre: 2.72 (2.72) Post: 2.17 (2.17) *F* = 0.14, *p* = .71 Effect size (d) = 0.06 JAQQ *Intervention group (M, SD)* Pre: 2.35 (1.34) Post: 1.95 (1.40) *Control group (M, SD)* Pre: 2.74 (1.36) Post: 2.27 (1.21) *F* = 0.25, *p* = .62 Effect size (d) = 0.20 *F-values given are baseline adjusted ANCOVAs.*	*Control group (M, SD)* Pre: 3.70 (1.98) Post: 4.16 (1.96) *F* = 19.64, *p* = .001* Effect size (d) = 1.32 Adherence – medication *Intervention group (M, SD)* Pre: 7.28 (3.01) Post: 8.14 (8.14) *Control group (M, SD)* Pre: 7.30 (2.63) Post: 7.50 (2.96) *F* = 0.42, *p* = .52 Effect size (d) = 0.26 Adherence – exercise *Intervention group (M, SD)* Pre: 7.00 (2.78) Post: 5.05 (3.78) *Control group (M, SD)* Pre: 4.16 (2.99) Post: 4.68 (3.26) *F* = 3.31, *p* = .09 Effect size (d) = 1.11 Self-efficacy – symptoms *Intervention group (M, SD)* Pre: 6.14 (1.67) Post: 7.47 (1.89) *Control group (M, SD)* Pre: 5.39 (2.85) Post: 6.55 (2.75) *F* = 0.08, *p* = .78 Effect size (d) = 0.11 Self-efficacy- emotions *Intervention group (M, SD)* Pre: 7.42 (2.39) Post: 7.96 (2.38) *Control group (M, SD)* Pre: 7.43 (2.82) Post: 8.11 (2.22) *F* = 0.07, *p* = .79 Effect size (d) = 0.31 Self-efficacy – activities *Intervention group (M, SD)* Pre: 6.85 (2.28) Post: 7.88 (2.42) *Control group (M, SD)* Pre: 6.99 (2.81) Post: 7.60 (2.72) *F* = 0.63, *p* = .43 Effect size (d) = 0.16 *F-values given are baseline adjusted ANCOVAs.*

						(Barlow et al., 2001), and adherence (CARQ/ PARQ) (April et al., 2006) were measured as mediating variables.							
Teens taking charge: managing arthritis online	White et al. (2012)	Canada	$N = 14$ Age range: 12 to 18 years Age (M) = 14.6 years (SD 1.2) Male: $n = 4$ (28.6%) Female: $n = 10$ (71.4%) Intervention group from RCT (Stinson et al., 2010b)	JIA	Mixed-methods (evaluation)	Participants were from the intervention arm, described in Stinson et al. (2010b) (14 out of 22). Outcome measures in this study were taken to explore the therapeutic alliance between the telephone support coach and the participants that were completing the 12-week online intervention – Teens taking charge. All data was collected by telephone at the end of the RCT. This included the working alliance inventory scale (WAI-C) (Horvath & Greenberg, 1989), and the distance experience questionnaire (DEQ) (Lingley-Pottie & McGrath, 2007). Research assistants administering assessments had no prior association with participants.	Not specified in this research paper.	Not specified in this paper (see Stinson et al. 2010a)	HCP input to the intervention is indicated in Stinson et al. (2010a).	DEQ – qualitative outcomes – 'exploring the distance experience' Relationship The most common descriptors of the relationship with the coach were ''really great'' (36%) and ''understanding'' (21%). Example quote: *''It was a good relationship. We understood what we wanted to do and worked well together to accomplish that.''* Level of comfort Overall comments were positive about sharing things with the therapist. Key phrases used were ''good/nice'' (36%), ''easy'' (21%), ''comfortable'' (21%), and ''understanding''(14%). Example quote: *''Helpful, it was kind of nice being able to talk to someone about things going on who aren't your friends, parents or doctor.''* Advantages and disadvantages Key cited advantages of phone contact were convenience (43%) and anonymity (36%). Disinhibition was also mentioned as an advantage of distance treatment (14%). Example quote: *''You don't know the person and you never meet them face-to-face.so it is not embarrassing.''* Key disadvantages of distance treatment mentioned were inability to use visual cues (43%), unable to meet coach (21%), inclination to lie (14%). 86% of participants indicated that in hindsight they would choose distance treatment over face-to-face treatment.	Reported pain (RPI) and WAI-C global scores were negatively correlated, based on outcome data from the RCT ($r = 0.625$, $p = .03$).	N/A	WAI-C (7-point scales) *Global score* M = 230.52 (SD = 10.95) 95%CIs: 224.79, 236.26 *Task Agreement* M = 77 (SD =4.43) 95%CIs: 74.83, 79.47 *Goal Agreement* M = 75 (SD = 4.46) 95%CIs: 72.27, 76.93 *Bond* M = 79 (SD = 3.79) 95%CIs: 72.27, 76.93 The WAI-C scores were also compared to a face-to face study of adolescents ($n = 13$) with haematological disorders, who were rating their relationship with their physician (Ely, Alexander & Reed, 2005). Scores were also compared to scores from children participating in a 'family help' (distance) treatment ($n = 55$) for anxiety or recurrent headache (Lingley-Pottie & McGrath, 2008) There were no significant differences between this study and the face-to-face comparator ($t = 1.37$, p = .18, 95CIs: –2.83, 14.07) or the distance treatment comparator ($t = 1.51$, p = .15, 95%CIs: –2.01, 12.97) DEQ – participant ratings *Relationship rating (5-point scale, 5 = very strong)* M = 4.2, SD = 0.6 *Level of comfort rating (5-point scale, 5 = very comfortable* M = 4.4, SD = 0.8 DEQ – quantitative data (%) *Could talk to coach versus someone face-to-face* Less than (7%) Same as (57%) More than (36%) *Treatment preference if starting over* Over the phone (86%) In clinic face-to-face (14%) *Coach gender preference* Female (36%) Male (0%) No preference (64%) *Coach role preference* Trained peer with arthritis (36%) Trained non-healthcare professional (43%) No preference (21%)
Teens taking charge: managing arthritis online	Connelly et al. (2019)	USA	$N = 289$ Control group Age, M (SD) = 14.5 (1.7)	JIA	RCT	All content was made available in Spanish (and reviewed for cultural sensitivity) for this trial.	Not specified in this research paper.	Not specified in this paper (see Stinson et al. 2010a)	Content of Teens Taking Charge was refined for this trial by an interdisciplinary team of experts in	N/A	Pain intensity (0-10, NRS) *Intervention group (M, SD)* Baseline: 3.6 (2.3) Post: 3.1 (2.5) 6-month FU: 2.9 (2.5) 12-month FU: 3.1 (2.5)	PedsQL (3.0) (range: 0-100) *Intervention group (M, SD)* Baseline: 72.6 (15.6) Post: 75.7 (16.2) 6-month FU: 77.3 (15.6) 12-month FU: 78.3 (16.2)	Self-efficacy (CASE) (11-items, scored 1-5; high score = high efficacy) *Intervention group (M, SD)* Baseline: 3.3 (1.0) Post: 3.8 (1.0)

	Male (n, %): 34 (23) Female (n, %): 111 (77) Intervention group Age, M (SD) = 14.6 (1.8) Male (n, %): 46 (32) Female (n, %): 98 (68)	Participants in the Teens Taking Charge (intervention) group (n =144) were assigned to the 12-week program (12 modules, of which no more than 2 could be completed per week). Access was password protected. Participants in the online education group (control) (n = 144) accessed a separate study website that contained links to 12 educational websites (pre-vetted for quality). They were instructed to view 1 per week. There was no CBT or opportunity for social interaction on these websites. Access was password protected. Participants in the intervention group received brief monthly telephone support calls by bilingual “health coaches” for 3-months. The health coach calls were scripted and used prompts to discuss content and review answers to modular knowledge quizzes. Calls were also received from health coaches in the online education group, to discuss the health information accessed. Separate groups of coaches were assigned to each group. Measures were computer administered self-reports, assessed at baseline, posttreatment (3-months after randomisation), 6-months and 12-months. Clinical data was also manually entered at these time points. $50 stipend awarded for completed health assessment visits. Pain intensity (past 2-weeks was measured using an 11-point NRS, pain interference was also measured across 5 categories (activities, mood,		the areas of pediatric rheumatology, pediatric psychology, pain, and adolescent development. Trial version description: The first few modules provided psychoeducation about arthritis and introduced the biopsychosocial model of pain. The next several modules were focused on cognitive and behavioural strategies; including managing stress, relaxation training, distraction methods, and cognitive coping skills. The final modules included additional content on optimizing health habits e.g., physical activity, healthy eating, and sleep habits), additional therapies and preventing and overcoming setbacks. Parents/ caregivers of the adolescent participants also were asked to complete two online modules about facilitating their child's self-management skills.	*Control (M, SD)* Baseline: 3.3 (2.4) Post: 2.9 (2.5) 6-month FU: 3.0 (2.3) 12-month FU: 2.7 (2.4) **Time** b = -.04 (SE = .01), β = -.04, t =-3.47* Effect size (d) = -.19 (95%CI: -.24) **Group X Time** b = -.01(SE = .02), β = -.02, t =.67 Effect size (d) = -.09 (95%CI: -.01) Pain interference (0-10; 0 = doesn't get in the way at all', 10 = ‘totally gets in the way') *Intervention group (M, SD)* Baseline: 2.6 (2.3) Post: 2.2 (2.4) 6-month FU: 2.2 (2.2) 12-month FU: 2.0 (2.2) *Control (M, SD)* Baseline: 2.5 (2.3) Post: 1.7 (2.2) 6-month FU: 1.8 (2.0) 12-month FU: 1.9 (2.2) **Time** b = -.04 (SE = .01), β = -.09, t =-3.99* Effect size (d) = -.21 (95%CI: -.25) **Group X Time** b = -.00 (SE = .02), β = -.01, t = -.19 Effect size (d) = -.09 (95%CI: -.02) PCQ (range: 1-5, higher scores = high frequency of use) *Approach coping* *Intervention group (M, SD)* Baseline: 2.6 (0.7) Post: 2.8 (0.9) 6-month FU: 2.8 (0.9) 12-month FU: 3.8 (1.0) *Control (M, SD)* Baseline: 2.6 (0.7) Post: 2.7 (0.8) 6-month FU: 2.5 (0.9) 12-month FU: 2.5 (0.9) **Time** b = .00 (SE = .01), β = .00, t = .05 Effect size (d) = .14 (95%CI: .16) **Group X Time** b = .01 (SE = .01), β = .01, t =.69 Effect size (d) = .14 (95%CI: .16) *Emotion-focused avoidance coping* *Intervention group (M, SD)*	*Control (M, SD)* Baseline: 72.4 (15.8) Post: 77.8 (16.2) 6-month FU: 77.1 (14.4) 12-month FU: 78.0 (14.3) **Time** b = .37 (SE = .05), β = .13, t =7.27* Effect size (d) = .21 (95%CI: .41) **Group X Time** b = .06 (SE = .10), β = .01, t =.55 Effect size (d) = -.16 (95%CI: .24) PROMIS *T-scores calculated from 8-items on a 5 point scale (‘never' to ‘almost always') regarding their experience over the past 7-days.* *Scores >50 indicate higher than average symptoms of anxiety and depression.* *Anxiety* *Intervention group (M, SD)* Baseline: 48.6 (11.8) Post: 46.8 (11.3) 6-month FU: 45.1 (12.1) 12-month FU: 45.3 (12.0) *Control (M, SD)* Baseline: 47.6 (10.7) Post: 45.5 (11.0) 6-month FU: 46.0 (10.8) 12-month FU: 46.0 (11.4) **Time** b = -.18 (SE = .04), β = -.07, t = -3.95* Effect size (d) = -.12 (95%CI: -.29) **Group X Time** b = -.13 (SE = .09), β = -.03 , t = -1.43 Effect size (d) = -.33 (95%CI: .03) *Depression* *Intervention group (M, SD)* Baseline: 47.2 (11.6) Post: 46.4 (11.2) 6-month FU: 45.6 (11.2) 12-month FU: 45.5 (11.0) *Control (M, SD)* Baseline: 46.5 (11.7) Post: 45.2(12.1) 6-month FU: 45.1 (11.4) 12-month FU: 45.0 (11.4) **Time** b = -.12 (SE = .05), β = -.05, t = 2.56* Effect size (d) = -.05 (95%CI: -.23) **Group X Time** b = -.02 (SE = .09), β = -.01, t = -.24	6-month FU: 3.8 (1.0) 12-month FU: 3.8 (1.0) *Control (M, SD)* Baseline: 3.3 (1.0) Post: 3.7 (0.9) 6-month FU: 3.7 (0.9) 12-month FU: 3.8 (1.0) **Time** b = .03 (SE = .01), β = .17, t =7.67* Effect size (d) = .38 (95%CI: .40) **Group X Time** b = -.01 (SE = .01), β = -.01, t =-.44 Effect size (d) = -1.5 (95%CI: -.12) Disease knowledge (MEPS) (range: 0-10, 0 = ‘none at all', 10 = ‘enough') *Intervention group (M, SD)* Baseline: 4.8 (2.0) Post: 6.3 (2.0) 6-month FU: 6.6 (2.4) 12-month FU: 6.5 (2.3) *Control (M, SD)* Baseline: 4.6 (2.3) Post: 6.5 (2.3) 6-month FU: 6.4 (2.5) 12-month FU: 6.6 (2.6) **Time** b = .12 (SE = .01), β = .25, t = 11.43* Effect size (d) = .60 (95%CI: .66) **Group X Time** b = -.01 (SE = .02), β = -.01, t =-.45 Effect size (d) = -.09 (95%CI: -.01) Adherence (websites use) *Considered adherent if viewed at least 75% of the assigned content, and completed at least 2 health coach calls.* 73% of the sample met the criteria for adherence A significantly higher proportion in the control condition (82%) compared to intervention (64%met adherence criteria, X^2(1, N = 289) = 12.12, p < .01). Adverse events (AEs)(n) AEs = 72 participants SAEs (hospitalisation) = 9 participants *Most common* infections = 18 arthritis flares = 17 suicidal thoughts = 4 participants (3 intervention group, 1 control) **p < .05.*

						walking, sleeping, enjoyment of life) using an 11-point NRS. Quality of life was measures using the PedsQL 3.0. Process outcomes included Self-efficacy (children's arthritis self-efficacy scale; CASE), pain coping questionnaire (PCQ) using 2 subscales, emotional adjustment (PROMIS: Pediatric Anxiety and Depression Short Forms (Irwin et al., 2010)), and disease knowledge (MEPS: Medical Issues, Exercise, Pain and Social Support questionnaire). Multilevel growth models (MLMs) were used to analyse the changes in primary outcomes and process outcomes. Two effects were estimated: average monthly rate of change since baseline through end of study, regardless of group assignment (time), and relative increase or decrease to the average monthly rate of change associated with being in the treatment condition (group X time). Regression coefficients were compared against a t-sampling distribution at p < .05 significance level. Moderators included age, sex, disease subtype, baseline disease severity, medication type and ethnicity.						Baseline: 2.1 (0.8) Post: 2.0 (0.8) 6-month FU: 1.9 (0.8) 12-month FU: 2.0 (0.9) *Control (M, SD)* Baseline: 2.0 (0.8) Post: 1.9 (0.8) 6-month FU: 1.9 (0.8) 12-month FU: 1.9 (0.8) **Time** b = 0.01 (SE = .01), β = -.04, t = -1.60 Effect size (d) = -.15 (95%CI: -.17) **Group X Time** b = .01 (SE = .01), β = .02, t =.94 Effect size (d) = .15 (95%CI: .17) *p < .05.	Effect size (d) = -.20 (95%CI: .16) *p < .05.	
In-person CBT followed by 6-week online skill review for IBD (no specific name)	McCormick et al. (2010)	USA	N = 24 (female only) Intervention group, age range: 12-17 years Wait-list control, age range: 11-17 years	Inflammatory bowel diseases (IBDs): Crohn's disease and ulcerative colitis (UC)	NRCT	Participants were allocated into either the intervention group (n = 13), or to the wait-list control (n = 11). The intervention group took part in an intensive one day, in-person, course followed by a 6-week online skill review. The day session was a skills-based CBT-based intervention (7 modules for adolescents and parents). Information on the content of the in-person sessions are summarized in	- CBT	Not specified	Web sessions were facilitated by research assistants, however HCP input is not specified.	N/A	*No significant between-group differences pre-post on the primary variables (API and CSI)* API (abdominal pain) – child *Intervention (M, SD)* Pre: 9.96, 5.26 Post: 8.88, 5.92 Follow-up: 6.77, 5.72 Pre-post comparison: F = 0.62, p = .224 Pre-FU comparison: F = 3.12 , p = .054 *Control (M, SD)* Pre: 11.95, 8.33 Post: 10.86, 6.53 API (abdominal pain) – parent *Intervention (M, SD)*	N/A	ARCS – protective behaviour (parents) *Intervention (M, SD)* Pre: 25.62 8.82 Post: 21.35 9.59 Follow-up: 20.18 8.64 Pre-post comparison: F = 4.346, p = .030* Pre-FU comparison: F = 7.69, p = .010** *Control (M, SD)* Pre: 27.00, 14.64 Post: 25.60, 6.85 *p ≤ .05 **p ≤ .01

	Table 1 of this paper. The web sessions were delivered via separate parent and adolescent sites. Homework assignments were completed online and followed up in a monitored group web-chat (30 minutes). Facilitators helped with problem solving skills. Measures were taken pre and posttest, and at 6-month follow up for the intervention group. Wait-list group was only measured pre-test at time-points 1 and 2. This was done by telephone questionnaire or by paper if requested. These included; PCQ (parent and child), CSI-24, abdominal pain index (API parent and child (Walker et al., 1995)), PCS-C and PCS-P (catastrophising), and ARCS (protective scale only). Incentives: $20 gift cards were issued after each round of data collection, as well as a $25 gift certificate at end of the study.		Pre: 10.31, 7.19 Post: 11.54, 6.48 Follow-up: 8.10, 6.45 Pre-post comparison: *F* = 0.32, *p* = .292 Pre-FU comparison: *F* =0.88, *p* = .186 *Control (M, SD)* Pre: 12.40, 9.49 Post: 10.20, 7.02 CSI – child (somatic symptoms) *Intervention (M, SD)* Pre: 16.92, 15.28 Post: 11.42, 9.21 Follow-up: 15.00, 13.85 Pre-post comparison: *F* = 8.32, *p* = .007** Pre-FU comparison: *F* = 0.69, *p* = .213 *Control (M, SD)* Pre: 22.00, 19.30 Post: 17.91, 13.35 CSI - parent (somatic symptoms) *Intervention (M, SD)* Pre: 17.62, 10.35 Post: 12.38, 9.27 Follow-up: 14.32, 10.91 Pre-post comparison: *F* = 7.48, *p* = .009** Pre-FU comparison: *F* =5.48, *p* = .021* *Control (M, SD)* Pre: 19.90, 11.88 Post: 20.50, 16.60 PCQ – child (approach) *Intervention (M, SD)* Pre: 2.89, 0.72 Post: 2.64, 0.97 Follow-up: 2.68, 0.86 Pre-post comparison: *F* = 1.38, *p* = .133 Pre-FU comparison: *F* = 0.893, *p* = .184 *Control (M, SD)* Pre: 2.87, 0.97 Post: 2.82, 0.88 PCQ – parent (approach) *Intervention (M, SD)* Pre: 2.59, 0.76 Post: 3.06, 0.54 Follow-up: 2.96, 0.83 Pre-post comparison: *F* = 9.11, *p* = .006** Pre-FU comparison: *F* = 1.75, *p* = .108 *Control (M, SD)* Pre: 2.97, 0.32 Post: 2.75, 0.43 Following Bonferroni corrections, the intervention group had higher scores on	

		the 'approach' scale of the PCQ compared to the control condition at the end of the treatment period, *F* (1, 20) = 7.87, *p* = .005 (parent-report only). PCQ – child (distraction) *Intervention (M, SD)* Pre: 3.18 0.54 Post: 2.82 1.03 Follow-up: 3.53 0.58 Pre-post comparison: *F* = 3.21, *p* = .051 Pre-FU comparison: *F* = 1.91, *p* = .099 *Control (M, SD)* Pre: 3.30, 0.87 Post: 3.63, 0.72 PCQ – parent (distraction) *Intervention (M, SD)* Pre: 2.72, 0.80 Post: 3.13, 0.69 Follow-up: 3.07, 0.53 Pre-post comparison: *F* = 6.44, *p* = .013* Pre-FU comparison: *F* = 0.69, *p* = .213 *Control (M, SD)* Pre: 3.45, 0.66 Post: 2.99, 1.02 PCQ – child (avoidance) *Intervention (M, SD)* Pre: 1.60 0.48 Post: 1.38 0.38 Follow-up: 1.44 0.44 Pre-post comparison: *F* = 3.63, *p* = .042*** Pre-FU comparison: *F* = 0.21, *p* = .330 *Control (M, SD)* Pre: 1.85, 0.66 Post: 1.62, 0.42 PCQ – parent (avoidance) *Intervention (M, SD)* Pre: 2.17, 0.64 Post: 2.06, 0.79 Follow-up: 1.74, 0.51 Pre-post comparison: *F* = 0.63, *p* = .220 Pre-FU comparison: *F* = 4.78, *p* = .027*** *Control (M, SD)* Pre: 2.31, 0.88 Post: 2.21, 0.62 PCS-C (catastrophizing) *Intervention (M, SD)* Pre: 14.23, 11.43 Post: 12.54, 9.88 Follow-up: 8.55, 7.30 Pre-post comparison: *F* = 1.02, *p* = .116 Pre-FU comparison: *F* = 2.15, *p* = .087

											Control (M, SD) Pre: 20.20, 15.79 Post: 17.90, 12.90 PCS-P (catastrophizing) *Intervention (M, SD)* Pre: 19.69, 11.17 Post: 15.85, 6.84 Follow-up: 15.82, 10.22 Pre-post comparison: F = 3.25, p = .048* Pre-FU comparison: F = 2.61, p = .069 *Control (M, SD)* Pre: 19.55, 11.28 Post: 15.20, 8.44 *p ≤ .05 **p ≤ .01 *** p –value became non-significant after Bonferroni corrections		
Internet-based self-help for paediatric recurrent headache (no specific name)	Trautmann and Kröner-Herwig (2008)	Germany	N = 18 Age range: 10 to 18 years Age (M) = 13.4 years (SD 2.6)	Recurrent headache: migraine or tension type headache (TTH)	RCT	Participants were randomly assigned to either the intervention group (CBT) or an education-only alternative. Both were internet-based. CBT included 6 self-help sessions focused on headache education, stress management, relaxation, cognitive restructuring, self-assurance, and problem solving. Sessions could be downloaded on a weekly basis and combined with weekly chat sessions with a trainer (see HCP input). Downloads and handouts also available. The education-only control group received the same first session, as well as the chat communication, focused on diary records (used for outcome assessment). Both groups had 2 additional chat booster sessions (weeks 4 and 8). Headache frequency, duration, and intensity (VAS 0-10) was assessed by an internet-based 4-week diary. This included the PCS-C in addition (pre-post and 6-month follow-up). Post-treatment satisfaction was also measured using a	• CBT • Headache education	N/A	3 clinical psychology graduates served as 'trainers' supporting participants (via the chat).Intensive training for this was provided by PhD students/ psychotherapist in training. Input from fully-qualified HCPs is not evident.	N/A	Headache frequency (M, SD) *CBT* Pre: 15.2 (10.9) Post: 8.1 (8.0) Follow-up: 8.0 (7.8) Within-group pre-post: t = 2.480, p <.05* *Education-only:* Pre: 13.8 (10.1) Post: 12.3 (8.6) Within-group pre-post: t = 1.016, p >.05 *Clinical significance* *(defined as a reduction of 50% or more in headache frequency, pre-post)* - CBT; n = 5 - Education; n = 1 No significant difference between-groups (post-treatment); t = 0.239, p >.05 Duration (median, range) *CBT* Pre: 3.8 (2–24) Post: 3.5 (2–24) Follow-up: 3.3 (1–23) Within-group pre-post: z = −0.681, p >.05 *Education-only:* Pre: 6.0 (5–24) Post: 5.1 (2–23) Within-group significance: z = 1.483, p >.05 No significant difference between-groups (post-treatment); t = −0.995, p >.05 Intensity - VAS (M, SD) *CBT* Pre: 4.7 (0.8) Post: 4.7 (1.3) Follow-up: 4.2 (1.9) Within-group pre-post: t = −0.708, p >.05 *Education-only:*	N/A	Treatment satisfaction (overall) [0= not satisfied, 3 = very satisfied] CBT group: Child rating; Median = 3.0, range 2-3 Parent rating; Median = 2.0, range 1-3 Education-only group: Child rating; Median = 2.0, range 1-3 Parent rating; Median = 2.0, range 1-3 U = 16.0, p >.05 No significant differences Patient-therapist alliance (0-3) CBT: Median = 2.8, range 2-3 Education-only: Median = 2.7, range: 2-3 U = 21.0, p >.05 No significant differences Coping with problems (0-3) CBT: Median = 2.0, range 1-3 Education-only: Median = 1.0, range 0-2 U = 6.0, p <.05 Significant between-group difference

						posted questionnaire.					Pre: 5.8 (1.5) Post: 5.0 (1.3) Within-group significance: t = 0.881, p >.05 No significant difference between-groups (post-treatment); U = 27.0, p >.05 PCS-C (catastrophizing; M, SD) *CBT* Pre: 33.0 (6.5) Post: 30.0 (5.9) Follow-up: 28.3 (5.8) Within-group pre-post: t = 2.427, p <.05* *Education-only:* Pre: 36.4 (9.7) Post: 37.3 (7.9) Within-group significance: t = 0.010, p >.05 No significant difference between-groups (post-treatment); t = −2.051, p >.05 * statistically significant note: treatment effects were maintained at follow-up		
Internet-based self-help for paediatric recurrent headache (no specific name)	Trautmann and Kröner-Herwig (2010)	Germany	N = 65 Age (M) = 12.7 years (SD 2.2) Male: n = 30 Female: n = 36	Recurrent primary headache: migraine, TTH or combined headache	RCT	Participants were split into three groups: 1) multimodal CBT, 2) applied relaxation (AR) (progressive relaxation, cue-controlled relaxation, and differential relaxation), 3) education only (EDU). CBT addressed headache education, stress management/ coping, relaxation, cognitive restructuring self-assurance and problem solving. In CBT and AR, weekly e-mails with therapists responded to the assigned exercises and to discuss diary records. EDU received the same first session and then had the same amount of email contact to discuss diary records only. All groups had 2 additional email boosters (weeks 4 and 8). CDs with relaxation instructions was offered to the CBT group (1 exercise) and AR group (4	• CBT • Headache education	Not specified	7 clinical psychology graduates served as therapists supporting children and adolescents via e-mail. The graduate students were extensively trained in both treatments and the EDU condition and were provided with detailed treatment manuals. Therapists attended weekly group supervision, with a psychotherapist in training. Input from fully-qualified HCPs is not evident.	N/A	*All effect sizes given in Hedges g. For time x group interactions, see Table 3 within this paper.* Headache frequency (M, SD) *CBT* Pre: 11.5 (8.2) Post: 4.9 (4.3) Effect size (90% CIs): 0.96 (0.49; 1.42) Follow-up: 6.0 (4.8) Effect size (90% CIs): -0.24 (-0.72; 0.26) *AR* Pre:10.3 (7.8) Post: 7.4 (7.6) Effect size (90% CIs):0.37 (-0.03; 0.77) Follow-up: 5.3 (6.6) Effect size (90% CIs): 0.29 (-0.03; 0.77) *EDU* Pre: 10.7 (7.4) Post: 6.7 (6.5) Effect size (90% CIs): 0.56 (0.12; 0.99) Follow-up: 7.3 (8.4) Effect size (90% CIs): -0.08 (-0.61; 0.44) Between-groups pre-post: F (2, 47) = 0.45, p =.64 Between-groups post-FU: F (2, 34) = 0.20, p = 0.82 Within groups pre-post: F (1, 47) = 17.99, p =.00 Within-groups post-FU: F (1, 34) = 0.56, p =.46 *Clinical significance*	KINDL-R *CBT* Pre: 3.6 (0.5) Post: 3.6 (0.4) Effect size (95% CIs): 0 (-0.42; 0.42) Follow-up: 3.9 (0.4) Effect size (95% CIs): 0.72 (0.22; 1.22) *AR* Pre: 3.8 (0.6) Post: 3.8 (0.6) Effect size (95% CIs): 0 (-0.39; 0.39) Follow-up: 4.0 (0.5) Effect size (95% CIs): 0.40 (-0.06; 0.76) *EDU* Pre: 3.8 (0.3) Post: 3.9 (0.3) Effect size (95% CIs): 0.24 (-0.66; 0.19) Follow-up: 3.8 (0.3) Effect size (95% CIs): -0.32 (-0.83; 0.18) Between-groups pre-post: F (2, 51) = 1.57, p = .22 Between-groups post-FU: F (2, 36) = 0.04, p = .96 Within groups pre-post: F (1, 51) = 0.13, p =.72 Within-groups post-FU: F (1, 36) = 1.02, p =.32	CDI *CBT* Pre: 10.2 (6.6) Post: 11.0 (9.2) Effect size (95% CIs): -0.10 (-0.52; 0.32) Follow-up: 7.7 (7.1) Effect size (95% CIs):0.38 (-0.13; 0.89) *AR* Pre: 8.5 (4.8) Post: 8.1 (9.0) Effect size (95% CIs): 0.06 (-0.34; 0.45) Follow-up: 6.8 (5.2) Effect size (95% CIs): 0.17 (-0.26; 0.59) *EDU* Pre: 9.2 (4.8) Post: 7.7 (5.2) Effect size (95% CIs): 0.29 (-0.13; 0.72) Follow-up: 6.6 (3.7) Effect size (95% CIs): 0.22 (-0.30; 0.74) Between-groups pre-post: F (2, 50) = 0.68, p = .51 Between-groups post-FU: F (2, 31) = 0.25, p =.78 Within groups pre-post: F (1, 50) = 0.30, p =.56 Within-groups post-FU: F (1, 31) = 0.69, p = .41 SDQ *CBT* Pre: 11.8 (3.5) Post: 11.2 (4.3) Effect size (95% CIs): 0.15 (-0.27; 0.58)

	exercises, including that delivered to the CBT group). Headache frequency (yes/ no, daily), duration (hours) and intensity (VAS 0-10) was assessed by a 4-week diary (paper). Diary also asked about medication. Additional pre-post and 6-month follow-up measures included the PCS-C, CDI, health-related quality of life (German; KINDL-R (Ravens-Sieberer & Bullinger, 1998)); these were all postal. Patient-therapist alliance was assessed using an internet questionnaire (Krampen & Wald, 2001), and treatment satisfaction was measured using a posted form.		*(defined as a reduction of 50% or more in headache frequency, pre-post)* CBT: 63% (10/16) AR: 32% (6/19) EDU: 19% (2/16) Kruskal–Wallis test revealed a significant difference between the three groups (X^2 = 6.83, df = 2, *p* = .03). Pairwise comparisons showed a significant difference between CBT and EDU only (*U* = 72.00, *p* = .03) Intensity - VAS (M, SD) *CBT* Pre: 5.0 (1.8) Post: 5.0 (2.4) Effect size (90% CIs): 0 (-0.46; 0.46) Follow-up: 4.9 (1.4) Effect size (95% CIs): 0.05 (-0.46; 0.56) *AR* Pre: 5.1 (1.7) Post: 5.6 (1.9) Effect size (95% CIs): -0.27 (-0.69; 0.15) Follow-up: 5.5 (1.9) Effect size (95% CIs): 0.05 (-0.38; 0.48) *EDU* Pre: 5.2 (1.7) Post: 5.4 (2.0) Effect size (95% CIs): -0.11 (-0.57; 0.36) Follow-up: 5.5 (1.6) Effect size (95% CIs): -0.05 (-0.65; 0.55) Between-groups pre-post: *F* (2, 39) = 0.07, *p* =.93 Between-groups post-FU: *F* (2, 29) = 1.01, *p* = .38 Within groups pre-post: *F* (1, 39) = 1.34, *p* = .25 Within-groups post-FU: *F* (1, 29) = 0.29, *p* = .59 Duration (M, SD) *CBT* Pre: 6.8 (4.0) Post: 4.8 (2.9) Effect size (95% CIs): 0.54 (0.07; 1.01) Follow-up: 5.5 (2.5) Effect size (95% CIs): -0.25 (-0.76; 26) *AR* Pre: 8.1 (6.7) Post: 6.2 (3.9) Effect size (95% CIs):0.34 (-0.08; 0.76) Follow-up: 7.7 (5.3) Effect size (95% CIs): -0.32 (-0.75; 0.11) *EDU* Pre: 7.8 (5.8) Post: 6.1 (5.1) Effect size (95% CIs): 0.30	Follow-up: 9.3 (3.7) Effect size (95% CIs): 0.45 (-0.05; 0.96) *AR* Pre: 8.9 (4.5) Post: 9.5 (4.2) Effect size (95% CIs): -0.13 (-0.53; 0.26) Follow-up: 7.1 (4.8) Effect size (95% CIs): 0.54 (0.09; 0.94) *EDU* Pre: 10.7 (3.9) Post: 10.0 (4.9) Effect size (95% CIs): 0.16 (-0.26; 0.57) Follow-up: 8.4 (4.8) Effect size (95% CIs): 0.32 (-0.20; 0.84) Between-groups pre-post: *F* (2, 49) = 1.60, *p* =.21 Between-groups post-FU: *F* (2, 33) = 0.40, *p* =.67 Within groups pre-post: *F* (1, 49) = 0.42, *p* =.52 Within-groups post-FU: *F* (1, 33) = 1.97, *p* =.17 Treatment satisfaction (overall) [0= not satisfied, 3 = very satisfied] Significant between-group differences (child report). CBT (M) = 2.3 (0.60) AR (M) = 2.7 (0.57) EDU (M) = 2.0 (0.90) *F*(2,48) = 3.49, *p* = .03 Post hoc comparisons indicated significant differences between the AR and EDU groups (*p* = .04); AR reported more satisfaction. No significant differences were found for CBT vs. EDU (*p* = .53) or CBT vs. AR (*p* = .32) . Patient-therapist alliance (0-3) No significant differences CBT (M) = 2.6 (0.51) AR (M) = 2.6 (0.48) EDU (M) = 2.4 (0.79) *F*(2,46) = 0.98, *p* = .38 Coping with problems (0-3) Significant between-group differences. CBT (M) = 2.1 (0.42) AR (M) = 2.2 (0.43) EDU (M) = 1.2 (0.53) *F*(2,45) = 13.20, *p* = .00 . Pairwise comparisons indicated that differences were between CBT and EDU (*p* = .00) and AR compared to EDU (*p* = .00). No significant differences were found between the two treatment groups (CBT vs. AR; *p* = .90).

											(-0.14; 0.75) Follow-up: 7.1 (5.3) Effect size (95% CIs):-0.19 (-0.47; 0.37) Between-groups pre-post: F (2, 39) = 0.42, p = .66 Between-groups post-FU: F (2, 29) = 0.56, p =.58 Within groups pre-post: F (1, 39) = 5.22, p =0.02 Within-groups post-FU: F (1, 29) = 2.88, p = .10 PCS-C (M, SD) *CBT* Pre: 32.5 (8.5) Post: 27.1 (7.1) Effect size (95% CIs): 0.67 (0.24; 1.10) Follow-up: 23.6 (4.3) Effect size (95% CIs): 0.55 (0.07; 1.04) *AR* Pre: 34.9 (7.8) Post: 34.7 (8.8) Effect size (95% CIs): 0.02 (-0.37; 0.41) Folow-up: 26.3 (9.7) Effect size (95% CIs): 0.89 (0.46; 1.32) *EDU* Pre: 32.2 (10.4) Post: 31.7 (8.3) Effect size (95% CIs): 0.05 (-0.36; 0.47) Follow-up: 28.1 (9.9) Effect size (95% CIs):0.39 (-0.12; 0.90) Between-groups pre-post: F (2, 52) = 1.93, p = .15 Between-groups post-FU: F (2, 37) = 2.66, p =.08 Within groups pre-post: F (1, 52) = 4.45, p = .04 Within-groups post-FU: F (1, 37) = 10.13, p = .00		
Web-MAP (Web-based Management of Adolescent Pain)	Long and Palermo (2008)	USA	N = 11 [adolescent-parent dyads] [a] Recovered adolescents: n = 5 dyads Age range; 13 to 17 years, M = 15.8 (SD 1.2) Male: n = 2 Female: n = 3 Treatment-seeking adolescents; n = 6 dyads	Chronic pain (mixed)	Mixed-methods (iterative)	Website usability ratings were obtained during two evaluation stages from two separate groups of patients. In stage one, recovered patients (n = 5) were given access to preliminary program content for 2-weeks. Participants rated the content of each module and basic website function. Module content was adjusted based on feedback from stage one. In stage two, treatment-seeking patients (n = 6) were	The adolescent program contains topics which are considered core components of evidence-based CBT for chronic pain, including: • Education, • Relaxation training • Other cognitive-behavioural strategies that fall under this framework (coping, thought challenging, mindfulness) Also derived from existing evidence-based treatments, the parent program includes:	Three phase program evaluation model (Rand, 2004) (see page 512).	Intervention content was reviewed by an independent expert in CBT for adolescents with chronic pain, and several experts in paediatric pain from the fields of nursing, psychology and medicine (paediatrics and anaesthesiology).	*Responses to open-ended questionnaire questions* Parents (Stage 1) reported that the content was helpful, particularly content about pain and stress, instructions for reinforcing positive coping, modelling, and information about lifestyle factors. Adolescents (Stage 1) reported that content was helpful; particularly information about the pain pathway, stress and worry, and instructions for using relaxation and distraction strategies. Users also provided suggestions for improvement, including removal of certain images, and highlighted areas of	N/A	N/A	*Stage 1 results* Perceived usefulness & ease of use (0-5 Likert) Moderate to high; range: 3.20- 4.80 Appearance rating (0-5 Likert) High; M = 4.60 (SD 0.52) Theme (0-5 Likert) High; M = 4.65 (SD 0.67) *Stage 2 results* Perceived usefulness & ease of use (0-5 Likert) Ease of use: high (M = 4.50, SD = 0.64). Usefulness: moderate (M = 3.58, SD = 1.62). Appearance rating (0-5 Likert) Moderate; M = 3.67 (SD 1.30) Theme (0-5 Likert) Moderate; M = 3.42 (SD 1.56)

			Age range: 12 to 16 years, M = 14.6 (SD 1.6) Male: *n* = 2 Female: *n* = 4			given access to the full website for 8-weeks and provided overall ratings of content. Data regarding their interaction with the program was also collected.	• Training on reinforcement of positive coping, • Reward systems for activity participation, • Modelling positive coping, • Communicating with teenagers			content that were too difficult, lengthy, or repetitive. The intervention was altered based on these comments prior to Stage 2.			*While treatment-seeking patients' (Stage 2) ratings were lower than those of recovered patients (Stage 1), differences were not statistically significant.* Interactivity and engagement Completion time; M = 10.26 weeks (SD 2.33) Interactive fields completed – teens: M = 30.17 (SD 4.40) out of 35 Total word count of assignments: range: 121 to 280 (M = 187.33, SD = 53.14). Message system usage: range = 1 to 7 messages (M = 3.00; SD = 2.10). Interactive fields completed – parents: M = 26.17 (SD 5.88) out of 44 Total word count of assignments: range: 204 to 879 (M = 497.50, SD = 241.93). Message system usage: range = 1 to 11 messages (M = 4.00; SD = 3.90).
Web-MAP	Palermo et al. (2009)	USA	*N* = 48 [adolescent-parent dyads] [a] Age range: 11 to 17 years Age (M) = 14.8 years (SD 2.0) Male: *n* = 13 (27.1%) Female: *n* = 35 (72.9%)	Chronic pain (mixed)	RCT	Children were randomly assigned to a wait-list control group (*n* = 22) or internet treatment group (*n* = 26). Wait-list received usual medical care. The intervention group received usual medical care plus 8 –weeks of online modules (covering: relaxation, cognitive strategies, sleep, daily activities, communication. Parent modules were accessed via a separate website and covered similar topics, as well as operant reinforcement of child behaviours and modelling. The program was travel themed. Children and parents were asked to log in once a week to complete a module (each contained an assignment). 'Postcard' reminders were sent in some weeks as a reminder to practice previously learnt skills. Participants could not proceed to the next module without completing the current one. An online therapist (postdoctoral fellow) responded via a message centre to assignments, and to offer encouragement and help problem solve. Participants	• CBT • Social Learning Theory	See Long and Palermo (2008).	See Long and Palermo (2008). Online therapist was a postdoctoral fellow with a PhD – 1 year experience in face-to-face CBT for children with chronic pain.	N/A	Pain intensity (0-10; 10 = worst pain) *Intervention group (M, SD)* Pre (diary): 5.45 (2.25) Post (diary): 3.54 (2.42) Pre (retrospective): 6.63 (1.87) Post (retrospective): 4.96 (2.18) Follow-up (retrospective): 4.27 (2.00) *Control (M, SD)* Pre (diary): 5.17 (1.65) Post (diary: 4.76 (1.84) Pre (retrospective): 6.16 (1.84) Post (retrospective): 5.45 (2.04) *Between group difference pre-post (diary):* *F*(1, 45) = 5.28, *p* = .03 n^2 = .11 *Between group difference pre-post (retro.):* *F(*1, 45) = .53, *p* = .47 n^2 = .01 *Within-group effect (intervention)* *F*(2, 24) = 15.02, *p* < .001 T1–T2: significant (*p* = .02) T1–T3: significant (*p* < .001) n^2 = .34 Effect sizes reported as n^2; small effect = 0.01, medium effect size = 0.06, large effect ≥ 0.13 Clinically significant improvement in pain *Defined as a 50% reduction in diary-reported pain intensity – dichotomous.* Clinically significant improvement was greater in the treatment group comparatively to the control (38.5% vs. 13.6%).	Child Activity Limitations Interview (range; 0-32) *Children are asked to pick 8 activities from a list of 21, according to which are most difficult due to pain. Importance of each activity is measured on a 5-point scale (0-4; 4 = extremely important)* *Intervention group (M, SD)* Pre (diary): 5.89 (4.92) Post (diary): 3.60 (2.86) Pre (retrospective): 20.54 (5.80) Post (retrospective): 12.69 (6.29) Follow-up (retrospective): 10.27 (8.04) *Control (M, SD)* Pre (diary): 6.30 (4.61) Post (diary): 6.62 (4.76) Pre (retrospective): 18.82 (6.59) Post (retrospective): 16.00 (6.34) *Between group difference pre-post (diary):* *F*(1, 45) = 9.25, *p* = .004 n^2 = .17 *Between group difference pre-post (retro):* *F*(1, 45) = 4.20, *p* = .05 n^2 = .09 *Within-group effect (intervention)* *F*(2, 24) = 14.03, *p* < .001 T1–T2: significant (*p* < .001) T1–T3: significant (*p* < .001) n^2 = .43 Effect sizes reported as n^2; small effect = 0.01, medium effect size = 0.06, large effect ≥ 0.13	Depressive symptoms *Intervention group (M, SD)* Pre: 56.08 (13.65) Post: 58.96 (13.10) Follow-up: 53.45 (16.16) *Control (M, SD)* Pre: 57.91 (15.04) Post: 61.59 (18.67) No significant between group difference *Within-group effect (intervention)* *F*(2, 24) = 3.47, *p* = .05 T2–T3: significant (*p* = .04) n^2 = .07 ARCS – parent report *Intervention group (M, SD)* Pre: 28.77 (8.11) Post: 19.91 (9.76) Follow-up: 15.54 (8.57) *Control (M, SD)* Pre: 24.55 (7.88) Post: 19.11 (10.15) No significant between group difference *Within-group effect (intervention)* *F*(2, 24) = 19.71, *p* < .001 T1–T2: significant (*p* < .001) T1–T3: significant (*p* < .001) T2–T3 : significant (*p* = .04) n^2 = .54 ARCS – child report *Intervention group (M, SD)* Pre: 26.92 (9.78) Post: 22.91 (8.28) Follow-up: 19.86 (12.36) *Control (M, SD)* Pre: 23.18 (8.97) Post: 21.45 (11.83) No significant between group difference *Within-group effect (intervention)* *F*(2, 24) = 3.52, *p* = .05 T1–T2: significant (*p* =.05)

						were not allowed to initiate additional psychotherapy treatment whilst taking part in the study. Outcomes were recorded using an online diary (daily), and included pain intensity (0-10 NRS), activity limitations (Child Activity Limitations Interview (Palermo et al., 2004)). Secondary measures were depressive symptoms (Major Depressive Disorder subscale of the Revised Child and Anxiety depression Scale) (Chorpita et al., 2005), parental response (ARCS) Comparisons were made pre, post and at 3-month follow-up.					X^2 (1) = 3.72, *p* = .05 NNT: 3.4		T1–T3: significant (*p* =.04) n^2 = .19 Effect sizes reported as n^2; small effect = 0.01, medium effect size = 0.06, large effect ≥ 0.13 Acceptability and satisfaction (1- 5; 5 = strongly agree) *Acceptable way of dealing with pain* Child report: M = 3.55, SD = .80 Parent report: M = 3.82, SD = .50 Reports positively correlated: *r* = .50, *p* = .02 *Global satisfaction (positivity* Child report M = 3.68, SD = .84 Parent report M = 4.09, SD = .61 Reports positively correlated: *r* = .53, *p* = .01
Web-MAP	Murphy et al. (2012)	USA	*N* = 26 [adolescent parent-dyads] Age range: 11 to 17 years Age (M) = 14.3 years (SD 2.1) Male: *n* = 6 (23.1%) Female: *n* = 20 (76.9%) Intervention group from RCT (Palermo et al., 2009)	Chronic pain (mixed)	Pre-post	Evaluation of treatment participation in the intervention group from Palermo et al. (2009). An analysis was completed investigating associations between the content of messages from participants to the online therapist. And treatment outcomes. Participation measures included number of logins, and number of sent messages, completion of interactive fields, and weekly assignments.	- CBT - Social Learning Theory	See Long and Palermo (2008).	See Long and Palermo (2008).	N/A	Relationship between therapist support & pain intensity (NRS 0-10) Significant association between messages initiated by adolescents, in the category of ‘treatment content’ & intensity: β =.20, *p* =.002 No relationship found between initiating messages in the ‘rapport’ category & intensity. β = .15, *p* = .04 No relationship between the content of messages sent by parents and pain intensity. β = .03-.07, *p* >.01 *Controlled for age, gender, number of logins and baseline pain intensity. Significance set at p < .01.*	Relationship between therapist support & activity limitations (Child Activity Limitations Interview) Significant association between messages initiated by adolescents and global activity limitation scores. These were in the categories of ‘rapport’ (β =.18, *p* = .005) and ‘treatment content’ (β =.17, *p* = .006). No relationship between the content of messages sent by parents and activity limitations. β = .02-.07, *p* >.24 *Controlled for age, gender, number of logins and baseline activity limitations scores. Significance set at p < .01.*	Program usage *Adolescents* 77% of adolescents completed all 8 treatment modules. Number of logins; M = 24.50 (15.52) Number of messages sent; M = 1.23 (1.70) % complete interactive fields: M = 75.51 (25.66) % complete assignments: M = 89.10 (24.92) 81% completed all the assignments Higher baseline pain intensity was associated with more frequent use of messaging by adolescents (*r* =.38, *p* =.05). Category of message (M, SD): Rapport; 0.42 (.86) Treatment; 0.35 (.89) Technical issue; 0.77 (1.31) *Parents* 54% of parents completed all 8 treatment modules. Number of logins; M = 13.65 (9.02) Number of messages sent; M = 1.88 (2.63) % complete interactive fields: M = 56.94 (27.31) % complete assignments: M = 84.07 (26.90) 62% completed all the assignments Category of message (M, SD): Rapport; 0.42 (1.10) Treatment; 0.54 (1.10) Technical issue; 1.62 (2.28)

													Differences between adolescents and parents (MANOVA) A statistically significant difference in program usage (logins and messages) was found between adolescents and parents: $F(3,48) = 4.71$, $p = .002$, $n^2 = .23$ Teens logged in significantly more frequently than parents ($p < .01$)
Web-MAP	Law et al. (2015)	USA	*N* = 83 [adolescent-parent dyads] [a] Age range: 11 to 17 years Age (M) = 14.5 years (SD 1.7) Male: *n* = 15 Female: *n* = 68	Chronic headache	RCT	Adolescents were randomly allocated to either internet CBT adjunctive to specialized headache treatment (*n* = 44) or specialized headache treatment alone (*n* = 39). All patients were new to the specialised treatment program. See description of internet intervention content in Palermo et al. (2009). Participants in the specialised headache treatment only group received medication management (*n* = 21), psychological therapy [CBT/ biofeedback] (*n* = 6) and physical therapy (*n* = 11). Participants in the internet CBT group received medication management (*n* = 27), psychological therapy [CBT/ biofeedback] (*n* = 10), and physical therapy (*n* = 12). Primary outcome assessed was number of headache days via a 7-day online diary (completed pretest and posttest.); diary was also used to assess pain intensity (0-10 NRS), and activity limitations (Child Activity Limitations Interview). Other measures sent by post included: depressive symptoms (CDI), anxiety (revised children's manifest anxiety scale: RCMAS-2 (Reynolds & Richmond, 2008)) and parent protective behaviours (ARCS). There was also an optional sleep assessment – this was a 7-day sleep log and actigraphy	• CBT • Social Learning Theory	Not specified in this research paper	See Long and Palermo (2008). Online therapist (assignment assessor for internet CBT) for this study was a postdoctoral fellow with a PhD, experienced in face-to-face CBT for children with chronic pain.	N/A	Headache pain intensity (0-10; 10 = worst pain) *Internet CBT (M, SD)* Pre: 4.97 (2.47) Post: 4.13 (2.42) 3-month FU: 4.19 (2.45) *Specialised treatment (M, SD)* Pre: 4.35 (2.15) Post: 3.83 (2.26) 3-month FU: 3.70 (2.54) Between group difference over time: $F(2, 129) = .59$, $p = .555$ *Effect sizes [group difference over time]* Pre-Post: d = -.07 Pre- FU: d = .26 Clinically significant reduction in headache - intensity *Defined as 50% reduction in headache intensity from pre-treatment to posttreatment and pre-treatment to follow-up (dichotomous).* Internet CBT (post): 22.7% improved Internet CBT (FU): 18.2% improved Specialised treatment (post): 17.9% improved Specialised treatment (FU): 23.1% improved Posttest comparison non-significant; $X^2(1) = .23$, $p = .63$ FU comparison non-significant; $X^2(1) = .38$, $p = .54$ Headache days (frequency) *Internet CBT (M, SD)* Pre: 5.82 (1.72) Post: 4.63 (2.14) 3-month FU: 3.86 (2.19) *Specialised treatment (M, SD)* Pre: 5.18 (2.00) Post: 4.70 (2.23) 3-month FU: 3.91 (2.39) Between group difference over time: $F(2, 134) = .94$, $p = .395$ *Effect sizes [group difference over time]* Pre-Post: d = -.40 Pre- FU: d = -.34 Clinically significant reduction in headache - frequency *Defined as 50% reduction in headache days from pre-treatment to posttreatment and pre-treatment to follow-up (dichotomous).*	Child Activity Limitations Interview (range 0-32) *Children are asked to pick 8 activities from a list of 21, according to which are most difficult due to pain. Importance of each activity is measured on a 5-point scale (0-4; 4 = extremely important)* *Internet CBT (M, SD)* Pre: 6.54 (4.79) Post: 4.83 (4.78) 3-month FU: 5.19 (5.02) *Specialised treatment (M, SD)* Pre: 6.12 (4.34) Post: 4.86 (4.40) 3-month FU: 5.27 (4.61) Between group difference over time: $F(2, 128) = .11$, $p = .89$ *Effect sizes [group difference over time]* Pre-Post: d = -.04 Pre- FU: d = .04	ARCS – parent protective responses *Internet CBT (M, SD)* Pre: 1.66 (.49) Post: 1.40 (.52) 3-month FU: 1.36 (.39) *Specialised treatment (M, SD)* Pre: 1.45 (.48) Post: 1.44 (.58) 3-month FU: 1.34 (.59) Between group difference over time: $F(2, 99) = .51$, $p = .60$ *Effect sizes [group difference over time]* Pre-Post: d = -.27 Pre- FU: d = -.26 CDI (depression) *Internet CBT (M, SD)* Pre: 48.56 (10.48) Post: 46.30 (10.03) 3-month FU: 44.75 (9.52) *Specialised treatment (M, SD)* Pre: 49.59 (9.67) Post: 47.48 (9.50) 3-month FU: 43.74 (6.45) Between group difference over time: $F(2, 96) = 1.64$, $p = .20$ *Effect sizes [group difference over time]* Pre-Post: d = .06 Pre- FU: d = .46 RCMAS-2 (anxiety) *Internet CBT (M, SD)* Pre: 49.68 (10.50) Post: 46.33 (8.99) 3-month FU: 45.82 (10.96) *Specialised treatment (M, SD)* Pre: 49.03 (10.96) Post: 48.32 (10.81) 3-month FU: 45.36 (9.90) Between group difference over time: $F(2, 103) = .71$, $p = .50$ *Effect sizes [group difference over time]* Pre-Post: d = -.24 Pre- FU: d = .09 Sleep duration (minutes) *Internet CBT (M, SD)* Pre: 371.75 (56.76) Post: 369.52 (75.39) *Specialised treatment (M, SD)* Pre: 371.40 (65.79) Post: 383.83 (58.92) Between group difference over time: $F(1, 44) = 1.09$, $p = .30$ *Effect sizes [group difference over time]* Pre-Post: d = -.29

						monitor. 53 participants enrolled in the sleep assessment (26 in intervention group; 27 in standalone treatment)					Internet CBT (post): 27.3% improved Internet CBT (FU): 43.2% improved Specialised treatment (post): 17.9% improved Specialised treatment (FU): 25.6% improved Posttest comparison non-significant; X^2 (1) = .90, *p* = .34 FU comparison non-significant; X^2 (1) = 2.54, *p* = .11		Pre- FU: d = incomplete Sleep efficiency *Calculated as the ratio of estimated total sleep time divided by the sleep period. % values closer to 100 indicate more time asleep and less time awake in bed.* *Internet CBT (M, SD)* Pre: 75.89 (9.53) Post: 75.79 (12.42) *Specialised treatment (M, SD)* Pre: 76.50 (11.60) Post: 78.33 (9.30) Between group difference over time: *F*(1, 44) = 1.09, *p* = .30 *Effect sizes [group difference over time]* Pre-Post: d = -.34 Pre- FU: d = incomplete Treatment engagement, satisfaction, acceptability. High engagement; average of 7 out of 8 modules completed by adolescents (SD = 1.42); average of 6 out of 8 modules completed by parents (SD = 2.78) *Posttreatment* Satisfaction (1-5) (adolescents): M = 3.6 (.50) Satisfaction (1-5) (parents): M = 3.73 (.47) Acceptable (1-5) (adolescents): M = 3.38 (.74) Acceptable (1-5) (parents): M = 3.89 (.55) *Follow-up* Satisfaction (1-5) (adolescents): M = 3.33 (.59) Satisfaction (1-5) (parents): M = 4.18 (.65) Acceptable (1-5) (adolescents): M = 3.43 (.63) Acceptable (1-5) (parents): M = 3.89 (.65)
Web-MAP2	Palermo et al. (2015)	USA & Canada	*N* = 135 Age range: 11 to 17 years Age (M) = 14.7 years (SD 1.6) Male *n* = 30 (22.2%) Female *n* = 105 (77.8%) Intervention group from RCT (Palermo et al., 2016)	Chronic pain (mixed)	Pre-post	Immediate post-test analysis conducted on data from the RCT by Palermo et al. (2016). New paediatric chronic pain patients were recruited over a 3-year period from 14 participating multidisciplinary pain clinics. Random-effects growth mixture models were used to establish pain and functional disability trajectories over the course of 8-weeks internet CBT treatment (see	• CBT • Social Learning Theory • Family Systems	Not specified in this research paper	HCP input to original version of intervention is described in Long and Palermo (2008).	N/A	Pain intensity (0-10; 10 = worst pain) Pre (M, SD): 5.72, 2.24 Post (M, SD): 4.53, 3.05 within-subject change: paired *t*(134) = 5.66, *p* <.001 Effect size (d) = 0.45 (marked improvement) Trajectories A class 4 solution was the best fit for the data. Data was grouped as follows: No or little improvement; weak trend, linear (*n* = 84, 62.2%). Pain dropped at a rate of 0.08 units per week (*p* <.05). Substantial improvement; strong trend, linear (*n* = 23,	Functional limitations (scale 0-8 for this analysis) Pre (M, SD): 3.95, 2.15 Post (M, SD): 2.81, 2.07 within-subject change: paired *t*(100) = 5.40, *p* <.001 Effect size (d) = 0.52 (marked improvement) Trajectories A class 5 solution was the best fit for functioning data. This was grouped as follows: No or little improvement; weak trend, linear (*n* = 77, 57.0%). Pain dropped at a rate of 0.16 units per week (*p* <.001).	N/A

						Palermo et al., 2016).					17.0%). Pain dropped at a rate of 0.82 units per week (*p* <.001). Moderate improvement; moderate trend, linear (*n* = 22, 16.3%). Pain dropped at a rate of 0.46 units per week (*p* <.001). Upward quadratic trend (*n* = 6, 4.4%) *Baseline pain and pain location were predictive of subsequent intensity ratings.*	Substantial improvement; strong trend, linear (*n* = 14, 10.4%). Disability levels dropped at a rate of 0.63 units per week (*p* <.001). Moderate improvement; moderate trend, linear (*n* = 31, 23.0%). Disability levels dropped at a rate of 0.43 units per week (*p* <.001). Downward quadratic trend (*n* = 7, 5.2%) Upward quadratic trend (*n* = 6, 4.4%) *Baseline functional disability, age, sex, and pain location were predictive of subsequent functioning scores.* Pain & functioning changes relative to baseline No differences in rate of change in pain and disability after module 1. Changes in pain and function occur concurrently throughout treatment (see Figure 3 of this research paper).	
Web-MAP2	Palermo et al. (2016)	USA & Canada	*N* = 273 [adolescent-parent dyads] Adolescents Age range: 11 to 17 years Age (M) = 14.7 years (SD 1.6) Male *n* = 68 (24.9%) Female *n* = 205 (75.1%) Parents *Parent age range/ mean not reported.* Female: *n* = 257 (94.1%)	Chronic pain (mixed)	RCT	New paediatric chronic pain patients were recruited over a 3-year period from 14 participating multidisciplinary pain clinics. Adolescents were randomly assigned to either internet-delivered CBT (*n* = 138) or internet-delivered education (*n* = 135). The CBT group received access to the full Web-MAP2 program. The new iteration of the program has five components (1) treatment modules (x8), (2) daily diaries and assessments (3) audio files for relaxation (compass), (4) a progress tracker ('passport'), and (5 message centre for communication with online therapist (standardised manual for therapist reference). Website remained travel themed. Participants were asked to log in to complete 1 module per week (30min each). Skills were also encouraged to be practiced throughout.	• CBT • Social Learning Theory • Family Systems	Not specified in this research paper.	Online assignments were reviewed by 5 study coaches, one had a master's degree and 4 were PhD level psychology postdoctoral fellows. All coaches had previous experience in CBT. All coaches supervised by licensed clinical psychologist throughout study. HCP input to original version of intervention is described in Long and Palermo (2008).	N/A	Pain intensity (0-10; 10 = worst pain) *CBT (M, SD)* Pre: 6.23 (1.72) Post: 5.87 (2.05) 6-month FU: 5.85 (1.97) *Education (M, SD)* Pre: 5.78 (1.94) Post: 5.59 (2.15) 6-month FU: 5.55 (2.02) Between group difference pre-post: b = -0.28, *p* = .24 Between group difference pre-FU: b = -0.30, *p* = .07.	Child Activity Limitations Interview (range 0-32) *Children are asked to pick 8 activities from a list of 21, according to which are most difficult due to pain. Importance of each activity is measured on a 5-point scale (0-4; 4 = extremely important)* *CBT (M, SD)* Pre: 7.42 (4.52) Post: 5.68 (4.38) 6-month FU: 5.46 (4.32) *Education (M, SD)* Pre: 7.01 (4.56) Post: 5.65 (4.69) 6-month FU: 6.16 (5.04) Between group difference pre-post: b = -0.43, *p* = .39 Between group difference pre-FU: b = -1.13, *p* = .03*, effect size (d) = -0.25 BAPQ – depression (range 0-30) *CBT (M, SD)* Pre: 11.31 (4.95) Post: 9.71 (5.10) 6-month FU: 9.55 (5.13) *Education (M, SD)* Pre: 9.94 (4.80) Post: 9.32 (5.37) 6-month FU: 9.49 (5.58) Between group difference pre-post: b = -0.59, *p* = .04*, effect size (d) = -0.09 Between group difference pre-FU: b = -0.93, *p* = .08 . BAPQ – anxiety (pain-related) (range 0 to 28)	Treatment expectancy No significant difference between internet CBT and education groups; Adolescents: *t*(265) = 1.22, *p* = .23 Parents: *t*(266) = 0.64, *p* = .52 Sleep quality (ASWS; range 1-6) *CBT (M, SD)* Pre: 3.49 (0.80) Post: 3.75 (0.76) 6-month FU: 3.76 (0.80) *Education (M, SD)* Pre: 3.63 (0.80) Post: 3.77 (0.84) 6-month FU: 3.76 (0.77) Between group difference pre-post: b = 0.13, *p* = .07 Between group difference pre-FU: b = 0.14, *p* = .04*, effect size (d) = 0.16 ARCS – protect *CBT (M, SD)* Pre: 1.44 (0.56) Post: 1.05 (0.57) 6-month FU: 1.00 (0.58) *Education (M, SD)* Pre: 1.41 (0.62) Post: 1.29 (0.60) 6-month FU: 1.17 (0.63) Between group difference pre-post: b = -0.26, *p* <.001*, effect size (d) = -0.49 Between group difference pre-FU: b = -0.19, *p* = .001, effect size (d) = -0.40 ARCS – minimise *CBT (M, SD)* Pre: 0.96 (0.51)

	Adolescent program was separate from parent version. Adolescent modules: (1) chronic pain education, (2) recognizing stress and negative emotions, (3) deep breathing and relaxation, (4) implementing coping skills at school, (5) cognitive skills, (6) sleep hygiene and lifestyle, (7) staying active, and (8) relapse prevention. Parent modules: (1) education about chronic pain, (2) recognizing stress and negative emotions, (3) operant strategies i, (4) operant strategies ii, (5) modelling, (6) sleep hygiene and lifestyle, (7) communication, and (8) relapse prevention. Message centre allowed communication between participants and coach about weekly assignments however participants could also initiate messages as needed. Control version contained: (1) modules with information from publicly available educational web sites about pediatric chronic pain management (e.g. National Headache Foundation), and (2) diary and assessments. Measures were assessed at pre-treatment, posttreatment and 6-month follow-up. All data was collected online. All participants completed a pre-treatment measure of expectancy (10 questions, 5-point scales). The primary outcome was activity limitations (Child Activity Limitations Interview - diary). Secondary outcomes included pain intensity (0-10 NRS). Emotional functioning was measured using the			*CBT (M, SD)* Pre: 13.79 (6.04) Post: 10.56 (5.91) 6-month FU: 10.35 (6.12) *Education (M, SD)* Pre: 12.66 (5.28) Post: 10.85 (6.10) 6-month FU: 10.23 (5.45) Between group difference pre-post: b = -1.33, *p* = .04*, effect size (d) = -0.13 Between group difference pre-FU: b = -0.89, *p* = .17). *Statistical significance at *p* <.05	Post: 0.95 (0.47) 6-month FU: 0.95 (0.49) *Education (M, SD)* Pre: 0.99 (0.65) Post: 0.99 (0.68) 6-month FU: 0.97 (0.68) Between group difference pre-post: b = -0.02, *p* = .79 Between group difference pre-FU: b = 0.06, *p* = .93 ARCS – distract *CBT (M, SD)* Pre: 2.74 (0.56) Post: 2.46 (0.68 6-month FU: 2.39 (0.71) *Education (M, SD)* Pre: 2.69 (0.61) Post: 2.51 (0.63) 6-month FU: 2.47 (0.67) Between group difference pre-post: b = -0.09, *p* = .16 Between group difference pre-FU: b = -0.13, *p* = .06 HHI-pain (child) *CBT (M, SD)* Pre: 33.86 (9.86) Post: 31.41 (8.30) 6-month FU: 31.69 (9.26) *Education (M, SD)* Pre: 33.52 (9.41) Post: 34.24 (9.10) 6-month FU: 34.13 (8.83) Between group difference pre-post: b = -3.06, *p* = .002*, effect size (d) = -0.30 Between group difference pre-FU: b = -2.66, *p* = .007*, effect size (d) = -0.26 HHI-pain (parent) *CBT (M, SD)* Pre: 32.99 (8.57) Post: 31.64 (9.04) 6-month FU: 31.52 (9.08) *Education (M, SD)* Pre: 33.01 (9.48) Post: 33.38 (9.20) 6-month FU: 33.12 (9.10) Between group difference pre-post: b = -1.59, *p* = .08 Between group difference pre-FU: b = -1.52, *p* = .09 BAPQ-PIQ (impact of parenting a child with pain) Treatment produced many positive changes in parent pain-related impact. These included: Anxiety symptomatology; pre- FU: b = -1.37, *p* =.02*, effect size (d) = -0.39 [no significant effect pre-post] Depressive symptomatology; pre-post: b = -1.44, *p* =.05*, effect size (d) = 0.27. This effect increased over time. Pre-FU: b =-2.25, *p* = .002*, effect size (d) =0.44

Bath Adolescent pain Questionnaire (BAPQ) – pain-related anxiety and depression subscales (Eccleston et al., 2005). Sleep quality was measured using the adolescent sleep wake scale (ASWS (LeBourgeois et al., 2005)). ARCS – parental response to pain behaviour; protect minimise and distract scales used (full measure), and miscarried helping (HHI-Pain – child & parents report (Harris et al., 2008)) were assessed. Treatment acceptability, satisfaction and engagement (TEI-SF (Kelley et al., 1989)) was also evaluated.		Behaviour responses to adolescent pain; pre-post: b = -2.55, *p* = .001*, effect size (d) = -0.45 [not maintained at follow-up] Reduction in self-blame; pre-post: b = -1.72, *p* = .03*, effect size (d) = 0.31. Pre-FU; b = -2.24, *p* - .003*, effect size (d) = -0.34 *Statistical significance at *p* <.05 Treatment acceptability & satisfaction (TEI-SF) (score range: 9 -45) Moderate satisfaction and acceptability overall for the education group. Posttreatment: youth: M = 29.9, SD = 5.0; parent: M = 30.2, SD = 4.9 Follow-up: youth, M = 29.7, SD = 5.9; parent, M = 29.6, SD = 6.0 There was significantly higher acceptability and satisfaction in the CBT group; Posttreatment: youth: M = 32.2, SD = 4.7, *t*(253) = 3.84, *p* < .001; parent: M = 33.0, SD = 4.5, *t*(254) = 4.89, *p* <.001 Follow-up: youth: M = 31.9, SD = 4.9, *t*(246) = 3.25, *p* < .001; parent: M = 32.8, SD = 5.2, *t*(243) = 4.48, *p* < .001 Satisfaction (website) Moderate satisfaction overall. Adolescents in the CBT group rated higher preference for the appearance of the program, the theme, and rated the overall usefulness as higher. Results were similar for parent groups. Adolescents – appearance; CBT: M = 4.1, SD = 0.8 vs education: M = 3.8, SD = 1.0, *t*(252) = 2.31, *p* = .02 Adolescents – theme; CBT: M = 4.2, SD = 1.0 vs education: M = 3.9, SD = 1.1, *t*(255) = 2.60, *p* = .01 Adolescents – usefulness; CBT: M = 4.1, SD = 0.8 vs education: M = 3.8, SD = 1.0, t(253) = 2.13, *p* = .03 Parents – appearance; CBT: M = 4.4, SD = 0.7 vs education: M = 4.1, SD = 0.8, *t*(251) = 3.89, *p* <.0001 Parents– theme; CBT: M = 4.3, SD = 0.9 vs education: M = 4.0, SD = 0.9, *t*(252) = 2.95, *p* = .003 Parents – usefulness; CBT: M = 4.5, SD = 0.7 vs education: M = 4.0, SD = 0.9, t(245) = 4.46, *p* < .0001 Engagement Participants completed an average of 7 to 8 modules in both groups (high engagement) – this includes adolescents and parents. 67% of families in the CBT group completed all modules.

													80% of families in the education group completed all modules.
Web-MAP2	Fisher et al. (2017)	USA & Canada	*N* = 122 [adolescent-parent dyads] [a] Age range = 11 to 17 years Age (M) = 14.6 years (SD = 1.6) Male: 21.7% Female: 78.3 % Intervention group from RCT (Palermo et al., 2016)	Chronic pain (mixed)	Pre-post	Secondary analysis conducted on data from the RCT by Palermo et al. (2016). Adolescents and parents from the CBT arm of the study selected two treatment goals each. These were selected in the web-based program: "... Here is a list of activities that you said are difficult for you because of pain. Read through this list and pick two activities that you would like to try and do more of during this program." A similar statement was given to parents on their version of the website, regarding activities they would like their child to increase. Pain intensity and functioning were measured at baseline, posttest, 6 and 12-month follow-up; dyads that agreed on goals were compared to dyads that no agreement in this analysis. To measure goal agreement, a dichotomous variable was created; 'in agreement' was categorized as those who has one or matching goal, and 'no agreement' was coded for those who had no matching goals. Goals had three categories; active, routine and other activities – the other activities category was highly heterogeneous and hence excluded from the analyses. Three final groups were thereby created: 1. agreement on routine treatment goals; 2. agreement on (physically) active treatment goals; 3. no agreement.	- CBT - Social Learning Theory - Family Systems	Not specified in this research paper.	HCP input to original version of intervention is described in Long and Palermo (2008).	N/A	Pain intensity (0-10; 10 = worst pain) Comparisons made between dyads who agreed on goals verses no agreement. Dyads that had agreement on any goal reported significantly reduced pain at each time point, compared to those with no agreement. Posttreatment: *F*(1,88) = 8.00, n^2 = 0.08, *p* = .006 Agreement M = 5.59, SD = 2.05; No agreement M = 6.64, SD = 1.73 6-month FU: *F*(1,88) = 5.15, n^2 = 0.55, *p* = .026 Agreement M = 5.58, SD = 1.98; No agreement M = 6.43, SD = 1.62 and 12-month FU: *F*(1,88) = 4.94, n^2 = 0.05, *p* = .029 Agreement M = 5.52, SD = 1.91; No agreement M = 6.40, SD = 1.73 *Baseline pain levels used as covariate.* Routine verses active goals MANCOVAs used to investigate whether goal type (routine/ active) were associated with pain intensity. Significantly reduced pain intensity was found in dyads that agreed on active treatment goals compared to those who agreed on routine goals and those who had no agreement at posttest; *F*(2,84) = 4.95, n^2 = 0.11, *p* = .009 Significantly reduced pain intensity was found in dyads that agreed on active treatment goals compared to those who had no agreement an 6 and 12-month follow-up; 6-month FU: *F*(2,84) = 3.56, n^2 = 0.08, *p* = .033 12-month FU: *F*(2,84) = 3.59, n^2 = 0.08, *p* = .032 *Baseline pain levels controlled for.*	Child Activity Limitations Interview (range 0-32) *Children are asked to pick 8 activities from a list of 21, according to which are most difficult due to pain. Importance of each activity is measured on a 5-point scale (0-4; 4 = extremely important)* Comparisons made between dyads who agreed on goals verses no agreement. Dyads that had goal agreement did not differ in functioning scores at any time point, compared to those with no agreement. Posttreatment: *F*(1,102) = 3.40, n^2 = 0.03, *p* = .068 Agreement M = 5.11, SD = 3.92; No agreement M = 6.50, SD = 4.74 6-month FU: *F*(1,102) = 3.23, n^2 = 0.03, *p* = .075 Agreement M = 4.90, SD = 4.27; No agreement M = 6.11, SD = 4.30 and 12-month FU: *F*(1,102) = 0.24, n^2 < 0.01, *p* = .623 Agreement M = 4.50, SD = 4.11; No agreement M = 4.86, SD = 3.86 *Baseline functioning used as covariate.* Routine verses active goals MANCOVAs used to investigate whether goal type (routine/ active) were associated with levels of functioning. Improved functioning was found in dyads that agreed on an active treatment goal compared to dyads that had no agreement. This effect was only significant at 6-month follow-up; *F*(2,97) = 3.07, n^2 = 0.06, *p* = .051 MANCOVAs at posttest and 12-month follow-up were not significant: Posttest: *F*(2,97) = 1.90, n^2 = 0.04, *p* = .155 12-month FU: *F*(2,97) = 0.64, n^2 = 0.01, *p* = .528 *Baseline functioning levels controlled for.*	Treatment goal concordance Overall moderate agreement of goals (at least 1 goal) within the sample; Κ = .520, *p* <.001. However, there was little agreement on two matching treatment goals; Κ = -.008, *p* =.720 Goal agreement (n (%)) No agreement: 48 (39) Agreement on one or more goals: 74 (61) Agreement on active goals: 28 (23) Agreement on routine goals: 41 (33) Agreement on other goals: 5 (4) Most frequently selected goal by adolescents and parents was 'going to school', followed by 'sports' for adolescents, and 'sleep' for parents.
Web-MAP2	Law et al. (2018)	USA	*N* = 228 [adolescent-	Chronic pain (mixed)	RCT	Secondary data analysis examining the effect of	- CBT - Social Learning Theory	Not specified in this	HCP input to original version of intervention	N/A	N/A	N/A	Health Care Cost Outcomes (USD $: M, (SD))

		Canadian participants were removed from this analysis.	parent dyads] [a] Age range: 11 to 17 years Age (M) = 14.7 years (SD = 1.7) Male: 25.1% Female: 74.9%		[Secondary data analysis (Palermo et al., 2016)]	adolescent participation in the RCT of Web-Map2 on longitudinal health care costs. The intervention and procedure for the main study is provided in Palermo et al. (2016). This study analysed 112 participants from the CBT internet treatment group, and 116 participants from the parallel internet education group (EDU). Health care cost outcomes were measured at pre-treatment and 12-month follow-up using the Client Service Receipt Inventory; this is a parent report measure of health care costs over 12 months retrospectively, Analyses were broken down into direct medical costs, direct non-medical costs (i.e. out-of-pocket expenses) and indirect costs (i.e. productivity loss).	- Family Systems	research paper.	is described in Long and Palermo (2008).				The reduction in total costs was not statistically different between the CBT group and the EDU group (b = .77, *p*= .32, 95%CI = .46–1.29) *Direct medical costs* CBT (pre): 12,291 (17,566) CBT (12mnth FU): 10,529 (20,383) EDU (pre): 9,965 (9,841) EDU (12mnth FU): 7,743 (13,358) No significant difference between groups in change in costs over time: (b = .84, *p* = .50, 95%CI = .51–1.39) *Direct non-medical costs* CBT (pre): 929 (2,732) CBT (12mnth FU): 815 (2,518) EDU (pre): 1,397 (4,546) EDU (12mnth FU): 1,048 (5,899) No significant difference between groups in change in costs over time: (b = .45, *p* = .09, 95%CI = .18–1.12) *Indirect costs* CBT (pre): 3,791 (13,071) CBT (12mnth FU): 2,487 (9,748) EDU (pre): 4,543 (13,310) EDU (12mnth FU): 1,518 (4,391) No significant difference between groups in change in costs over time: (b = .36, *p* = .07, 95%CI = .12–1.07)
Web-MAP2	Chen et al. (2019)	USA & Canada	*N* = 123 [adolescent-parent dyads] [a] Age range: 11 to 17 years Age (M) = 14.7 years (SD = 1.6) Male, n(%) = 26 (21.1) Female, n (%) = 97 (78.9)	Chronic pain (mixed)	RCT (intervention group only) [Secondary data analysis (Palermo et al., 2016)]	Textual and visual analytic approach to investigate participant engagement with Web-MAP2. Data analysis focused on understanding the content of messages between coaches and participants. Topic modelling (Latent Dirichlet Allocation within the MAchine Learning for LanguagE Toolkit (MALLET)) was used to identify topics discussed, followed by cluster analysis, using the Communication History Analysis Interface (CHAI, via Python), to identify subgroups of participants with similarities. Clusters are compared using ANOVAs and Chi-squared where appropriate. Comparisons include number of messages, message length, module completion rates, and percentage of interactive fields completed.	- CBT - Social Learning Theory - Family Systems	Not specified in this research paper.	HCP input to original version of intervention is described in Long and Palermo (2008). All assignments throughout the study were reviewed by 1 of 5 coaches. Coaches used the message centre to provide participants with feedback on behavioural tasks throughout the study. Adolescents and parents could also initiate conversations. A manual was used to standardise messages and coaches were supervised by a licenced clinical psychologist.	N/A	N/A	N/A	Message data (n) All messages = 3426 Coaches = 2692 Parents = 347 Adolescents = 387 Topic modelling 15-topic solution chosen to establish a balance between topic diversity and ease of interpretability. *See original paper for quoted examples of each topic & visualisations.* Coaches: Topics and themes identified: *Theme 1:* Treatment content *Topics (and proportion of messages assigned, %):* 1. reinforcing behaviours in parents (4.6) 2. relaxation skills (3.8) 3. working toward goals (8.9) 6. encouraging parents to share their coping strategies (4.3) 8. thought replacement/ stopping (6.9) 10. encouragement and strategies of how to utilise the program (7.4) 12. lifestyle changes (8.7) 13. touching base on progress (8.2) *Theme 2:* Administrative and Technical *Topics:* 5. reminders to complete the web-based diary (10.3) 7. responding to questions and information about assignments (7.5)

Demographic variables were also compared by cluster using ANOVA and Fisher Exact tests. This study excluded 15 participants from the original CBT intervention group (n = 138) who did not send any messages. 1 participant was excluded as they “did not meet the eligibility criteria for the main study”.		9. first greeting and general instructions (11.2) 11. introduction to Web-MAP2 and general instructions (5.4) *Theme 3:* Rapport building *Topics:* 4. responding to participants descriptions of activities, interests, family (8.0) 14. expressing empathy, followed by constructive feedback (3.2) 15: asking for updates about life and general treatment progress (1.6) Adolescents and parents: Topics and themes identified: *Theme 1:* Health Management and Treatment Content *Topics (and proportion of messages assigned, %):* 3. progress in learning pain and stress management techniques (11.8) 4. pain (16.1) 5. medications, nutrients and lab results (0.5) 11. rewards system, coping and achieving goals (3.3) 14. fatigues, sleep, relaxation techniques (4.6) *Theme 2:* Questions and concerns *Topics:* 1. references to assignments (13.6) 2. suggestions (2.2) 8. questions (3.8) *Theme 3:* Activities and interests *Topics:* 15. fun with friends and family (16.6) 6. creative arts (3.3) 7. music, sports and school (1.5) 10. drama and reading 2.4) 13. trips (1.9) *Theme 4:* Other topics: 9. family (2.2) 12. time (16.6) Cluster analysis k-means clustering: 4-cluster solution *See original paper for visualisation.* Cluster 1: assignment focused (n = 16) Cluster 2: short-message histories (n = 62) Cluster 3: Pain-focused (n = 20) Cluster 4: Activity focused (n = 25) There were statistically significant differences in participation and demographic variables between-clusters for: • adolescent age, $F(3, 119) = 3.1$, $p = .03$ • number of messages (adolescents), $F(3, 119) = 16.2$, $p < .001$ • number of messages (parents), $F(3, 119) = 8.7$, $p < .001$ • module completion rate (adolescents), $F(3, 119) = 2.8$, $p = .05$ • interactive fields completed (adolescents), $F(3, 119) = 3.8$, $p = .01$

													Engagement *Modules completed, M (SD)* Adolescents = 7.5 (1.3) Parents = 7.3 (1.5) *Interactive fields completed, M(SD)* Adolescents = 79.6 (15.4) Parents = 72.8 (19.6)
Web-MAP2	Murray et al. (2019)	USA & Canada	*N* = 273 [adolescent-parent dyads] [a] Age range = 11 to 17 years Age (M) = 14.71 years (SD = 1.62) Male = 24.9% Female = 75.1%	Chronic pain (mixed)	RCT [Secondary data analysis (Palermo et al., 2016)]	This study aimed to identify individual characteristics for which CBT yielded the greatest clinical benefit among adolescents participating in the Web-MAP2 trial at 12-month follow up. Note that the original trial reported 6-month follow-up (Palermo et al., 2016). Intervention group (CBT), n = 138 dyads allocated. Control group (pain education), n = 135 dyads allocated. Final sample consisted of 269 dyads; CBT n = 134, pain education n = 135. Multilevel growth modelling (MLM), guided by the Fournier Approach, was used to test adolescent- and parent-level moderators and ‘general predictors’ of change in pain-related disability (primary outcome). Adolescent moderators: adolescent age, sex, pain intensity (NRS 0 to 10), emotional distress (BAPQ), and sleep quality (ASWS). Parent moderators: 2) parent education level, and protective parenting behaviour (ARCS). Separate multilevel models were developed for each domain of functional disability. Effect sizes presented using Cohen’s ds (d = .20, d = .50, and d = .80 are interpreted as small, moderate, and large effects). Post-hoc power analyses were performed for the most complex model.	• CBT • Social Learning Theory • Family Systems	Not specified in this research paper.	HCP input to original version of intervention is described in Long and Palermo (2008).	N/A	N/A	Pain-related disability *Pre-treatment:* CBT: M= 7.4, SD = 4.4; Education: M= 7.0; SD = 4.6 *6-month follow-up* CBT: M= 5.5, SD = 4.3; Education: M= 6.2, SD = 5.0 Adolescents in the CBT group achieved statistically greater reductions in disability than the education group from pre-treatment to 6-month follow-up (b = 2.29, *p* = .002, d = -.25) Clinical significance: CBT group; 27.2% improved or recovered, education group; 21.8 % (X^2 (2) = 1.36, *p* = .507) *12-month follow-up* CBT: M= 5.0, SD = 4.3 Education: M= 5.3, SD = 4.5 There were not significant differences in disability from pre-treatment to 12-month follow-up (b = 1.40, *p* = .054, d = -.16) Clinical significance: CBT group; 35.0% improved or recovered, education group; 27.3 % (X^2 (2) = 2.27, *p* = .321)	**Predictors and moderators of changes in disability** *Only slopes that reached significance in Step 4 are reported.* Pre- 6-month slopes *Child-level model* Treatment X Time: b = 2.29 , t = 3.13, *p* = .002 Pain intensity X Time: b = -1.16, t = -4.41, *p* < .001 Sleep Quality X Time: b = - .52 , t = -1.94 , *p* = .052 Adolescent age X time: b = 1.55, t = 2.15, *p* = .032 Adolescent age X Treatment X Time: b = -2.82, t = 2.81, *p* = .005 *Parent-level model* Treatment X Time: b = 1.16, t = 2.18, *p* = .030 Distress X Time: b = .79, t = 1.71, *p* = .087 Distress X Treatment X Time: b = -.69, t = 2.18, *p* = .261 *Combined (final) model* Treatment X Time: b = 2.29, t = 3.13, *p* = .002 Pain intensity X Time: b = - 1.22, t = - 4.65, *p* < .001 Sleep Quality X Time: b = -. 46, t = -1.76, *p* = .079 Adolescent age X time: b = 1.39, t = 1.94 , *p* = .053 Distress (parent) X Time: b = .79, t =1.79 , *p* = .074 Adolescent age X Treatment X Time: b = -2.85, t = 2.77, *p* = .006 Distress (parent) X Treatment X Time: b = -.42, t = -.70, *p* = .486 Pre- to 12-month slopes *Child-level model* Treatment X Time: b = 1.36, t = 1.86, *p* = .063 Pain intensity X Time: b = - 1.73, t = -6.62 , *p* < .001 Sleep Quality X Time: b = -.83, t = -3.12, *p* = .002 Adolescent age X time: b = 1.75, t = 2.42, *p* = .016 Adolescent age X Treatment X Time: b = - 2.13, t = - 2.06, *p* = .040 *Parent-level model* Treatment X Time: b = .90, t = 1.69, *p* = .092 Distress X Time: b = 1.47, t = 3.19, *p* = .001 Distress X Treatment X Time: b = -1.25, t = -2.02, *p* = .044 *Combined (final) model* Treatment X Time: b = 1.40, t = 1.93, *p* = .054 Pain intensity X Time: b = -1.84, t = -7.04, *p* < .001 Sleep Quality X Time: b = -2.86, t = -7.04, *p* = .004 Adolescent age X time: b = 1.60, t = 2.20 , *p* = .028

			Distress (parent) X Time: b = 1.57, t = 3.53, *p* <. 001 Adolescent age X Treatment X Time: b = -2.07, t = -2.02, *p* = .044 Distress (parent) X Treatment X Time: b = -1.20, t = -2.00, *p* = .046 **Post-hoc analyses of significant moderators** **Adolescent age X treatment X time** CBT was associated with improvements in disability only for younger adolescents (aged 11-14 years) and not for older adolescents (aged 15-17 years) *[see Figure 2. in original paper].* *Younger adolescents* **Pre- 6months:** CBT: b = -2.92, SE = .51, *p* < .001; Education: b = -.46, SE = .53, *p* = .388 t[755] = -4.84, *p* < .001 effect size (d) = -.50 **Pre- 12months:** CBT: b = -3.34, SE = .51 *p* < .001; Education: b = -1.81, SE = .53, *p* = .001 t[755] = -3.10, *p* = .001 effect size (d) = -.20 *Older adolescents* **Pre- 6months:** t[755] = -.73, *p* = .234, effect size (d) = .01 **Pre- 12months:** t[755] = -.47, *p* = .320, effect size (d) = .04 **Parent distress X treatment X time** CBT was associated with significant improvements in disability at 12-month follow-up only where parents had low levels of distress at pre-treatment *[see Figure 3. in original paper].* *Low parent distress* **Pre- 12months:** CBT: b= -4.15, SE = .62, *p* < .001 Education: b = -2.07, SE = .47, *p* = .001 t[755] = 2.79, *p* = .003, effect size (d) = -.45 *High parent distress* **Pre- 12months:** t [755] = .78, *p* = .219, effect size (d) = -.09

[a] Age and sex of parents (within adolescent-parent dyads) was not reported in this paper

Supplementary Table 3. Criteria for Reporting the Development and Evaluation of Complex Interventions in healthcare: revised guideline (CReDECI 2). Checklist for 13 identified interventions

Aim To Decrease Anxiety and Pain Treatment (ADAPT)	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention's underlying theoretical basis	Cunningham et al. (2018), pp. 2
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Cunningham et al. (2018), pp. 3, 13
3. Illustration of any intended interactions between different components	Cunningham et al. (2018), pp. 3
4. Description and consideration of the context's characteristics in intervention modelling	Cunningham et al. (2018), pp. 2
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Cunningham et al. (2018)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Not reported
7. Description of the strategy for delivering the intervention within the study context	Not reported
8. Description of all materials or tools used delivery the intervention	Not reported
9. Description of fidelity of the delivery process compared the study protocol	Not reported
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported

Internet CBT for children with pain-related gastrointestinal disorders (no specific name)	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention's underlying theoretical basis	Bonnert et al. (2014), pp. 142
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Lalouni et al. (2017)
3. Illustration of any intended interactions between different components	Lalouni et al. (2017)
4. Description and consideration of the context's characteristics in intervention modelling	Lalouni et al. (2017), pp. 2
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Bonnert et al. (2019);Lalouni et al. (2017); Bonnert et al. (2014)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Bonnert et al. (2016), pp. 153
7. Description of the strategy for delivering the intervention within the study context	Bonnert et al. (2016), pp. 153

8. Description of all materials or tools used delivery the intervention	Bonnert et al. (2016), pp. 153-154
9. Description of fidelity of the delivery process compared the study protocol	Bonnert et al. (2016), pp. 154, 156
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Bonnert et al. (2016), pp. 160
13. Description of costs or required resources for the delivery of the intervention	Lalouni et al. (2019); Sampaio et al. (2019)
Customized CBT for adolescents with pain and emotional distress (no specific name)	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention's underlying theoretical basis	Flink et al. (2016), pp. 43-44
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Flink et al. (2016), pp.44-46
3. Illustration of any intended interactions between different components	Flink et al. (2016), pp.44-45
4. Description and consideration of the context's characteristics in intervention modelling	Flink et al. (2016), pp.44
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Flink et al. (2016)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Not reported
7. Description of the strategy for delivering the intervention within the study context	Not reported
8. Description of all materials or tools used delivery the intervention	Not reported
9. Description of fidelity of the delivery process compared the study protocol	Not reported
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported
DARWeb	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention's underlying theoretical basis	Nieto et al. (2015), pp. 494
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Nieto et al. (2015), pp. 494-495
3. Illustration of any intended interactions between different components	Nieto et al. (2015), pp. 494-495
4. Description and consideration of the context's characteristics in intervention modelling	Nieto et al. (2015), pp. 494

Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Nieto et al. (2015)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Not reported
7. Description of the strategy for delivering the intervention within the study context	Nieto et al. (2019), pp. 1513-1514
8. Description of all materials or tools used delivery the intervention	Nieto et al. (2019), pp. 1514
9. Description of fidelity of the delivery process compared the study protocol	Not reported
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported
Rheumates@Work	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention's underlying theoretical basis	Armbrust et al. (2015), pp. 3
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Armbrust et al. (2015), pp. 3-6
3. Illustration of any intended interactions between different components	Armbrust et al. (2015), pp. 3-5
4. Description and consideration of the context's characteristics in intervention modelling	Armbrust et al. (2015), pp. 2
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Armbrust et al. (2015)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Lelieveld et al. (2010), pp. 698
7. Description of the strategy for delivering the intervention within the study context	Lelieveld et al. (2010), pp. 698-699
8. Description of all materials or tools used delivery the intervention	Lelieveld et al. (2010), pp. 698-699
9. Description of fidelity of the delivery process compared the study protocol	Lelieveld et al. (2010), pp. 700-701
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Lelieveld et al. (2010), pp. 702
13. Description of costs or required resources for the delivery of the intervention	Not reported
Move It Now - guided interactive internet CBT for adolescents with chronic pain	
Item	Reported on page or in publication
First stage: Development	

1. Description of the intervention’s underlying theoretical basis	Voerman et al. (2015), pp. 1115-1116
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Voerman et al. (2015), pp. 1117-1118
3. Illustration of any intended interactions between different components	Voerman et al. (2015), pp. 1117-1118
4. Description and consideration of the context’s characteristics in intervention modelling	Voerman et al. (2015), pp. 1116
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Voerman et al. (2015)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Not reported
7. Description of the strategy for delivering the intervention within the study context	Not reported
8. Description of all materials or tools used delivery the intervention	Not reported
9. Description of fidelity of the delivery process compared the study protocol	Voerman et al. (2015), pp. 1117
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported
iCanCope with Pain™	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Stinson et al. (2014)
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Stinson et al. (2014)
3. Illustration of any intended interactions between different components	Stinson et al. (2014), pp.261
4. Description and consideration of the context’s characteristics in intervention modelling	Stinson et al. (2014)
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Lalloo et al. (2019)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Lalloo et al. (2019), pp. 3
7. Description of the strategy for delivering the intervention within the study context	Lalloo et al. (2019), pp. 3
8. Description of all materials or tools used delivery the intervention	Lalloo et al. (2019), pp. 3-4
9. Description of fidelity of the delivery process compared the study protocol	Not reported
10. Description of a process evaluation and its underlying theoretical basis	Not reported

11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Lalloo et al. (2019), pp. 10-11
13. Description of costs or required resources for the delivery of the intervention	Not reported

Interactive website for dysmenorrhea (no specific name)

Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Yeh et al. (2013), pp. 2
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Yeh et al. (2013), pp. 2-3
3. Illustration of any intended interactions between different components	Yeh et al. (2013), pp. 2-3
4. Description and consideration of the context’s characteristics in intervention modelling	Yeh et al. (2013), pp. 2
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Not reported
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Yeh et al. (2013), pp. 2
7. Description of the strategy for delivering the intervention within the study context	Not reported
8. Description of all materials or tools used delivery the intervention	Yeh et al. (2013), pp. 2-3
9. Description of fidelity of the delivery process compared the study protocol	Yeh et al. (2013), pp. 3-4
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported

Prototype website for web-based skills training for adolescents with migraine (no specific name)

Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Donovan et al. (2013), pp. 667
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Donovan et al. (2013), pp. 667-668
3. Illustration of any intended interactions between different components	Donovan et al. (2013), pp. 667-668
4. Description and consideration of the context’s characteristics in intervention modelling	Donovan et al. (2013), pp. 667
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Donovan et al. (2013)
Third stage: Evaluation	

6. Description of the control condition (comparator) and reasons for the selection	Not reported
7. Description of the strategy for delivering the intervention within the study context	Not reported
8. Description of all materials or tools used delivery the intervention	Not reported
9. Description of fidelity of the delivery process compared the study protocol	Not reported
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported

Teens taking charge: managing arthritis online	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Stinson, Toomey, et al. (2008)
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Stinson et al. (2010a)
3. Illustration of any intended interactions between different components	Stinson et al. (2010a)
4. Description and consideration of the context’s characteristics in intervention modelling	Stinson, Toomey, et al. (2008)
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Stinson et al. (2010a); Stinson et al. (2010b)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Connelly et al. (2019), pp. 365-366
7. Description of the strategy for delivering the intervention within the study context	Connelly et al. (2019), pp. 364-365
8. Description of all materials or tools used delivery the intervention	Connelly et al. (2019), pp. 364-365
9. Description of fidelity of the delivery process compared the study protocol	Connelly et al. (2019), pp. 367-368
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Not reported
13. Description of costs or required resources for the delivery of the intervention	Not reported

In-person CBT followed by 6-week online skill review for IBD (no specific name)	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	McCormick et al. (2010), pp. 3
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	McCormick et al. (2010), pp. 4
3. Illustration of any intended interactions between different components	McCormick et al. (2010), pp. 3-4
4. Description and consideration of the context’s characteristics in intervention modelling	McCormick et al. (2010), pp. 2
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Not reported
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	McCormick et al. (2010), pp. 2
7. Description of the strategy for delivering the intervention within the study context	McCormick et al. (2010), pp. 3
8. Description of all materials or tools used delivery the intervention	McCormick et al. (2010), pp. 3-4
9. Description of fidelity of the delivery process compared the study protocol	McCormick et al. (2010), pp. 5

10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	McCormick et al. (2010), pp. 9
13. Description of costs or required resources for the delivery of the intervention	Not reported
Internet-based self-help for paediatric recurrent headache (no specific name)	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Trautmann and Kröner-Herwig (2008), pp. 241-242
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Trautmann and Kröner-Herwig (2010), pp. 31
3. Illustration of any intended interactions between different components	Trautmann and Kröner-Herwig (2010), pp. 31
4. Description and consideration of the context’s characteristics in intervention modelling	Trautmann and Kröner-Herwig (2010), pp. 28
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Trautmann and Kröner-Herwig (2008)
Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Trautmann and Kröner-Herwig (2010), pp. 29
7. Description of the strategy for delivering the intervention within the study context	Trautmann and Kröner-Herwig (2010), pp. 32
8. Description of all materials or tools used delivery the intervention	Trautmann and Kröner-Herwig (2010), pp. 31
9. Description of fidelity of the delivery process compared the study protocol	Trautmann and Kröner-Herwig (2010), pp. 33, 36
10. Description of a process evaluation and its underlying theoretical basis	Not reported
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Not reported
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Trautmann and Kröner-Herwig (2010), pp. 36
13. Description of costs or required resources for the delivery of the intervention	Trautmann and Kröner-Herwig (2010), pp. 35
Web-MAP (Web-based Management of Adolescent Pain)/ Web-MAP2	
Item	Reported on page or in publication
First stage: Development	
1. Description of the intervention’s underlying theoretical basis	Palermo et al. (2009), pp. 209
2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	Palermo et al. (2009), pp. 208-209
3. Illustration of any intended interactions between different components	Palermo et al. (2009), pp. 208-209
4. Description and consideration of the context’s characteristics in intervention modelling	Palermo et al. (2009), pp. 208
Second stage: Feasibility and piloting	
5. Description of the pilot test and its impact on the definite intervention	Long and Palermo (2008)

Third stage: Evaluation	
6. Description of the control condition (comparator) and reasons for the selection	Palermo et al. (2016), pp.175
7. Description of the strategy for delivering the intervention within the study context	Palermo et al. (2016), pp. 175
8. Description of all materials or tools used delivery the intervention	Palermo et al. (2016), pp. 176-177
9. Description of fidelity of the delivery process compared the study protocol	Palermo et al. (2016), pp.179
10. Description of a process evaluation and its underlying theoretical basis	Murray et al. (2019)
11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	Murray et al. (2019)
12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	Fisher et al. (2017); Palermo et al. (2016), pp. 183
13. Description of costs or required resources for the delivery of the intervention	Not reported

Supplementary Table 4. Colour scale table indicating items on the CReDICI 2 checklist that were ‘present’ or ‘absent’ for each intervention included in the content analysis.

CReDICI 2 items	1.Description of the intervention’ s underlying theoretical basis	2. Description of all intervention components, including the reasons for their selection as well as their aims / essential functions	3. Illustration of any intended interactions between different components	4. Description and consideration of the context’ s characteristics in intervention modelling	5. Description of the pilot test and its impact on the definite intervention	6. Description of the control condition (comparator) and reasons for the selection	7. Description of the strategy for delivering the intervention within the study context	8. Description of all materials or tools used delivery the intervention	9. Description of fidelity of the delivery process compared the study protocol	10. Description of a process evaluation and its underlying theoretical basis	11. Description of internal facilitators and barriers potentially influencing the delivery of the intervention as revealed by the process evaluation	12. Description of external conditions or factors occurring during the study which might have influenced the delivery of the intervention or mode of action (how it works)	13. Description of costs or required resources for the delivery of the intervention
ADAPT	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪
CBT for children with gastrointestinal disorders (no specific name)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟩	🟩
Customized CBT for adolescents with pain (no specific name)	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪
DARWeb	🟩	🟩	🟩	🟩	🟩	🟪	🟩	🟩	🟪	🟪	🟪	🟪	🟪
Rheumates@Work	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟩	🟪
Move It Now	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟪	🟩	🟪	🟪	🟪	🟪
iCanCope with Pain™	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟩	🟪
Website for dysmenorrhea (no specific name)	🟩	🟩	🟩	🟩	🟪	🟩	🟪	🟩	🟩	🟪	🟪	🟪	🟪
Web-based skills training for adolescents with migraine (no specific name)	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟪	🟪	🟪	🟪	🟪	🟪
Teens Taking Charge	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟪	🟪
CBT with 6-week online skill review for IBD (no specific name)	🟩	🟩	🟩	🟩	🟪	🟩	🟩	🟩	🟩	🟪	🟪	🟩	🟪
Self-help for paediatric recurrent headache (no specific name)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪	🟪	🟩	🟩
Web-MAP/ Web-MAP2	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟪

Key:

🟩	🟪
Present	Absent

Supplementary Table 5. Search strategy (search terms by Higgins et al. (2018).

PubMed. Search in: Title, Abstract

Online	Ehealth OR e-health OR Mobile health OR mhealth OR m-health OR ICT OR e-pain OR computer* OR technolog* OR software OR internet* OR world wide web OR web-based OR email OR e-mail OR online OR phone* OR mobile* cellphone* OR cell phone* OR apps smartphone* OR smart phone* OR text messag* OR texting OR SMS
	AND
Pain	Pain* OR Fibromyalgia OR Irritable bowel syndrome OR Arthrit* OR Osteoarthrit* OR Headache* OR Migraine* OR Neuralgi* OR Neuropath* OR Complex regional pain syndrome OR Needle* OR inject* OR immuni* OR vaccin* OR Blood draw
	AND
Intervention	Intervention* OR Therap* OR Psychotherap* OR Selfmanag* OR self-manag* OR Assist* OR Treat* OR Assess* OR Measure* OR Monitor* OR Track*
	AND
Paediatric	Child* OR Adolescen* OR Teen* OR Youth* OR Infant* OR Pediatric* OR Paediatric* OR Newborn OR New-born OR Baby OR Toddler* OR Minors OR Boy* OR Girl* OR Kid* OR Schoolchild* OR Juvenil*

PsycINFO. Search in: Abstract

Online	Ehealth OR e-health OR Mobile health OR mhealth OR m-health OR ICT OR e-pain OR computer* OR technolog* OR software OR internet* OR world wide web OR web-based OR email OR e-mail OR online OR phone* OR mobile* cellphone* OR cell phone* OR apps smartphone* OR smart phone* OR text messag* OR texting OR SMS
	AND
Pain	Pain* OR Fibromyalgia OR Irritable bowel syndrome OR Arthrit* OR Osteoarthrit* OR Headache* OR Migraine* OR Neuralgi* OR Neuropath* OR Complex regional pain syndrome OR Needle* OR inject* OR immuni* OR vaccin* OR Blood draw
	AND
Intervention	Intervention* OR Therap* OR Psychotherap* OR Selfmanag* OR self-manag* OR Assist* OR Treat* OR Assess* OR Measure* OR Monitor* OR Track*
	AND
Paediatric	Child* OR Adolescen* OR Teen* OR Youth* OR Infant* OR Pediatric* OR Paediatric* OR Newborn OR New-born OR Baby OR Toddler* OR Minors OR Boy* OR Girl* OR Kid* OR Schoolchild* OR Juvenil*

CINAHL. Search in: Abstract

Online	Ehealth OR e-health OR Mobile health OR mhealth OR m-health OR ICT OR e-pain OR computer* OR technolog* OR software OR internet* OR world wide web OR web-based OR email OR e-mail OR online OR phone* OR mobile* cellphone* OR cell phone* OR apps smartphone* OR smart phone* OR text messag* OR texting OR SMS
	AND
Pain	Pain* OR Fibromyalgia OR Irritable bowel syndrome OR Arthrit* OR Osteoarthrit* OR Headache* OR Migraine* OR Neuralgi* OR Neuropath* OR Complex regional pain syndrome OR Needle* OR inject* OR immuni* OR vaccin* OR Blood draw
	AND
Intervention	Intervention* OR Therap* OR Psychotherap* OR Selfmanag* OR self-manag* OR Assist* OR Treat* OR Assess* OR Measure* OR Monitor* OR Track*
	AND
Paediatric	Child* OR Adolescen* OR Teen* OR Youth* OR Infant* OR Pediatric* OR Paediatric* OR Newborn OR New-born OR Baby OR Toddler* OR Minors OR Boy* OR Girl* OR Kid* OR Schoolchild* OR Juvenil*

EMBASE. Search in: Title. Limit to: *English Language*

Online	Ehealth OR e-health OR Mobile health OR mhealth OR m-health OR ICT OR e-pain OR computer* OR technolog* OR software OR internet* OR world wide web OR web-based OR email OR e-mail OR online OR phone* OR mobile* cellphone* OR cell phone* OR apps smartphone* OR smart phone* OR text messag* OR texting OR SMS
	AND
Pain	Pain* OR Fibromyalgia OR Irritable bowel syndrome OR Arthrit* OR Osteoarthrit* OR Headache* OR Migraine* OR Neuralgi* OR Neuropath* OR Complex regional pain syndrome OR Needle* OR inject* OR immuni* OR vaccin* OR Blood draw
	AND
Intervention	Intervention* OR Therap* OR Psychotherap* OR Selfmanag* OR self-manag* OR Assist* OR Treat* OR Assess* OR Measure* OR Monitor* OR Track*
	AND
Paediatric	Child* OR Adolescen* OR Teen* OR Youth* OR Infant* OR Pediatric* OR Paediatric* OR Newborn OR New-born OR Baby OR Toddler* OR Minors OR Boy* OR Girl* OR Kid* OR Schoolchild* OR Juvenil*

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