Preliminary Development of a Clinical Decision Support (CDS) Triage Tool Series for Interdisciplinary Pediatric Chronic Pain Programs

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A thesis submitted in accordance with the requirements for the Doctorate in Philosophy degree in Nursing at The University of Ottawa, Faculty of Health Sciences, School of Nursing

Preface

Personal Impetus

I am the Nurse Practitioner with the Chronic Pain Service at the Children's Hospital of Eastern Ontario (CHEO). I have earned a Master of Science in Nursing with a Graduate Diploma in Primary Health Care for Nurse Practitioners with the University of Ottawa in 2015. Prior to becoming a Nurse Practitioner, I worked as a Registered Nurse in orthopedic surgery, general surgery, emergency medicine and with the acute pain service at The Ottawa Hospital. I was the primary researcher, who founded the topic of this dissertation and was responsible for executing the three studies, writing each manuscript, and writing this dissertation. My personal impetus was ignited after starting my clinical role as a Nurse Practitioner in pediatric chronic pain. Part of my role was to triage patients referred to our interdisciplinary chronic pain program. It became quickly evident that these decisions were complex with no evidence-based guidance available. I witnessed how inaccurate triage decisions lead to inefficient access to care and prolonged suffering of the patient and family. This enticed me to search endlessly for literature that may help to describe the topic of triage in interdisciplinary pediatric chronic pain programs. I quickly realized this area has been largely understudied, which awakened my drive to rigorously investigate triage in this context with the goal of producing a clinically useful and evidence-based triage tool.

I did not seek funding for this dissertation; however I was awarded $500 for the CHEO Nursing Research Knowledge Translation award in 2022. This dissertation has received ethics approval from both the University of Ottawa's Research Ethics Board and the CHEO Research Ethics Board. My dissertation was developed in collaboration with my thesis committee members.

Contributions of Collaborators

My main collaborators included my supervisor, Dr. Janet Elaine Squires, and my thesis committee members Dr. Krystina B. Lewis, Dr. Lindsay Jibb, Dr. Tracey Bucknall and Dr. Christine Lamontagne. Dr. Squires is a Registered Nurse with clinical experience in intensive care. She is a Full Professor with the University of Ottawa's School of Nursing and is the University Research Chair in Health Evidence Implementation at the University of Ottawa. Dr. Squires is also a senior scientist with the Ottawa Hospital Research Institute. Her research focuses on improving knowledge translation, research utilization, measurement, and intervention design. Dr. Squires has widespread methodological expertise in quantitative and mixed methods research, including systematic reviews. Dr. Krystina Lewis is a Registered Nurse with an extensive background in cardiology and is an Associate Professor in the School of Nursing at the University of Ottawa. Dr. Lewis has developed a program of research with a focus on shared decision-making, interventions for decision support and patient-clinician communication interventions. Dr. Jibb is a Registered Nurse with pediatric oncology experience. Dr. Jibb holds the Signy Hildur Eaton Chair in Pediatric Nursing Research at the Hospital for Sick Children and at the University of Toronto. Her research program focuses on improving care for children, adolescents, and young adults with cancer. Dr. Jibb is also a Professor at Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Dr. Tracey Bucknall is a Registered Nurse and Professor at the School of Nursing and Midwifery at Deakin University in Melbourne Australia. Dr. Bucknall is also the Foundational Chair of Clinical Nursing and Director of Nursing Research for Alfred Health. She is considered by her university as a pioneer decision scientist, who focuses on improving clinical decision-making to improve patient outcomes. Dr.

Christine Lamontagne is an Anesthesiologist and Medical Director of the Chronic Pain Service at CHEO and has experience with clinical research.

Dr. Squires, Dr. Lewis, Dr. Jibb and Dr. Bucknall provided methodological expertise throughout the dissertation proposal and implementation of all three studies. Dr. Squires and Dr. Jibb were particularly helpful in guiding the systematic review, while Dr. Lewis and Dr. Bucknall were especially supportive in guiding the qualitative study. Dr. Lamontagne provided clinical expertise and justification for the overarching dissertation objective and helped to develop the diagnostic criteria outlined in the Delphi study. All committee members offered constructive and thoughtful feedback for all three manuscripts. I also acknowledge Melissa Demery Varin who was a doctoral Nursing Student at the University of Ottawa and Ashley Sokalski, previous research assistant at CHEO, who participated in the search and data extraction for the systematic review. Jennifer Leese, who is a postdoctoral fellow with the School of Epidemiology with the University of Ottawa participated in coding interviews for the qualitative study.

Dissertation Abstract

Background: Pediatric chronic pain is prevalent and comes with diagnostic uncertainty and biopsychosocial complexity. The literature significantly lacks evidence and clinical guidance to inform triage decisions to interdisciplinary pediatric chronic pain programs, which likely impacts timely and appropriate access to much needed interdisciplinary care.

Purpose: To methodically conduct foundational investigation into triage within interdisciplinary pediatric chronic pain programs to develop a preliminary series of Clinical Decision Support (CDS) triage tools grounded in evidence to facilitate nurses' triage decision-making.

Methods: A pragmatic, multi-method study was conducted and fundamentally guided by the Knowledge to Action Framework (KTA). Included studies involved: 1) A modified Delphi study to attain expert consensus on the diagnostic expectations of pediatric patients referred to interdisciplinary chronic pain programs; 2) A systematic review of multidimensional biopsychosocial tools used in the pediatric chronic pain population, guided by the Multidimensional Biobehavioral Model of Pediatric Pain; and 3) An explorative descriptive qualitative study guided by the Cognitive Continuum Theory (CCT) and the Theoretical Domains Framework (TDF) to explore and describe the decision-making practices of and contextual influences on nurses triaging patients to interdisciplinary pediatric chronic pain programs.

Findings: Following two survey rounds, the Delphi study demonstrated consensus on 84% of diagnostic items and general agreement regarding the diagnostic expectations of referred patients. The systematic review revealed six valid and reliable multidimensional biopsychosocial tools and highlighted 84 significant relationships between pain and functional interference across 11 biopsychosocial variables. The qualitative study emphasized the leading and complex triage

role nurses lead in interdisciplinary pediatric chronic pain programs, and comprehensively described the triage process and determinants of the triage decision.

Conclusions: Findings from the three studies have been integrated into the preliminary development of a series of CDS triage tools to be used in interdisciplinary pediatric chronic pain programs. This series offers decision guidance to accept or redirect care based on diagnostic clarity and a strategy to prioritize access to interdisciplinary care based on biopsychosocial needs. To determine clinical utility and validity of the tool, future research will target end-users to finalize tool development.

Acknowledgements

I would first like to express sincere gratitude to my esteemed supervisor, Dr. Janet Elaine Squires who has offered endless support and encouragement throughout this five-year endeavour. Dr. Squires is a significant inspiration who has provided me with ample opportunity to build my academic career. Her extensive and impactful research has inspired me to strive for excellence. I have been so privileged to work with my PhD committee advisors, Dr. Krystina Lewis, Dr. Lindsay Jibb, Dr. Tracey Bucknall and Dr. Christine Lamontagne. Dr. Lewis and Dr. Jibb have both established the perfect balance between parenting young children and attaining substantial academic achievements. Witnessing their personal and professional success has helped me to envision this for myself. Dr. Lewis' expertise and insight has motivated me to highlight the patient and family voice in clinical decision-making. Dr. Jibb's impressive development of various pain related apps in the pediatric oncology population have modelled the pinnacle of knowledge translation. All the way from Australia, Dr. Bucknall has so graciously offered her wisdom and expert knowledge in decision-making and triage. Her commitment to my work was evident through her participation in many early morning meetings and thoughtful feedback. Dr. Lamontagne has been my greatest clinical mentor. Without her vision, our interdisciplinary chronic pain program at CHEO would not exist. I will be forever grateful for all that she has taught me over the past seven years.

I would also like to extend my heartfelt thanks to my interdisciplinary colleagues at CHEO for their unconditional devotion to our pediatric pain population, and to my patients and families who have been my utmost clinical inspiration. I am also so grateful to have been recognized and awarded the CHEO Nursing Research Knowledge Translation award in 2022.

To my parents, Andy Greenough and Charlotte Leitch. I would not be the person I am today without you both. From my earliest memories, you have always believed in me and have raised me to value hard work, compassion for others and sticking up for what is right. Without this foundation, I would not have the confidence or ambition to strive for success and advocate for optimal patient care. I am forever grateful for my husband and partner Kyle Chadwick who has been my number one cheerleader for 11 years. My accomplishments would not be possible without your unwavering support and constant words of encouragement. Lastly, to my beautiful daughters, Lauryn Chadwick and Gwen Chadwick. Being your Mom will forever be my greatest life accomplishment. You have both been on this journey with me since the day you were born, and your precious smiles have kept me going throughout the many sleepless nights. My aspiration for you both is to live a fulfilling life and never shy away from your hopes and dreams. I hope I inspire you to believe in yourselves and persevere through your greatest and most challenging life endeavours. I love you infinitely.

Glossary of Terms

Assessing Appropriateness: The act of evaluating how appropriate or ready a patient is to participate in an interdisciplinary pediatric chronic pain program, based primarily on diagnostic clarity.

Biopsychosocial Complexity: The complex interactions between nociceptive processing, affect, sociocultural context and behavioral and cognitive mechanisms that have a multidirectional effect on the pain related health of children and youth with chronic pain.

Clinical Decision Support Triage Tool: An evidence-based guide to support the ease and trustworthiness of triage decisions.

Chronic Pain: Pain that lasts longer than 3 months in duration.

Chronic Primary Pain Syndrome: Chronic pain that cannot be explained by organic pathology.

Chronic Secondary Pain Syndrome: Chronic pain that is linked to an underlying condition.

Consensus: An agreement achieved amongst a group of pediatric chronic pain experts.

Deciding When to Re-Direct Care: The act of evaluating if and when a patient should be re-directed to an alternate service provider if pain is no longer their primary concern, and they require alternate speciality services that could better meet their needs.

Diagnostic Clarity: Clarifying the underlying source or pain or pain etiology, and any additional co-morbid conditions.

Diagnostic Process: A step-wised procedure for assigning a diagnosis for a patient based on a combination of clinical, diagnostic, and historical data.

Diagnostic Expectations: Requirements regarding the confirmation of the source of pain or pain etiology prior to referral to an interdisciplinary pediatric chronic pain program.

Diagnostic Uncertainty: Lack of clarity around the etiology or underlying source of chronic pain.

External Influences on Triage Decision-Making: The factors beyond the personal judgement of the triage nurse that impact triage decisions.

Functional Interference: The degree that pain interferes with functioning from a biopsychosocial perspective.

Functional Status Variables: From the Multidimensional Biobehavioral Model of Pediatric Pain, that includes activities of daily living, school attendance, depressive symptoms, anxious symptoms, behavioral problems, and interpersonal relations.

Interdisciplinary: The involvement of two or more disciplines (e.g., nursing, medicine, psychology, physiotherapy, etc.) to align resources and work within the same team to provide patient care.

Intervening Variables: From the Multidimensional Biobehavioral Model of Pediatric Pain, that includes biological predispositions, family environment, cognitive appraisal, coping strategies, and perceived social support.

Knowledge to Action Framework: A planned action framework developed by Graham and colleagues aimed to facilitate the transfer of sustainable and evidence-based interventions that consists of both knowledge creation and action phases.

Multidimensional Biobehavioral Model of Pediatric Pain: A conceptual model developed by Vari and colleagues that accounts for the wide variability of pediatric pain perception, pain behavior and functional status.

Multidimensional Biopsychosocial Tool: A chronic pain patient reported outcome measure that includes at least two variables of the Multidimensional Biobehavioral Model of pain domains, including pain, precipitant variables, intervening variables, and functional status variables.

Nurse-Led Triage Determinants: Triage factors, initiatives and outcomes that are driven by the triage nurse.

Patient Reported Outcome Measures: A measurement tool that patients use to provide information on aspects of their health status that are relevant to their health.

Precipitant Variables: From the Multidimensional Biobehavioral Model of Pediatric Pain, that includes pain related diagnoses/ disease, injury, stress and/ or pain producing procedures.

Prioritize Patients Based on Biopsychosocial Complexity: The act of determining how urgently a patient must be seen by an interdisciplinary pediatric chronic pain team based on the biopsychosocial impact of their chronic pain.

Prioritization: A process for determining order of importance or urgency.

Process of Triage Decision-Making: The steps and logistics that occur from the point of referral to the triage decision.

Referral: The act of directing a patient to a specialty service for consultation and possible treatment.

Revised Cognitive Continuum Theory: A decision-making framework revised by Standing, from Hamm's work on the Cognitive Continuum Theory that describes the combination of intuitive and analytical modes of cognition in formulating judgements.

Severity: The degree or nature of the illness or disease process.

Significant Clinical Indicators/ Clinical Red Flags: Clinical indicators that may reflect possible serious underlying pathology.

Theoretical Domains Framework: A determinant framework developed by Cane and colleagues that was formulated from 33 behavioral change theories and consists of 128 key theoretical constructs related to behavior change resulting in 14 domains.

Triage: A sorting procedure in which a nurse evaluates patients to assess and determine severity of presenting problems, process patients into a triage category and determine access to appropriate treatment and effectively and efficiently assign appropriate human health resources.

Triage is an Ever-Evolving Decision: The notion that a triage decision may inevitably change along various time points of the patient's chronic pain trajectory, based on their everchanging pain, functional status, and co-morbid symptoms.

Urgency: Incorporates concepts of timelines and is influenced by resources available to treat the patient.

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Chapter 1 Introduction

The purpose of this doctoral research was to investigate triage decisions in the setting of interdisciplinary pediatric chronic pain programs. The overarching goal was to develop a preliminary series of Clinical Decision Support (CDS) triage tools for the common yet ambiguous primary pediatric chronic pain diagnoses. The objective of this chapter is to highlight the significance of the research problem and present the theoretical models and frameworks that guided this mixed methods research.

1.1 Problem Statement

Prior to this dissertation, there was a notable lack of research on triage decision-making within interdisciplinary pediatric chronic pain programs, with only one study found that described the triage process across adult multidisciplinary chronic pain clinics (Page et al., 2017). Consequently, there was no evidence-based guidance available to facilitate the triage process and enhance the reliability of triage decisions in such programs. Without such, triage decisions are at risk for being haphazard which impacts timely access to interdisciplinary chronic pain care for those at highest risk for pain related functional disability.

1.1.1 Triage in the Context of Interdisciplinary Pediatric Chronic Pain Programs

The National Emergency Nurses' Affiliation (NENA) considers the triage process to be a sorting procedure in which a nurse evaluates patients quickly to: 1) assess and determine severity of presenting problems, 2) process patients into a triage category, 3) determine access to appropriate treatment, and 4) effectively and efficiently assign appropriate human health resources (NENA Position Statement, 2002). A triage tool can be considered a guide to standardizing the triage process which could improve the trustworthiness of triage decisions and ultimately lead to improved patient outcomes. As outlined by Gerdtz and Bucknall (1999), the

accountability of triage decisions and the outcomes of those decisions on patients and practice drive nurses to draw on data that is obtained through a variety of assessment processes. Although most triage tools have been developed in acute and emergency settings, the fundamental concepts of triage can be adopted in interdisciplinary pediatric chronic pain settings to enable the standardization of the triage process. Due to the limited number of such programs across Canada (Peng et al., 2007), wait times may be long, which delays access to interdisciplinary treatment for those in highest need which highlights the importance of triage decisions.

It has been well established that the treatment of pediatric chronic pain requires an interdisciplinary approach (Hechler et al., 2015). Interdisciplinary pediatric chronic pain programs consist of multiple disciplines (i.e., medical, nursing, psychology, physiotherapy, etc.) who work in an integrated fashion to provide multimodal treatment based on a biopsychosocial model of pain (Miro et al., 2017). Prior to this dissertation, it was suspected that triage decisions in these programs were based solely on referral data. The lack of physical presence of patients during the triage process creates uncertainty, leaving critical decisions dependent solely on referral data. Moreover, triage decisions differ from treatment decisions and thus may require different information than that obtained through typical observational and self-report assessment tools used to guide pain treatment.

1.1.2 Common Primary Chronic Pain Diagnoses in Pediatrics

Chronic pain has been defined as "pain that extends beyond the expected period of healing" (Treede et al., 2015). It affects between one-fourth to one-third of youth (King et al., 2011) and is at great risk to continue into adulthood (Hestbaek et al., 2006; Sherman et al., 2013). The International Association for the Study of Pain (IASP) developed a systematic classification that distinguishes chronic primary pain and chronic secondary pain syndromes

(Treede et al., 2015). Different from chronic secondary pain syndromes that are caused by an underlying disease process (Treede et al., 2015), chronic primary pain cannot be better explained by another condition, persists or recurs for longer than three months, and is associated with substantial emotional distress and/ or functional disability (Nicholas et al., 2019). Chronic primary pain diagnoses include chronic primary headaches (e.g., tension headaches, migraines), chronic primary visceral pain (e.g., chronic abdominal pain, chronic pelvic pain), chronic primary musculoskeletal pain (e.g., nonspecific chronic low back pain), chronic widespread pain (e.g., chronic myofascial pain) and Complex Regional Pain Syndrome (CRPS) Type 1 (Treede et al., 2019).

A systematic review conducted in 2011 examined prevalence studies of chronic pain in pediatrics and found variable prevalence rates of the following diagnoses: headache (8-83%), abdominal pain (4-53%), back pain (14-24%), musculoskeletal pain (4-40%), multiple pains (4-49%) and other pains (5-88%) (King et al., 2011). Friedrichsdorf et al. (2016) also suggested the most common primary chronic pain diagnoses in youth include headaches, abdominal pain and musculoskeletal pain (including back pain), as well as CRPS Type 1. Chronic pelvic pain has also existed in women of reproductive ages (including adolescents) and has been estimated to be between 5.7 to 26.6% (Ahangari, 2014). It has been highlighted that chronic pain disorders are common, under-diagnosed and under-treated in children and adolescents (Friedrichsdorf et al., 2016). Primary chronic pain diagnoses were focused on in this dissertation due to their prevalence and elusiveness in the pediatric population.

1.1.3 Diagnostic Uncertainty in the Pediatric Chronic Pain Population

It has been well documented that children and adolescents with chronic pain often

encounter significant delays between the onset of pain and the time of their first assessment by a pain specialist. Studies have shown that children with chronic pain have on average three consultations with speciality services before being referred to a pain team (Zernikow et al., 2012), and that the average time it takes to see a pediatric pain specialist is up to 12 months (Konijnenberg et al., 2005). It is possible that these delays are related to diagnostic uncertainty in the pediatric chronic pain population since there is little empirical evidence to support the diagnosis of "medically unexplained" chronic pain in children (Konijenberg et al., 2006). Diagnostic uncertainty has been described as "the perceived lack of an accurate explanation of the patient's health problem" (Tanna et al., 2020), and likely complicates the diagnostic process in patients with primary chronic pain. This may lead to the occurrence of unnecessary diagnostic tests and subsequent incidental findings. For example, incidental findings were frequently found in children with headaches on brain MRIs (Strauss et al., 2017). A retrospective study of 241 children and adolescents who had MRI or CT imaging for headache found 20% of them to have benign abnormalities that did not result in change to headache management (Schwedt et al., 2006). Accordingly, obtaining neuroimaging on a routine basis is not indicated in children with recurrent and chronic headaches with a normal neurological exam (Lewis et al., 2002). Similarly, a clinical diagnosis of chronic abdominal pain in children aged four to 18 years based only on a comprehensive history and physical exam is suggested for those without significant clinical indicators (Korterink et al., 2015). Despite this, it has been posed that many practitioners order numerous diagnostic tests in fear of missing a secondary underlying cause to pain, which may create further patient distress and resource burden on the healthcare system (American Academy of Pediatrics & North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, 2005).

Although the prevalence of diagnostic uncertainty in the pediatric chronic pain population is largely unknown, it has been implied that it is common and central to the patient and family's experience in their adjustment, acceptance, and responsiveness to multimodal treatment (Pincus et al., 2018). Pain acceptance involves a willingness to experience pain with the goal of optimizing functionality and living a valued life despite pain (McCracken et al., 2010; Pielech et al., 2017). This is important since higher pain acceptance has been associated with better functioning (Kalapurakkel et al., 2015; Wallace et al., 2011; Weiss et al., 2013), less fear of pain (Crombez et al., 2013) and lower rates of depressive symptoms and pain catastrophizing (Weiss et al., 2013) in the pediatric population. Therefore improving diagnostic clarity may lead to improved pain acceptance, which may lead to improved response to interdisciplinary treatment. Thus, this dissertation was developed bearing in mind the importance of understanding pain etiology in informing the triage decision of complex patients who are accepted into interdisciplinary pediatric chronic pain programs.

1.1.4 Biopsychosocial Complexity of the Pediatric Chronic Pain Population

The chronic pain experience is multidimensional, comprised of interactions between nociceptive processing, affect, sociocultural context and behavioral and cognitive mechanisms (Gatchel et al., 2007; Melzack & Wall, 1965). Consequently, a variety of biopsychosocial factors have been shown to have a bidirectional effect on the pain related health of youth with chronic pain, such as depression, low self-esteem, sleep disturbances, increased fatigue, decreased physical functioning and other health conditions (Dunn et al., 2011; Hadden & Baeyer, 2002; Hotopf et al., 1999; Jones et al., 2007; King et al., 2011; Vetter et al., 2013). The developmental nature of the pediatric population adds complexity to this, since children and adolescents undergo rapid growth and change in biological, psychological, and social domains. This in turn

impacts their social roles, family and peer relationships, school functioning and overall autonomy (Essner et al., 2020). Since relationships between these factors and how they impact the pain experience varies considerably between pediatric patients (Gatchel et al., 2014), it is reasonable to recognize that some patients will experience more severe biopsychosocial impact and thus should be prioritized for interdisciplinary chronic pain care accordingly.

1.2 Guiding Theoretical Models and Frameworks

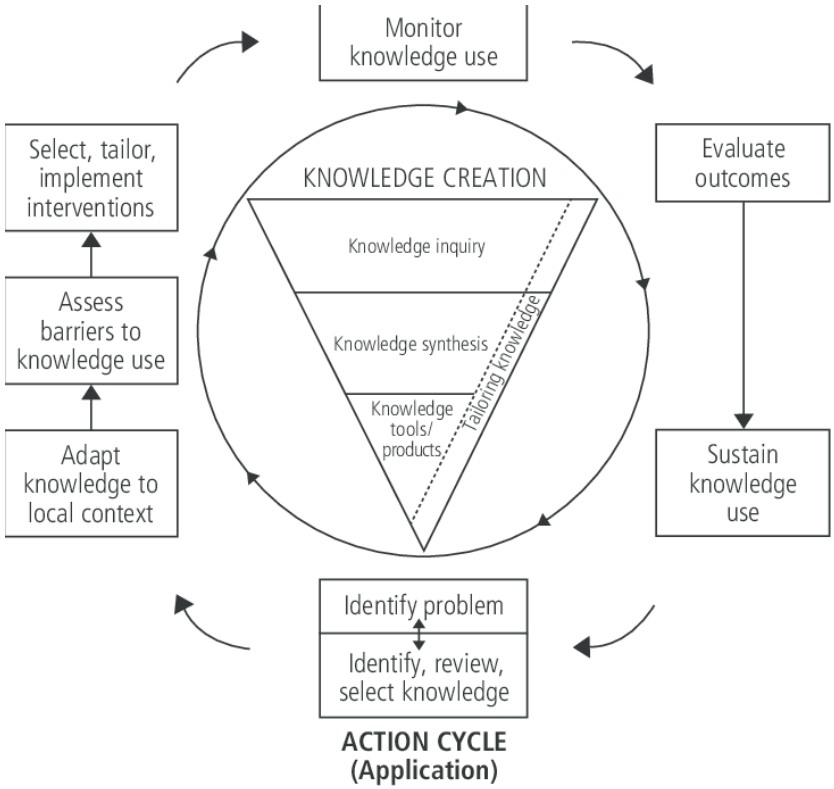
This dissertation was inspired and guided by three theoretical frameworks and one conceptual model. The *Knowledge to Action Framework* (KTA) (Graham et al., 2006) was selected to guide the overarching objectives of this dissertation. The *Multidimensional Biobehavioral Model of Pediatric Pain* was used to conceptualize the complex biopsychosocial chronic pain experience (Varni et al., 1995). The revised *Cognitive Continuum Theory* (Standing, 2008) provided a platform to investigate the components of decision-making and the *Theoretical Domains Framework* (Cane et al., 2012) was followed to capture the barriers and facilitators to triage decision-making in the setting of interdisciplinary pediatric chronic pain programs.

1.2.1 Knowledge to Action (KTA) Framework

The *KTA framework* developed by Graham and colleagues (2006) is a conceptual framework aimed to facilitate the transfer of sustainable, evidence-based interventions (Field et al., 2014). The knowledge component consists of the main types of knowledge used in health care that is filtered from knowledge inquiry to knowledge synthesis and then to knowledge tools/ products, which is considered the most refined form of knowledge (Graham et al., 2006). The action cycle represents the dynamic application of the knowledge that is iterative and influenced by the knowledge creation phase (Graham et al., 2006). For this dissertation, KTA fittingly addresses the selection of knowledge (i.e., what is needed to make sound triage decisions) to

implement and customize within the context (i.e., interdisciplinary pediatric chronic pain programs), through the identification of the barriers and facilitators to using the knowledge. This dissertation has focused on identifying, reviewing, and selecting the knowledge regarding triage decision-making in interdisciplinary pediatric chronic pain programs, adapting that knowledge to end-users (i.e., pediatric chronic pain providers), and assessing the barriers and facilitators to using this knowledge to promote sustained knowledge use.

Figure 1.1 – Knowledge to Action Framework



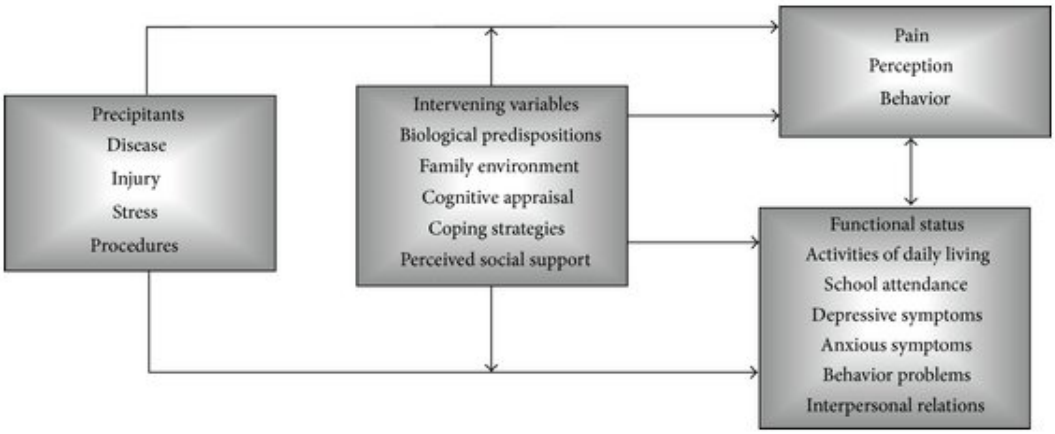
(From Graham, I., Logan, J., Harrison, M., Straus, S., Tetroe, J., Caswell, W., Robinson, N. (2006). Lost in translation: time for a map? *Journal of Continuing Education in the Health Professions*, 26, 13-24.)

1.2.2 Multidimensional Biobehavioral Model of Pediatric Pain

Varni and colleagues (1995) developed the *Multidimensional Biobehavioral Model of*

Pediatric Pain with the intent to account for the wide variability of pediatric pain perception, pain behavior and functional status. This model has been applied in the context of juvenile rheumatoid arthritis (Sawyer et al., 2005), headache and abdominal pain in adolescents (White & Farrell, 2006) and has been used to identify the factors associated with pediatric patients' self-reported chronic pain intensity and functional disability in a variety of chronic pain disorders (Vetter et al., 2013). This model categorizes the pain experience into: 1) precipitants, including pain related diagnoses/ disease, injury, stress and/ or pain producing procedures; 2) intervening variables, including biological predispositions, family environment, cognitive appraisal, coping strategies and perceived social support; 3) pain perception and behavior and 4) functional status, including activities of daily living, school attendance, depressive symptoms, anxious symptoms, behavioral problems and interpersonal relations. This model was particularly useful in categorizing the main dimensions of the pediatric chronic pain experience.

Figure 1.2 Multidimensional Biobehavioral Model of Pediatric Pain



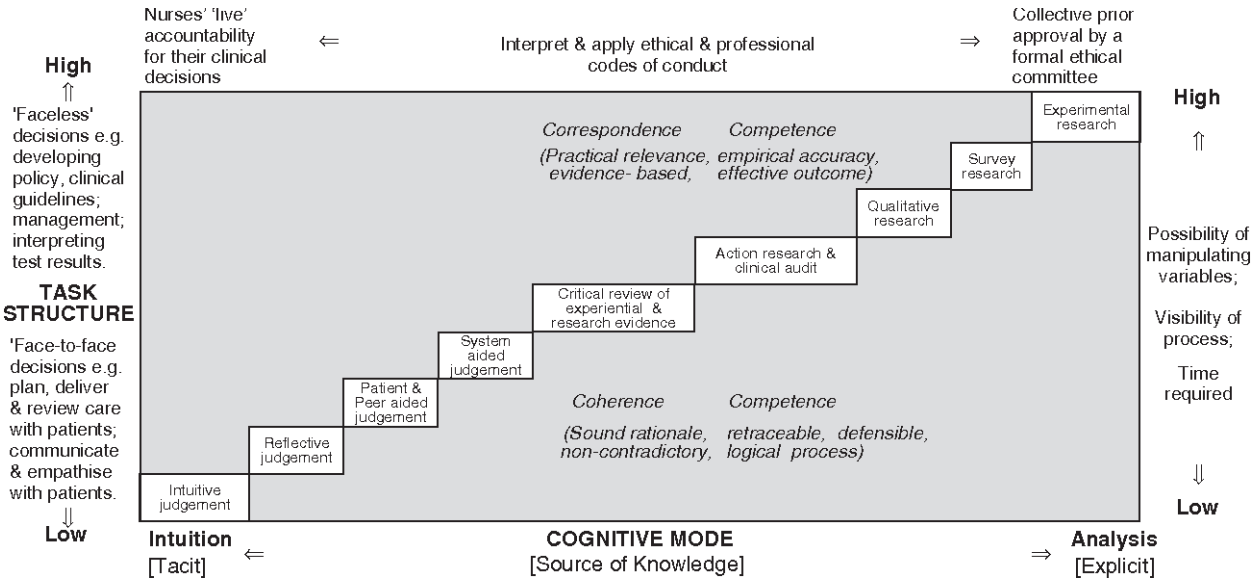
(From Vetter, T.R., McGwin, G., Bridgewater, C.L., Madan-Swain, A., Ascherman, L.I. (2013). Validation and clinical applications of a biopsychosocial model of pain intensity and functional disability in patients with a pediatric chronic pain condition referred to a subspecialty clinic. *Pain Research and Treatment,* 1-12.)

1.2.3 Cognitive Continuum Theory

The revised *Cognitive Continuum Theory* (CCT) (Standing, 2008) was chosen as the decision-making framework to guide this study. Stemming from Hamm's (1988, 1989) work on CCT that describes the combination of intuitive and analytical modes of cognition in formulating judgements, Standing (2008) has adapted and expanded the original six modes of reasoning to nine. It was suggested that this revision makes CCT more applicable to nursing (Standing, 2008). The modes of reasoning are presented on a spectrum from most analytical to most intuitive, as follows: 1) Experimental research, representing controlled trials and scientific experiments that are intended to induce hypothesis and assess cause and effect relationships. 2) Survey research, including targeted populations to identify attitude, trends, beliefs, and behaviors pertinent to clinical situations that inform decisions. 3) Qualitative research, which uses narration as a judgement process. 4) Action research and clinical audit, which is intended to identify strengths and weaknesses of clinical practice resulting in an audit process to enhance expertise of the system. 5) Critical review of experiential and research evidence, involving the critique of relevant research to expand the decision maker's understanding of a clinical situation that may impact judgement. 6) System-aided judgement, which includes use of clinical guidelines to inform the decision maker. 7) Patient and peer-aided judgement, involving the collaboration of others to enhance the decision-making process. 8) Reflective judgement, that involves the decision maker drawing on previous experiences that are similar to the current situation. And finally, 9) Intuitive judgement, which represents the most intuitive mode of decision making, known as the "know how" of reasoning. This framework was considered suitable to guide the investigation of triage decision-making because of its ability to explain the 'back and forth' or oscillation of triage decisions (Brown & Clark, 2014). The proposition that any decision will

elicit a particular mode of thinking in the decision maker provides a platform to not only describe the decision reasoning of nurses in interdisciplinary pediatric chronic pain programs, but also how different cues or tasks enable them to reason and analyze. This framework furthers its utility in offering a prescriptive element by means of the decision maker being able to locate a particular mode of reasoning, and then apply that mode to the decision task at hand (Standing, 2008).

Figure 1.3 Revised Cognitive Continuum Theory



(From Standing, M. (2008). Clinical judgement and decision-making in nursing – nine modes of practice in a revised cognitive continuum. *Journal of Advanced Nursing*, 62(1), 124-134.)

1.2.4 Theoretical Domains Framework

The *Theoretical Domains Framework* (TDF) (Cane et al., 2012) was selected to capture the determinants that influence nurses triaging patients to interdisciplinary pediatric chronic pain programs. The TDF was developed from 33 behavior change theories and consists of 128 key theoretical constructs related to behavior change, resulting in 14 domains, including: 1) Knowledge, 2) Skills, 3) Social/ Professional Role and Identify, 4) Beliefs about Capabilities, 5)

Optimism, 6) Beliefs about Consequences, 7) Reinforcement, 8) Intentions, 9) Goals, 10) Memory, Attention and Decision Processes, 11) Environmental Context and Resources, 12) Social Influences, 13) Emotion, and 14) Behavioral Regulation (Cane et al., 2012). Although this framework is widely used to facilitate the exploration of implementation problems, it was selected for exploring the triage decision-making practices of nurses because of its comprehensiveness and ability to identify barriers and facilitators of decision making in this context. It is important to note that the goal of utilizing TDF in this study was not to change behavior (i.e., decision-making), but rather to explore and describe the contextual factors that influence the decision-making of nurses triaging patients to interdisciplinary pediatric chronic pain programs.

1.3 Dissertation Purpose and Objectives

The purpose of this doctoral research was to investigate triage decisions in the setting of interdisciplinary pediatric chronic pain programs. The overarching goal was to develop a preliminary series of Clinical Decision Support (CDS) triage tools for the common yet ambiguous primary pediatric chronic pain diagnoses. The intention behind this was to facilitate optimal access to interdisciplinary chronic pain care based on improved diagnostic clarity of pain etiology and enhanced prioritization of patients at highest risk for pain related functional disability. It is anticipated that by doing so, appropriateness of patients accepted into such programs will improve, which may allow for better tailoring of interdisciplinary treatment with more apposite use of scarce interdisciplinary resources. This mixed-methods dissertation specifically aimed to address the following:

1) Identify necessary medical diagnostic investigations and significant clinical indicators/ clinical red flags that are required on patients prior to acceptance into interdisciplinary pediatric chronic pain programs.
2) Identify biopsychosocial assessment measures relevant to the pediatric chronic pain population.
3) Explore the decision-making practices and contextual influences of nurses triaging patients to interdisciplinary pediatric chronic pain programs.
4) Develop a preliminary draft of a series of CDS triage tools for common primary pediatric chronic pain diagnoses.

This dissertation is structured as manuscript based, and therefore the next three chapters will include the manuscripts of the three studies conducted. This dissertation involved a modified Delphi study (Chapter 2) to attain expert consensus on the significant clinical indicators/ clinical red flags relevant to six common primary chronic pain diagnoses in pediatrics. This study also addressed the diagnostic investigations that are required prior to referral to interdisciplinary pediatric chronic pain programs for patients without clinical red flags (objective 1). A systematic review (Chapter 3) was also conducted to identify multidimensional biopsychosocial tools used in pediatric chronic pain, synthesize their reliability and validity evidence, and draw on the evidence to describe the relationships between chronic pain and biopsychosocial domains (objective 2). Lastly, an exploratory descriptive qualitative study was done to explore and describe the decision-making practices and contextual influences of nurses triaging patients to interdisciplinary pediatric chronic pain programs (objective 3). The findings were then amalgamated to develop a series of CDS triage tools for five common primary pediatric chronic pain diagnoses, which can be found in Chapter 5 (objective 4).

Dissertation Program Logic Map

	Study 1 **Delphi Study**	**Study 2** **Systematic Review**	**Study 3** **Qualitative Study**
Citation	Greenough, M.J., Bucknall, T., Jibb, L., Lewis, K., Lamontagne, C., Squires, J.E. (2022). Attaining expert consensus on diagnostic expectations of primary chronic pain diagnoses for patients referred to interdisciplinary pediatric chronic pain programs: A delphi study with pediatric chronic pain physicians and advanced practice nurses. *Frontiers in Pain Research*, 1-16.	Greenough, M.J., Jibb, L., Lewis, K.B., Bucknall, T., Lamontagne, C., Demery Varin, M., Sokalski, A., Squires, J.E. (2023). A systematic review of the biopsychosocial dimensions impacted by chronic pain in children and adolescents: identifying reliable and valid pediatric multidimensional chronic pain assessment tools. *Pain Reports* (in production).	Greenough, M.J., Lewis, K.B., Bucknall, T., Jibb, L., Leese, J., Lamontagne, C., Squires, J.E. (2023). Triage decision-making in interdisciplinary pediatric chronic pain programs. *Pain Management Nursing* (revisions under review).
Objective	Identify medical diagnostic investigations and significant clinical indicators/ clinical red flags that are required on patients prior to acceptance into interdisciplinary pediatric chronic pain programs.	Identify biopsychosocial assessment measures relevant to the pediatric chronic pain population.	Explore decision-making practices and contextual influences of nurses triaging patients to interdisciplinary pediatric chronic pain programs.
Sample	Pediatric chronic pain advanced practice nurses and physicians. Round 1 (n=22) Round 2 (n=16)	6 multidimensional biopsychosocial tools across 64 eligible studies	12 pediatric chronic pain nurses across 11 different interdisciplinary pediatric chronic pain teams
Main Findings	• Good consensus on clinical red flags for 5 primary chronic pain diagnoses • In patients without clinical red flags, diagnostic investigations not generally necessary • Referring providers are responsible for diagnostic work-ups	• Revealed 6 valid and reliable multidimensional biopsychosocial tools • Outlined 84 significant relationships between chronic pain and functional interference across 11 biopsychosocial variables • Highlighted efficient and holistic PII	• Nurses have a complex and leading role in triage and triage development • Themes: nurse-led triage determinants, process of triage decision making & external influences of triage decisions • Recommendations: solidify recommendations, enhance diagnostic clarity, incorporate PROMS, accept that triage evolves and prepare for change & optimize communication and collaboration
Contribution to Triage Conceptualization	• Assessing appropriateness to programs based on diagnostic clarification • When to re-direct patients based on diagnostic indicators	• Prioritization based on biopsychosocial needs	• Prioritization based on biopsychosocial needs • Assessing appropriateness to programs • Triage as an evolving decision
Contribution to Triage Development	• List of clinical red flags • Course of action if clinical red flags present • Diagnostic tools (if available)	• Brief & holistic biopsychosocial assessment via PII • Decision algorithm (prioritization via PPI)	• Eligibility checklist • Mandatory components checklist • Listed roles and responsibilities of the referring provider • Decision algorithm (appropriateness assessment) • Decision algorithm (prioritization) • Encouragement of PROM adoption

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Chapter 2: Attaining Expert Consensus on Diagnostic Expectations of Primary Chronic Pain Diagnoses for Patients Referred to Interdisciplinary Pediatric Chronic Pain Programs: A Delphi Study with Pediatric Chronic Pain Physicians and Advanced Practice Nurses

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Keywords: chronic pain (1), interdisciplinary chronic pain program (2), referral practices (3), pediatric (4), diagnostic investigations (5), significant clinical indicators (6), red flags (7), primary chronic pain (8)

Abstract

Objective: Pediatric primary chronic pain disorders come with diagnostic uncertainty, which may obscure diagnostic expectations for referring providers and the decision to accept or re-direct patients into interdisciplinary pediatric chronic pain programs based on diagnostic completeness. We aimed to attain expert consensus on diagnostic expectations for patients who are referred to interdisciplinary pediatric chronic pain programs with six common primary chronic pain diagnoses.

Method: We conducted a modified Delphi study with pediatric chronic pain physicians, nurse practitioners and clinical nurse specialists to determine degree of importance on significant clinical indicators and diagnostic items relevant to each of the six primary chronic pain diagnoses. Items were identified through point of care databases and complimentary literature and were rated by participants on a 5-point Likert scale. Our consensus threshold was set at 70%.

Results: Amongst 22 experts across 14 interdisciplinary programs in round one and 16 experts across 12 interdisciplinary programs in round two, consensus was reached on 84% of diagnostic items, where the highest degree of agreement was with Complex Regional Pain Syndrome (CRPS), Type 1 (100%) and the lowest with chronic pelvic pain (67%).

Conclusion: This study demonstrated a general agreement amongst pediatric chronic pain experts regarding diagnostic expectations of patients referred to interdisciplinary chronic pain programs with primary chronic pain diagnoses. Study findings may help to clarify referral expectations and the decision to accept or re-direct patients into such programs based on diagnostic completeness while reducing the occurrence of unnecessary diagnostic tests and subsequent delays in accessing specialized care.

2.1 Introduction

Chronic pain in children and adolescents is prevalent and should be recognized as a major health concern in pediatrics internationally (1). The International Association for the Study of Pain (IASP) developed a classification of chronic pain diagnoses that distinguishes chronic primary pain and chronic secondary pain syndromes (2). Different from chronic secondary pain syndromes that are linked to an underlying condition (2), chronic primary pain cannot be explained by organic pathology (3). The most common pediatric primary chronic pain diagnoses include chronic headaches, chronic abdominal pain, chronic musculoskeletal and/ or joint pain, and chronic back pain (1). Complex Regional Pain Syndrome, Type 1 (CRPS type 1) is also frequently seen in pediatric chronic pain clinics (4) and can have a significant biopsychosocial impact on children and youth (5). Chronic pelvic pain is also thought to be common in adolescent females, however the exact prevalence is unknown (6).

Chronic pain disorders are under-diagnosed in children and adolescents (4), causing significant delays in receiving specialized treatment (7, 8). Such delays are often due to diagnostic uncertainty in the chronic pain population since there is minimal evidence to support the diagnosis of 'medically unexplained' pain in children (9). Pediatricians may especially experience diagnostic uncertainty in this population and there has been low agreement among pediatricians regarding chronic pain etiology and diagnostic approaches (10). Diagnostic uncertainty may be related to the tendency to complicate the diagnostic process in the chronic pain population (11) and likely increases the occurrence of unnecessary diagnostic tests. Conversely, misdiagnosing secondary pain syndromes as primary chronic pain can be harmful. Understanding pain etiology is considered the most important criterion when accepting and triaging patients to chronic pain programs (12), which highlights the need to enhance the

diagnostic process for patients with primary chronic pain diagnoses. The general diagnostic process is thought to be iterative, with the goal of reducing diagnostic uncertainty, narrowing down diagnostic possibilities, and developing a more precise and complete understanding of a patient's health problem (13). By adequately addressing the diagnostic process for pediatric primary chronic pain diagnoses, diagnostic expectations may be clarified which may reduce the occurrence of unnecessary diagnostic test, streamline the referral process and facilitate the decision to accept or redirect patients into interdisciplinary pediatric chronic pain programs based on diagnostic completeness.

The purpose of this study was to outline diagnostic expectations for common primary chronic pain diagnoses in the pediatric population from the perspectives of specialized pediatric chronic pain providers. Our primary objectives were to attain expert consensus on important significant clinical indicators (i.e., red flags/ signs of organic pathology) that are important to assess for in patients referred to interdisciplinary pediatric chronic pain programs, as well as to identify what diagnostic investigations are important to complete for patients who do not have significant clinical indicators, prior to acceptance into interdisciplinary pediatric chronic pain programs. For this study, diagnoses were limited to 1) Complex Regional Pain Syndrome, Type 1 (CRPS type 1), 2) Chronic Headaches, 3) Chronic Musculoskeletal and/ or Joint Pain, 4) Chronic Back Pain, 5) Chronic Abdominal Pain and 6) Chronic Pelvic Pain. Our secondary objective was to identify common courses of action that chronic pain providers take when patients are referred to them with significant clinical indicators/ red flags (e.g., re-directing the referral, denying the referral, etc.), as well as utilization of Clinical Decision Support (CDS) tools and Patient Reported Outcome Measures (PROMs) that inform the decision to accept patients based on appropriateness.

2.2 Materials and Methods

Design

We conducted a modified Delphi study, a well-recognized method for assessing expert opinion (14, 15), with pediatric chronic pain physicians, nurse practitioners and clinical nurse specialists. Our methodology was not considered a 'classical Delphi', which usually starts with an open-ended set of questions from participants (14). This approach has been critiqued to produce large amounts of questions that may not be well phrased which challenges the reliability and validity of the data and risks significant participant withdrawal (14). Instead, we conducted a literature search of relevant diagnostics and significant clinical indicators for each pain diagnosis lending to a more streamlined and evidence-based set of questions. We administered two-rounds of online surveys to develop consensus on the items that should be evaluated in the diagnostic investigation for the six pediatric primary chronic pain diagnoses listed above. Items included: 1) significant clinical indicators (i.e., red flags/ signs of organic pathology); and in the absence of significant clinical indicators/ red flags: 2) necessary laboratory investigations; 3) necessary diagnostic imaging investigations; and 4) necessary diagnostic procedure investigations. We also assessed experts' course of action if patients were referred with significant clinical indicators, as well as any CDS tools and PROMS they use in clarifying diagnoses and/ or facilitating their decision to accept patients into their programs.

Expert Participant Panel

Participants were eligible based on their role (pediatric chronic pain physicians, nurse practitioners, clinical nurse specialists) and experience working in an interdisciplinary pediatric chronic pain program (current or past). It is suggested that the quality of information obtained by

the Delphi technique is improved with numbers up to 13 participants (16). Therefore, the recruitment goal for this study was to have a minimum of 20 experts participate in the first round to account for attrition.

Study Procedures

This study was approved by the Research Ethics Boards at both the University of Ottawa (REB #H-11-19-5122) and the Children's Hospital of Eastern Ontario (REB #2020058). Our procedures, analysis and reporting of results was guided by *The Delphi Technique in Nursing and Health Research Handbook* (14) and align with the *Guidance on Conducting and Reporting Delphi Studies (CREDES)* recommendations (17). Pediatric chronic pain experts were invited to participate in this study through the Pediatric Pain List Serve, which is an international internet forum maintained by Dalhousie University in Halifax, Nova Scotia. Recruitment included snowball sampling as many interested participants shared the survey invitation with eligible colleagues. Interested participants were asked to contact the Principal Investigator to confirm their interest and ensure eligibility. Confirmed and eligible participants were then sent an online link (via RedCap) to complete the first Delphi survey. Informed consent was obtained after participants read through the study's Letter of Information, which stated "consent will be assumed upon completion of the questionnaire". Therefore, for both Delphi rounds, consent was assumed following completion of both questionnaires. Following analysis of the first-round survey, respondents were contacted individually via email to invite them to participate in the second-round survey. For both rounds, reminder emails were sent to non-responders weekly for up to three weeks. Please see Figure 2.1 for an outline of our Delphi process.

Survey Development

Both surveys were organized based on the objectives listed above. Items were generated largely on available diagnostic literature of the six chosen pediatric primary chronic pain diagnoses, which was searched primarily through two point of care databases (*DynaMed Plus* and *RxTx*), that update clinical information frequently. Some diagnoses were not listed in either database, therefore supplemental articles were used to capture diagnostic information for the surveys. For purposes of clinical validity, the first-round survey was piloted with two pediatric chronic pain physicians and one pediatric pain nurse practitioner, which resulted in additional items added based on their recommendations. Individuals who participated in the pilot survey were not study participants and their results were not included in our analysis. The first-round survey included a total of 148 diagnostic items across the six pain diagnoses (CRPS type 1, n= 14; Chronic Headaches, n=23; Chronic Musculoskeletal and/ or Joint Pain, n=30; Chronic Back Pain, n= 21; Chronic Abdominal Pain, n=34; Chronic Pelvic Pain, n= 26). The second-round survey involved 85 diagnostic items involving the original items that did not reach consensus in round-one, as well as 'other' items considered important by participants (CRPS type 1, n= 6; Chronic Headaches, n= 14; Chronic Musculoskeletal and/ or Joint Pain, n= 20; Chronic Back Pain, n= 10; Chronic Abdominal Pain, n=26; Chronic Pelvic Pain, n= 9). Questions regarding course of action for patients referred with significant clinical indicators were formatted as multiple choice and were not included in consensus. Participants also listed utilized CDS tools and PROMS and added additional feedback and comments as open-ended free text. The first-round and second-round surveys can be found in Supplemental File 1 and Supplemental File 2, respectively.

Data Collection and Analysis

Participants were asked to rate their perceived degree of importance of significant clinical indicators/ red flags and diagnostic items in the diagnostic investigation for each of the six chronic pain diagnoses on a 5-point Likert scale from 1 (not at all important) to 5 (extremely important). Since there is no standard threshold for defining consensus (i.e., recommendations have been found to be between 51% to 80%) (16), our analysis strategy was modeled after a Delphi study that evaluated expert consensus with the goal of developing a classification system for patients with low back pain (18). Responses with a rating of three or greater were considered important, while those with a rating of one or two were considered not important. To achieve group consensus in deeming an item important to consider or include in a referred patient, 70% or more of participants rated the item as important-extremely important. To achieve group consensus in deeming an item as not important to consider or include in a referred patient, 70% or more of participants rated the item as not at all important to somewhat important. Participants were also invited to offer 'other' items they believed were important to include. The second-round survey involved the items that had not reached consensus in the first round, as well as the 'other' items offered by participants. Participants were able to change their responses from the first-round survey based on the outlined results and were blinded to the identity of other participants to reduce response bias. A third round was not conducted since the overall degree of consensus met in Round 2 was high at 84%. Descriptive statistics including frequencies, percentages and medians and were used to describe responses across all participants, since the median is considered the optimal statistic for describing group agreement (15). Qualitative data was captured through additional feedback offered by participants and were analyzed by thematic analysis using an inductive approach (19). Data was coded by one author and all analytical decisions were validated by all other authors. There was general agreement from all authors.

2.3 Results

Expert Demographics

The first-round survey included a total of 22 pediatric chronic pain experts from 14 different interdisciplinary teams and 4 different countries. Two participants indicated that they previously worked in an interdisciplinary team, however both had 10-20 years of working experience with the pediatric chronic pain population and were therefore still included in the study. Sixteen (72%) of those participants, from 12 different interdisciplinary teams and 4 different countries participated in the second-round survey. Reasons for withdrawal were not provided by participants. A summary of participant demographics can be found in Table 1.

Degree of Consensus on Diagnostic Items

Across both rounds, 84% (157/187) of both original and "other" diagnostic items reached consensus. The highest level of overall agreement was with CRPS type 1, followed by chronic headaches, chronic musculoskeletal and/ or joint pain, chronic back pain, chronic abdominal pain, and chronic pelvic pain. Included in Table 2 lists the degree of consensus reached per pain location/ diagnosis and domain, as well as the items that reached consensus and their deemed importance. Items that did not reach consensus are also listed in Table 2. Course of action participants take for referred patients with significant clinical indicators/ red flags are listed in Table 3 and CDS tools used by participants to inform diagnoses are listed in Table 4.

Complex Regional Pain Syndrome, Type 1

CRPS type 1 was the only diagnosis that met 100% consensus within all domains. All significant clinical indicators/ red flags were deemed important to assess for, while all diagnostic investigations were considered not important to complete prior to referral for patients without significant clinical indicators/ red flags. Some participants (n=8, 36%) indicated that for patients

referred with significant clinical indicators/ red flags, they would re-direct the referral to a specialty service, while 27% (n=6) would accept the patient and assess themselves. CDS use was reported to be the highest with CRPS type 1, with 15 of 22 participates reporting that they use a CDS tool, 14 of whom specified that they follow the *Budapest Criteria* (20).

Chronic Headaches

Consensus was reached on 91% (n=32) of chronic headache diagnostic items, where most significant clinical indicators/ red flags were deemed important (n=17, 94%) to consider in referred patients. Most laboratory items (n=9, 90%) were considered not important to conduct prior to referral in patients without significant clinical indicators/ red flags, followed by 80% (n=4) of diagnostic procedures and 100% (n=2) of diagnostic imaging investigations. Some participants (n=8, 36%) indicated that for patients referred with significant clinical indicators/ red flags, they would re-direct them to an emergency department (n=8, 36%). Half of the sample (n=11, 50%) indicated that they use a CDS tool for chronic headache referrals, ten of whom specifically mentioned the *International Classification of Headache Disorders* (21).

Chronic Musculoskeletal and/or Joint Pain

Consensus was reached on 90% (n= 35) of chronic musculoskeletal and/ or joint pain diagnostic items, where 85% (n=11) of significant clinical indicators/ red flags were deemed important to consider in referred patients. In terms of diagnostics, 95% (n=18) of laboratory, 75% (n=3) of diagnostic imaging investigations and all diagnostic procedure investigations (n=3, 100%) were considered not important to conduct prior to referral in patients without significant clinical indicators/ red flags. Half of participants (n= 11, 50%) indicated that they would redirect referred patients with significant clinical indicators/ red flags to a speciality service. Few participants (n=2) reported using a CDS tool, one of whom mentioned the *Beighton criteria* (22).

Chronic Back Pain

Consensus was reached on 79% (n=19) of chronic back pain diagnostic items, with 86% (n=5) of significant clinical indicators/ red flags deemed important to consider in referred patients. Most laboratory (n=5, 83%) and half of diagnostic imaging (n=2, 50%) investigations were considered not important to conduct prior to referral in patients without significant clinical indicators/ red flags. A selection of participants (n=9, 41%) specified that they would re-direct referred patients with significant clinical indicator/ red flags to a specialty service, while only one participant reported using CDS tools for chronic back pain referrals, referencing the *American Academy of Pediatrics* (23), the *American Academy of Family Physicians* (24) and the *American College of Rheumatology* (25).

Chronic Abdominal Pain

Consensus was reached on 79% of chronic abdominal pain items, with 93% (n=13) of significant clinical indicators/ red flags deemed important to consider in referred patients. All diagnostic imaging (n=4, 100%) and diagnostic procedure (n=5, 100%) investigations were considered not important to conduct prior to referral in patients without significant clinical indicators/ red flags. A portion of laboratory investigations (n=12, 60%) met consensus and were also considered not important. Nearly half of participants (n=10, 45%) indicated that they would re-direct patients referred with significant clinical indicators/ red flags to a specialty service, while six participants reported using a CDS tool for chronic abdominal pain referrals, five of whom referenced the *American Academy of Pediatrics* (23) and one reported following the *Rome III criteria* (26).

Chronic Pelvic Pain

Consensus was reached on 68% (n=19) of chronic pelvic pain items, with 86% (n=12) of significant clinical indicators/ red flags deemed important to consider for referred patients. All four diagnostic procedure investigations and three of five (60%) diagnostic imaging investigations were considered not important to conduct prior to referral in patients without significant clinical indicators/ red flags. Consensus was not reached on any of the five laboratory investigations. Some participants (n=12, 55%) specified that they would re-direct patients with significant clinical indicators/ red flags to a speciality service and one participant reported using a CDS tool for chronic pelvic pain referrals, referencing the *American Academy of Family Physicians* (24).

Patient Reported Outcome Measures (PROMs)

The most frequently utilized PROMs that experts reported they prefer to have completed prior to referral are the: Patient Reported Outcome Measurement Information System (PROMIS) (27) (n=7/22 participants; 16/14 teams), Functional Disability Inventory (FDI) (28) (n= 7/22 participants; 5/14 teams), Numerical Rating Scale (NRS) (29) (n=6/22 participants; 4/14 teams), Pain Catastrophizing Scale (PCS) (30) (n= 4/22 participants; 3/14 teams), Pediatric Quality of Life Inventory (PedsQL) (31) (n= 2/22 participants; 2/14 teams), Faces Pain Scale Revised (FPS, R) (32) (n= 2/22 participants; 2/14 teams), Child Activity Limitations Interview (CALI) (33) (n= 2/22 participants; 2/14 teams). Only single participants from different teams mentioned each of the following PROMs: Self Determination Scale (34), Insomnia Severity Index (35), Pain Related Cognition Questionnaire for Children (PRCQ-C) (36), Childhood Sleep Habits Questionnaire (37), Patient Health Questionnaire-9 (PHQ-9) (38), CRAFT Substance Use Screening Tool (39), Symptom Severity Score (40), Children's Depression Inventory (CDI) (41),

Body Map (42), BATH Adolescent Pain Questionnaire (43) and the Brief Pain Inventory (BPI) (44).

Supporting Data

Participant feedback related to the contextual influences that impact their decision to accept or re-direct referred patients based on diagnostic completeness was grouped into four categories: 1) chronic pain program contexts, 2) diagnostic role, 3) quality of referral data, and 4) evidence-informed decision making. This data highlights that although there is variation in chronic pain models and philosophies, diagnostic completeness is considered important before accepting patients into chronic pain programs. Furthermore, the quality and quantity of referral data impacts how triage decisions are made after patients are accepted (i.e., how they are prioritized). It was also noted across this group of experts that it is typically not their role to complete diagnostic investigations, but rather to collaborate with referring providers and other speciality services who take responsibility for selecting and conducting diagnostic investigations. The lack of evidence-based guidance to inform the diagnostic process with pediatric chronic pain patients was highlighted, and there is participant interest in using CDS tools and PROMS to support the decision to accept or re-direct patients based on their diagnostic completeness and appropriateness. A summary of details and exemplar quotes can be found in Table 5.

2.4 Discussion

This study identified 72 significant clinical indicators/ red flags that were deemed important to assess for in the diagnostic investigation of six pediatric primary chronic pain diagnoses, as well as 85 diagnostic investigations that were considered not important to complete prior to chronic pain referral in the absence of significant clinical indicators/ red flags. Although classification of these items may help to reduce diagnostic uncertainty and clarify diagnostic

expectations from the perspectives of specialized pediatric chronic pain providers, it is prudent to recognize that additional research is needed to attain further consensus amongst common referring providers and other specialty services.

There was good consensus to support a general recommendation to not conduct diagnostic investigations in the absence of significant clinical indicators/ red flags prior to referral. This is in line with the general recommendations included in the CDS tools reported by participants. Despite this, there remains a delay between the onset of pain and the time that specialized care is received (7, 8). A recent prospective study investigating wait times for youth referred to interdisciplinary pediatric chronic pain programs found the average wait time to be 197.5 days, which caused increased anxiety and frustration for patients and families (44). Although reasons for long wait times were not examined, authors from that study emphasized the need to investigate referral practices of pediatric interdisciplinary chronic pain programs (44). One possible factor that increases wait times may be the prolonged extent of diagnostic investigations conducted on chronic pain patients prior to referral. A recent systematic review examining the magnitude and nature of inappropriately used clinical practices in Canada in all health sectors revealed that approximately 47% of diagnostic tests are over-used (45). Many practitioners order numerous diagnostic tests with chronic pain patients in fear of missing an organic cause to patients' pain, and in hopes of providing reassurance to patients and families (46). Interestingly, a qualitative study exploring the perception of diagnostic uncertainty in youth with chronic pain demonstrated that even if diagnostic tests were negative, they did not provide relief to families (47). It is possible that many unnecessary diagnostic tests are being ordered due to the range of ambiguous symptomatology reported by parents of children with chronic pain (48, 49), which may cloud the diagnostic picture and lead to treatment delays. A recent

qualitative study investigating the diagnostic uncertainty of pediatricians evaluating chronic pain patients suggests that the decision to stop diagnostic testing on patients with unexplained chronic pain is ambiguous, complicated, and determined by many patient and physician factors (50). Further complicating this decision includes patient and family readiness to accept their chronic pain diagnosis, since 40% of parents of youth referred to pediatric chronic pain programs do not (51). Instead, these families are described as 'relentlessly' searching for an alternative diagnosis they believe has been missed by their physician (51). This creates a unique circumstance for the referring provider who is attempting to juggle resource utilization and patient expectations, all the while ensuring secondary causes for pain have been ruled out.

Qualitative findings from this study highlight that many chronic pain providers do not assume a diagnostic role and that the quantity and quality of referral data is generally lacking. This presents a noteworthy gap between the expectations of referring providers and chronic pain providers who accept patients into chronic pain programs. Such challenges have potential to lead to inconsistent and complicated diagnostic processes that can influence referral practices and the decision to accept or re-direct a patient from a chronic pain program, which further worsens wait time to receiving specialized care.

2.5 Implications for Future Research

The identified list of significant clinical indicators/ red flags and diagnostic investigations that are required prior to referral to interdisciplinary pediatric chronic pain programs will be helpful to include in the development of a series of CDS tools aimed to clarify diagnostic expectations and guide the decision to accept or re-direct patients with primary chronic pain diagnoses into interdisciplinary pediatric chronic pain programs based on diagnostic completeness. Our next cumulative steps will be to: 1) conduct a qualitative study exploring the

decision-making practices of pediatric chronic pain nurses who accept and triage patients into their programs, and then 2) implement a user-centered design study with a team of referring providers and pediatric chronic pain providers to identify relevant items and acceptable processes that will expand to the development of clinically CDS triage tools for primary chronic pain diagnoses. Although it was not an objective of this study, future exploration should consider the influence that mental health symptoms have on chronic primary pain diagnoses from the perspectives of psychologists and other mental health providers, since it is considered a significant co-morbidity (52). We hope our study can be expanded in the future to include more participants from countries outside of North America to capture a more global view of diagnostic expectations for interdisciplinary pediatric chronic pain programs across the world.

2.6 Strengths

To our knowledge, this is the first study of its kind to attain expert consensus on a large list of significant clinical indicators/ red flags and required diagnostic investigations for six common pediatric primary chronic pain diagnoses from the perspectives of pediatric chronic pain experts. The diversity of respondents who were willing to participate in this study highlights an international and inter-role interest in the topic of diagnostic clarity for children and adolescents with primary chronic pain disorders. Justification for this study was qualitatively validated by participants, which highlights its relevancy to the population and community of chronic pain providers.

2.7 Limitations

It is important to acknowledge the influence of bias on the validity and reliability of the Delphi method. Because this method relies on judgements, variances of results can be influenced by situation and personal bias (13, 16). Only 16 of the 22 experts participated in the second-

round survey, challenging the generalizability of results. Further to this, most participants were from North America and thus findings are not geographically diverse. There is an element of selection bias, since only those subscribed to the Pain List Serve were recruited. Furthermore, this study was limited to two rounds. Although a high degree of overall consensus was met, conducting a third round may have influenced overarching results, particularly regarding chronic pelvic pain which demonstrated lowest degree of consensus. It is important to mention that the additional feedback offered by participants, identified as qualitative data, was not guided by traditional qualitative methodology, and therefore results should be interpreted with caution.

2.8 Conclusion

There is general agreement amongst pediatric chronic pain experts in this study regarding diagnostic expectations for patients referred to interdisciplinary chronic pain programs for six common primary chronic pain diagnoses. There is also a universal consensus not to require diagnostic tests prior to acceptance into such programs for patients without significant clinical indicators or red flags. Despite this, the literature points to significant delays in receiving specialized treatment, which amongst many other potential factors such as capacity and resource limitations, may be related to conducting unnecessary diagnostic tests and over complicating the diagnostic process. Items that met consensus in this study may help to clarify diagnostic expectations for patients with primary chronic pain diagnoses referred to interdisciplinary chronic pain programs. As a next step, it will be crucial to include the perspectives of referring providers and other relevant speciality services since they commonly assume the diagnostic role. Findings from this study, combined with our planned future work, will result in the development of a series of user-centered, evidence-based, and clinically useful CDS triage tools for interdisciplinary pediatric chronic pain programs. We believe this has potential to ease the

diagnostic process for referring providers, enhance the decision to accept or re-direct referred patients based on their diagnostic completeness and streamline the pathway to accessing specialized chronic pain evaluation and treatment. We hope this can ultimately reduce the burden of chronic pain on patients, their families, and the healthcare system.

Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Author Contributions

Authors 1, 2, 3, 4 and 6 contributed to the study design, methods and REB applications. Author 1 lead the project recruitment, data collection, analysis and manuscript preparation. All authors contributed to the interpretation of results and offered significant feedback to several manuscript drafts. Author 5 contributed to the clinical relevancy of the topic under study and facilitated participant recruitment.

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Figure 2.1 Delphi Process Flowchart

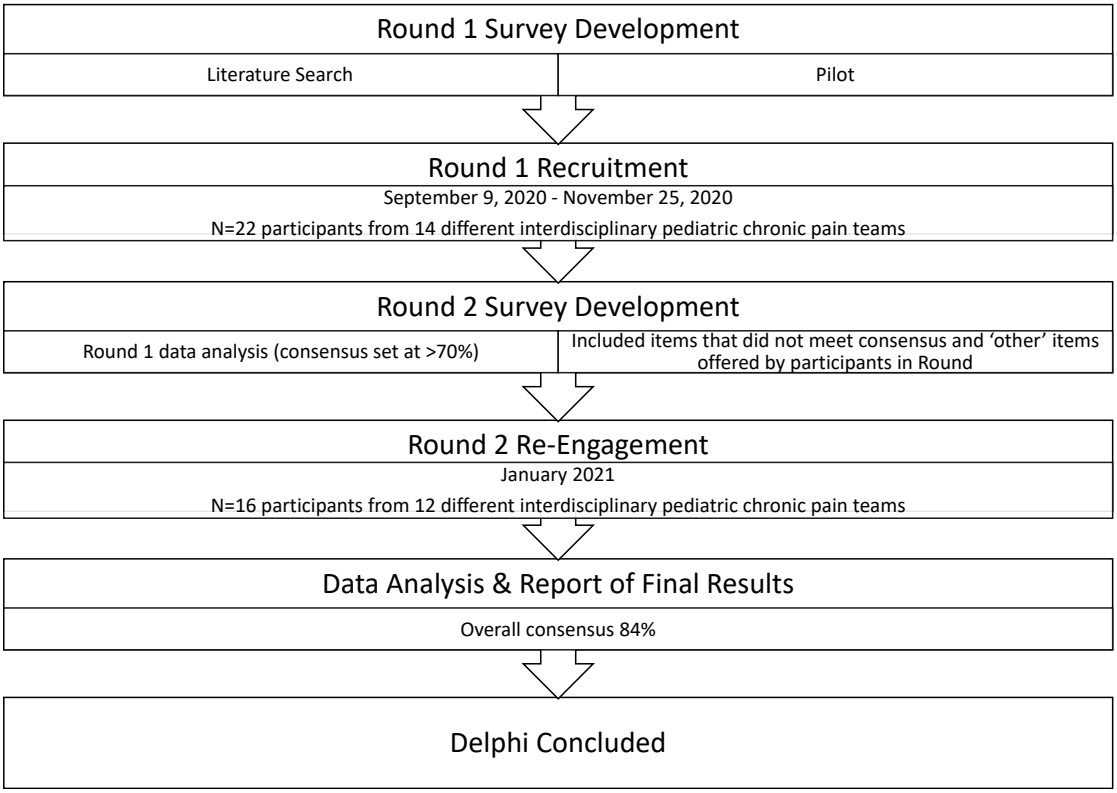

Table 2.1 Participant Demographics

Item		**Number of Participants**		**Number of Interdisciplinary Teams**	
		Round 1 n=22 (%)	**Round 2 n=16 (%)**	**Round 1 (n=14)**	**Round 2 (n=12)**
Geographical Area of Work	United States of America	11 (50)	9 (56)	7	6
	Canada	9 (41)	5 (31)	5	4
	France	1 (4.5)	1 (6)	1	1
	Australia	1 (4.5)	1 (6)	1	1
Clinical Designation	Anesthesiologist	7 (32)	4 (25)		
	Pediatrician	4 (18)	2 (12.5)		
	Pediatric Rheumatologist	1 (4.5)	1 (6)		
	Nurse Practitioner	6 (27)	6 (37.5)		
	Clinical Nurse Specialist	4 (18)	3 (19)		
Level of Education	Doctor of Medicine	12 (54.5)	-		
	Master's Degree	8 (36)	-		
	Doctoral Degree	1 (4.5)	-		
	Bachelor's Degree	1 (4.5)	-		
Years of Working Experience	0-5 years	3 (14)	3 (19)		
	5-10 years	6 (27)	4 (25)		
	10-20 years	9 (41)	8 (50)		
	20-30 years	2 (9)	1 (6)		
	30+ years	2 (9)	0		

**Note: 'Level of education' was only asked in the first-round survey to establish eligibility.*

Table 2.2 Consensus

Degree of Consensus by Pain Location/ Diagnosis	Degree of Consensus by Domain	Item	Original Item	'Other' Item added by Participant	Consensus Met	Decision
Complex Regional Pain Syndrome (CRPS), Type 1 18/18 items (100%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 7/7 items (100%)	Suspicion of active bone and/ or soft tissue damage	•		√	Important
		Suspicion of neuropathies	•		√	Important
		Fever and/ or chills	•		√	Important
		Neurovascular changes		•	√	Important
		History of pulselessness		•	√	Important
		History of trauma		•	√	Important
		History of surgery		•	√	Important
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 4/4 items (100%)	Erythrocyte Sedimentation	•		√	Not Important
		Serum C-Reactive Protein	•		√	Not Important
		Serum CBC	•		√	Not Important
		Serum Creatinine Kinase	•		√	Not Important
	Diagnostic Imaging Investigations Required for Patients WITHOUT Significant Clinical Indicators 5/5 items (100%)	Bone Scan of affected area(s)	•		√	Not Important
		X-Ray of affected area(s)	•		√	Not Important
		Magnetic Resonance Imaging of affected area(s)	•		√	Not Important
		Duplex Ultrasonography of affected area(s)	•		√	Not Important
		Computed Tomography	•		√	Not Important
	Diagnostic Procedures Required for Patients WITHOUT Significant Clinical Indicators 2/2 items	Local Anesthetic Injection Trial	•		√	Not Important
		Nerve Conduction Studies	•		√	Not Important

	(100%)					
Chronic Headaches 32/35 items (91%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 17/18 items (94%)	Neurological abnormalities	•		√	Important
		Child is between 3-5 years	•		√	Important
		Systematic signs and symptoms	•		√	Important
		Headache of sudden onset	•		√	Important
		Headache wakes from sleep	•		√	Important
		Described by patient as 'worst headache of life'	•		√	Important
		New or different severe headache	•		√	Important
		Headache that worsens with Valsalva	•		√	Important
		Change in headache frequency	•		√	Important
		Vomiting		•	√	Important
		Family history of neurological disease		•	√	Important
		History of cancer		•	√	Important
		History of ventriculoperitoneal (VP) shunt		•	√	Important
		Postural headache		•	√	Important
		Headache upon wakening		•	√	Important
		Loss of developmental milestones		•	√	Important
		Weight loss/ loss of appetite		•	√	Important
		History of tooth pain		•	X	*Did not reach consensus*
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 9/10 items (90%)	Serum Electrolytes	•		√	Not Important
		Serum Glucose	•		√	Not Important
		Serum Albumin	•		√	Not Important
		Serum Complete Blood Cell Count	•		√	Not Important
		Serum Blood Urea Nitrogen	•		√	Not Important
		Serum Calcium	•		√	Not Important

		Serum Creatinine	•		√	Not Important
		Serum Vitamin D		•	√	Not Important
		Serum Ferritin		•	√	Not Important
		Serum Thyroid Function	•		X	*Did not reach consensus*
	Diagnostic Imaging Investigations Required for Patients WITHOUT Significant Clinical Indicators 2/2 items (100%)	Magnetic Resonance Imaging	•		√	Not Important
		Computed Tomography	•		√	Not Important
	Diagnostic Procedures Required for Patients WITHOUT Significant Clinical Indicators 4/5 items (80%)	Temporomandibular Joint (TMJ) Assessment	•		√	Not Important
		Lumbar puncture	•		√	Not Important
		Sleep study	•		√	Not Important
		Papilledema assessment		•	√	Not Important
		Visual acuity exam		•	X	*Did not reach consensus*
Chronic Musculoskeletal and/ or Joint Pain 35/39 items (90%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 11/13 items (85%)	Unexplained weight loss	•		√	Important
		Systematic signs and symptoms	•		√	Important
		Pain and stiffness in the morning	•		√	Important
		Arthralgia with redness and edema	•		√	Important
		History of significant physical trauma	•		√	Important
		Radiculopathy	•		√	Important
		Bony tenderness	•		√	Important
		History of congenital anomalies	•		√	Important
		Pain at night	•		√	Important
		History of cancer		•	√	Important
		Positive trigger points		•	√	Important

		History of prior surgeries	•		X	*Did not reach consensus*
		Known Ehler's- Danlos Syndrome (EDS)		•	X	*Did not reach consensus*
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 18/19 items (95%)	Serum Creatinine Kinase	•		√	Not Important
		Serum C-Reactive Protein	•		√	Not Important
		Serum Complete Blood Cell Count	•		√	Not Important
		Serum Thyroid Function	•		√	Not Important
		Serum Tissue Transglutaminase	•		√	Not Important
		Serum Antinuclear Antibodies	•		√	Not Important
		Serum Rheumatoid Factor	•		√	Not Important
		Serum Calcium	•		√	Not Important
		Serum Blood Urea Nitrogen	•		√	Not Important
		Serum Albumin	•		√	Not Important
		Serum Glucose	•		√	Not Important
		Serum Creatinine	•		√	Not Important
		HLA B27		•	√	Not Important
		Vitamin D level		•	√	Not Important
		Vitamin B12 level		•	√	Not Important
		Folate level		•	√	Not Important
		Complement level		•	√	Not Important
		Urinalysis		•	√	Not Important
		Serum Erythrocyte Sedimentation Rate (ESR)	•		X	*Did not reach consensus*
	Diagnostic Imaging Required for Patients WITHOUT Significant Clinical Indicators 3/4 items (75%)	Ultrasound of affected area(s)	•		√	Not Important
		Magnetic Resonance Imaging of affected area(s)	•		√	Not Important
		Computed Tomography of affected area(s)	•		√	Not Important

		X-Ray of affected area(s)	•		X	*Did not reach consensus*
	Diagnostic Procedures Required for Patients WITHOUT Significant Clinical Indicators 3/3 items (100%)	Muscle biopsy	•		√	Not important
		Nerve Conduction Studies	•		√	Not important
		Electromyography	•		√	Not important
Chronic Back Pain 19/24 items (79%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 12/14 items (86%)	Incontinence (bladder and/ or bowel)	•		√	Important
		Unexplained weight loss	•		√	Important
		Fever and chills	•		√	Important
		History of cancer	•		√	Important
		Widespread neurological symptoms	•		√	Important
		History of immunocompromised condition	•		√	Important
		History of infection or trauma	•		√	Important
		Bilateral sciatica	•		√	Important
		Radiculopathy	•		√	Important
		Unrelenting night pain	•		√	Important
		Pain unrelated to activity	•		√	Important
		Redness/ edema of painful site		•	√	Important
		Constant pain		•	X	*Did not reach consensus*
		History of scoliosis		•	X	*Did not reach consensus*
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 5/6 items (83%)	Serum CBC	•		√	Not Important
		Serum Erythrocyte Sedimentation Rate	•		√	Not Important
		Serum Calcium	•		√	Not important
		Serum Alkaline Phosphate	•		√	Not important
		Antinuclear Antibody (ANA) level		•	√	Not Important

		Serum C-Reactive Protein	•		X	*Did not reach consensus*
	Diagnostic Imaging Investigations Required for Patients WITHOUT Significant Clinical Indicators 2/4 items (50%)	Computed Tomography of affected area(s)	•		√	Not important
		Ultrasound of affected area(s)	•		√	Not important
		X-Ray of Affected Area(s)	•		X	*Did not reach consensus*
		Magnetic Resonance Imaging (MRI) of Affected Area(s)	•		X	*Did not reach consensus*
Chronic Abdominal Pain 34/43 items (79%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 13/14 items (93%)	Bloody emesis	•		√	Important
		Bloody stools	•		√	Important
		Concern or diagnosis of an eating disorder	•		√	Important
		Unexplained weight loss	•		√	Important
		Systemic signs and symptoms	•		√	Important
		Persistent vomiting	•		√	Important
		Persistent diarrhea	•		√	Important
		History of prior surgeries	•		√	Important
		Persistent RUQ/RLQ pain	•		√	Important
		History of trauma		•	√	Important
		Referred back pain		•	√	Important
		Bilious emesis		•	√	Important
		Pain that wakes from sleep		•	√	Important
		Family history of gastrointestinal cancer		•	X	*Did not reach consensus*
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 12/20 items (60%)	Serum C-Reactive Protein	•		√	Not Important
		Serum Albumin	•		√	Not Important
		Serum Creatinine	•		√	Not Important
		Serum Blood Urea Nitrogen	•		√	Not Important
		Serum Thyroid Function	•		√	Not Important
		Fecal Culture & Sensitivity	•		√	Not Important
		Fecal Ova & Parasite	•		√	Not Important

		Urinalysis	•		√	Not Important
		Serum Calcium	•		√	Not Important
		Urine Culture & Sensitivity	•		√	Not Important
		Fecal Occult Blood Test	•		√	Not Important
		Serum Erythrocyte Sedimentation Rate		•	√	Not Important
		Serum Complete Blood Cell Count (CBC)	•		X	*Did not reach consensus*
		Serum Electrolytes	•		X	*Did not reach consensus*
		Serum Liver Function	•		X	*Did not reach consensus*
		Serum Glucose	•		X	*Did not reach consensus*
		Serum Lipase/ Amylase	•		X	*Did not reach consensus*
		Serum Tissue Transglutaminase (TTG)	•		X	*Did not reach consensus*
		H. Pylori screen		•	X	*Did not reach consensus*
		Fecal calprotectin		•	X	*Did not reach consensus*
	Diagnostic Imaging Investigations Required for Patients WITHOUT Significant Clinical Indicators 4/4 items (100%)	Abdominal Ultrasound	•		√	Not Important
		Abdominal X-Ray	•		√	Not Important
		Abdominal Magnetic Resonance Imaging	•		√	Not Important
		Abdominal Computed Tomography	•		√	Not Important
	Diagnostic Procedures Required for Patients WITHOUT Significant Clinical Indicators 5/5 items (100%)	Endoscopy with biopsies	•		√	Not Important
		Endoscopy without biopsies	•		√	Not Important
		Hydrogen Breath Test (for fructose/ lactose sensitivities)	•		√	Not Important
		Local anesthetic injection to rule in or out ACNES	•		√	Not Important

		Gastric emptying study		•	√	Not Important
Chronic Pelvic Pain 19/28 items (68%)	Significant Clinical Indicators (i.e., Clinical Red Flags/ Signs of Organic Pathology) 12/14 items (86%)	History of sexual trauma	•		√	Important
		Excessive or unexplained weight loss	•		√	Important
		Pelvic mass	•		√	Important
		History of physical trauma	•		√	Important
		Tenesmus	•		√	Important
		Testicular mass	•		√	Important
		History of congenital anomalies	•		√	Important
		Vaginal discharge	•		√	Important
		Rectal bleeding	•		√	Important
		Post-coital bleeding	•		√	Important
		Dysmenorrhea	•		√	Important
		Menorrhagia	•		√	Important
		Dyspareunia		•	X	*Did not reach consensus*
		Hematuria		•	X	*Did not reach consensus*
	Laboratory Investigations Required for Patients WITHOUT Significant Clinical Indicators 0/5 items (0%)	Urinalysis	•		X	*Did not reach consensus*
		Urine Culture & Sensitivity	•		X	*Did not reach consensus*
		Sexual Transmitted Infection Swab	•		X	*Did not reach consensus*
		Serum/ Urine Beta HcG	•		X	*Did not reach consensus*
		Serum Complete Blood Cell Count	•		X	*Did not reach consensus*
	Diagnostic Imaging Required for Patients WITHOUT Significant Clinical Indicators 3/5 items	Magnetic Resonance Imaging of Pelvis	•		√	Not important
		Transvaginal Ultrasound	•		√	Not Important
		Computed Tomography of Pelvis	•		√	Not important

	(60%)	Testicular Ultrasound	•		X	*Did not reach consensus*
		Abdominal & Pelvis Ultrasound	•		X	*Did not reach consensus*
	Diagnostic Procedures Required for Patients WITHOUT Significant Clinical Indicators 4/4 items (100%)	Colonoscopy	•		√	Not important
		Diagnostic Laparoscopy	•		√	Not important
		Barium Enema	•		√	Not important
		Cystoscopy	•		√	Not important

Consensus Threshold = To deem an item important to consider/include in a referred patient, >70% of participants must rate as 'important'-'extremely important'. To deem an item not important to consider/ include in a referred patient, >70% of participants must rate as 'not at all important'- 'somewhat important'.

Table 2.3 Course of Action if Patient has Significant Clinical Indicators (Red Flags) Prior to Acceptance into Interdisciplinary Pediatric Chronic Pain Program

Type of Pain	Deny patient with no suggestions to referring provider n (%)	Deny patient with suggestions to referring provider n (%)	Re-direct referral to Emergency Department n (%)	Re-direct referral to specialty service n (%)	Accept patient and request patient complete required work-up n (%)	Accept patient and assess yourself n (%)
Complex Regional Pain Syndrome Type 1	1 (4.5)	1 (4.5)	2 (9)	8 (36)	2 (9)	6 (27)
Chronic Headaches	0	2 (9)	8 (36)	4 (18)	3 (14)	4 (18)
Chronic Musculoskeletal/ Joint Pain	1 (4.5)	2 (9)	0	11 (50)	3 (14)	3 (14)
Chronic Back Pain	0	2 (9)	4 (18)	9 (41)	1 (4.5)	3 (14)
Chronic Abdominal Pain	0	3 (14)	0	10 (45)	4 (18)	1 (5)
Chronic Pelvic Pain	1 (4.5)	2 (9)	0	12 (55)	4 (18)	0

**Note: These questions were only included in the round one survey (n=22 participants)*

Table 2.4 Use of Clinical Decision Support Tools in Accepting Patients to Interdisciplinary Pediatric Chronic Pain Programs

Type of Pain	**Yes** *N (%)*	**No** *N (%)*	**List of Clinical Decision Support Tools/ Diagnostic Algorithms** *(number of participants who mentioned tool)*
Complex Regional Pain Syndrome Type 1	15 (68)	7 (32)	• Budapest Criteria (n=14)
Chronic Headaches	11 (50)	11 (50)	• The International Classification of Headache Disorders (n=10) • American Academy of Neurology and American Headache Society (n=1) • PedMidas (n=1)
Chronic Musculoskeletal/ Joint Pain	2 (9)	20 (91)	• Beighton score (n=1)
Chronic Back Pain	1 (5)	21 (95)	• American Academy of Pediatrics Recommendations (n=1) • American Academy of Family Practice Guidelines (n=1) • American College of Rheumatology Guidelines (n=1)
Chronic Abdominal Pain	6 (27)	15 (68)	• Rome III Criteria (n=1) • American Academy of Pediatrics (n=5)
Chronic Pelvic Pain	1 (5)	21 (95)	• American Academy of Family Practice Guidelines (n=1)

**Note: These questions were only included in the round one survey (n=22 participants)*

Table 2.5 Supporting Qualitative Data

Topic	Theme	Frequency	Belief Statement	Frequency	Exemplar Quote
Context of Chronic Pain Programs	Clinic Models and Philosophies	4	Chronic pain program models and philosophies vary	1	*The diagnostic approach is somewhat dependent on the clinic model/philosophy. There is a spectrum of clinic models from full diagnostic clinics to consultative only* ***(Nurse Practitioner)***
			Adequate completion of investigations is required prior to accepting patients into chronic pain programs	1	*In general - our clinic does not accept any patients who have not been adequately investigated for an acute medical illness that might explain the pain* ***(Pediatrician)***
			Screening patient data prior to accepting them into a chronic pain program is important	1	*A thorough screening is done prior to admitting into program. At times we will do a consultation and if needed then refer. If there is significant past trauma, there are times we will refer to tx then they can return to program if needed* ***(Nurse Practitioner)***
			Trusting in specialized colleagues is important when deeming work up complete	1	*We also trust that our specialty colleagues have more expertise in assessing than we do. For example - if rheumatology orders no tests for a kid with widespread pain - that is fine. They are the experts in assessing these symptoms. If GI does no investigations for a kid with abdo pain that is okay with us. So, it isn't really about assessing what prior test have been done - it is about WHO has seen the kid and who has made the referral to us* ***(Pediatrician)***
Diagnostic Role	Chronic pain clinician does not	21	Work in parallel collaboration with specialized provider	9	*Assess patient and then refer to appropriate specialty* ***(Anesthesiologist)***

	assume diagnostic role		Accept patient only after being seen by relevant specialist	4	*We only accept headache referrals if the patient has been assessed by a child neurologist. So even if these signs are present, we will accept the referral, assuming that the neurologist has assessed and done the necessary investigations* ***(Pediatrician)***
			Work in collaboration with Primary Care Provider	3	*If workup is not done, we would recommend the referral source arrange for this - but we do not redirect the referral. That is the family docs role (not ours)* ***(Pediatrician)***
			Accept patient but defer assessment until work up complete	2	*It is not uncommon to accept a patient but defer until further work up complete* ***(Nurse Practitioner)***
			Re-direct patient to ER to facilitate further work-up	2	*In our practice, going to ED is a way to facilitate getting the work up rather than waiting for insurance* ***(Nurse Practitioner)***
			Do not accept patient until work-up is complete	1	*We would only accept a patient who has had the necessary work-up for abdo pain* ***(Pediatrician)***
	Chronic pain clinician partially assumes diagnostic role	1	Depending on case, start work-up within chronic pain service	1	*If concern for disordered eating, would refer patient to adolescent medicine. If primary concern is GI pathology would start work-up myself and refer to GI for evaluation* ***(Pediatric Rheumatologist)***
Quality of Referral Data	When referral data is lacking	1	It is common to receive referrals that do not have adequate information to inform a triage decision	1	*We are generally just happy to receive patient records when we receive a referral, much less specifically documented criteria. While common among pain professionals, these types of evaluations are difficult to get from community providers. Even a numeric pain scale seems like a challenge* ***(Nurse Practitioner)***

	When referral data is optimal	2	When the work up is complete, triage decisions are easier to make	2	*Usually by the time we get them, the work up is complete- which makes it easy* ***(Nurse Practitioner)***
Evidence Informed Decision Making	CDS utilization	1	We do not use CDS tools but are interested in using them	1	*We do not use any decision support tools, but we'd love to know more about them if there are any validated for kids* ***(Anesthesiologist)***
	PROM utilization	2	Preference to have PROMs completed prior to first chronic pain assessment appointment	1	*Patient reported outcomes inform the diagnosis in the initial assessment. We would accept the referral but strongly recommend completion of these outcomes prior to their first appointment* ***(Clinical Nurse Specialist)***
			Availability of standardized data sets	1	*In Australia we have a national data set for referrals ePPOC this includes: FPS-R, Body map, PedsQL, FDI and over 13's complete pain related worries from BathAPQ* ***(Clinical Nurse Specialist)***
	Lack of evidence-based guidance	2	There is a lack of evidence-based guidance to inform diagnostic approach with pediatric chronic pain patients	2	*Unfortunately, there are no pediatric specific diagnostic approaches for chronic pain syndromes. This is a need that would provide us with a standard for which to diagnose and allow other specialists to refer to pain physicians sooner if there were better discriminating tool* ***(Anesthesiologist)***

Chapter 3: A Systematic Review of the Biopsychosocial Dimensions Impacted by Chronic Pain in Children and Adolescents: Identifying Reliable and Valid Pediatric Multidimensional Chronic Pain Assessment Tools

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Abstract

Introduction: Pediatric chronic pain is a complex experience that is often challenging to describe and measure. Multidimensional tools that evaluate the biopsychosocial impact of chronic pain in pediatrics can help clinicians to prioritize and tailor interdisciplinary pain care; yet the psychometric value and clinical utility of such tools has not yet been systematically studied in the literature.

Objective: The purpose of this review was to identify multidimensional biopsychosocial tools used in pediatric chronic pain, synthesize their reliability and validity evidence, and draw on this evidence to describe the relationships between chronic pain and biopsychosocial domains.

Methods: The search involved two phases to 1) identify eligible tools and 2) conduct a measured forward citation search of tool development articles. Tool eligibility was guided by the *Multidimensional Biobehavioral Model of Pediatric Pain* and study eligibility was focused on primary chronic pain diagnoses unrelated to disease. Data extraction was focused on reliability and validity evidence of eligible tools, guided by the *Standards for Educational and Psychological Testing*.

Results: Results yielded 6 tools that included 64 eligible studies, highlighting 84 significant relationships between pain and functional interference across 11 biopsychosocial variables. All tools were shown to have good internal consistency and evidence of validity, primarily through relationships to other variables.

Conclusions: Of the six tools, the most brief and easy to use were the most under studied. Further psychometric research is warranted for these tools to investigate their clinical utility and psychometric properties in guiding and prioritizing pain care for children and adolescents.

3.1 Introduction

Chronic pain in pediatrics is a multidimensional experience, involving interplay between nociceptive processing, affect, sociocultural context, and behavioral and cognitive mechanisms [14,48]. Consequently, a variety of biopsychosocial variables including depression, anxiety, low self-esteem, sleep disturbances, fatigue and decreased physical functioning interact to impact the functioning and health of children and adolescents living with chronic pain [42,12,23,22,15,27]. Since the pediatric chronic pain population often receive a variety of ineffective treatments by non-specialized providers [48], it is probable that treatment failure is related to limited tailoring of biopsychosocial needs. For these reasons, multimodal biopsychosocial approaches are considered gold standard for chronic pain treatment, thus interdisciplinary chronic pain programs are an ideal setting for this patient population [37]. Since the spectrum of disability between pediatric chronic pain patients widely varies [44], accurate measurement of the biopsychosocial impact of pain may help clinicians with referral processes, prioritization of care, and ongoing assessment of patient response to treatment within such chronic pain programs.

Existing systematic reviews have highlighted the psychometric qualities of single-item pain intensity scales [4,25,36], observational pain measures for children and adolescents [43] and tools that measure parent response to their child's pain [17]. Reviews have also shown that most adolescent chronic pain assessment tools focus solely on the psychological domain. A comprehensive understanding of multi-item tools that measure the biopsychosocial impact of pain across multiple domains of the pediatric chronic pain experience is lacking. Such a review is needed to illuminate the ways in which biopsychosocial variables are interpreted and weighed in predicting patient complexity in the pediatric chronic pain population, which may help to inform prioritization of care into and within interdisciplinary pediatric chronic pain programs.

The *Multidimensional Biobehavioral Model of Pediatric Pain* [40] is a framework to support the consideration of chronic pain as a biopsychosocial phenomenon. The model was specifically developed to account for the wide variability of pain perception, pain behavior and functional status [42]. It has been used to identify the factors associated with pain intensity and functional disability in a variety of pediatric chronic pain disorders [42]. The model categorizes variables of the pain experience into the following domains: 1) ***precipitants***, including pain related diagnoses/ disease, injury, stress and/ or pain producing procedures; 2) ***intervening*** variables, including biological predispositions, family environment, cognitive appraisal, coping strategies and perceived social support; 3) ***pain perception and behavior***; and 4) ***functional status***, including activities of daily living, school attendance, depressive symptoms, anxious symptoms, behavioral problems and interpersonal relations.

Objectives

The specific objectives of this review were to: 1) identify multidimensional biopsychosocial assessment tools used in the pediatric (i.e., ages 2-18yrs) chronic pain population; 2) describe the relationships between chronic pain and the biopsychosocial domains (precipitant variables, intervening variables and functional status variables) measured in each tool, as defined by the *Multidimensional Biobehavioral Model of Pain*; and 3) review the reliability and validity evidence of such tools and their biopsychosocial domains in the pediatric chronic pain population.

3.2 Methods

Design and Reporting

We conducted a systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 Checklist [30] which is outlined in Supplementary File 1 and Supplementary File 2.

Eligibility Criteria

Multidimensional biopsychosocial assessment tools included in this review were those that: 1) included variables reflecting at least two of the *Multidimensional Biobehavioral Model of Pain* domains of pain, precipitant variables, intervening variables, and functional status variables, 2) were developed specifically to measure the impact of pain rather than general functional interference not specific to pain, and 3) intended for use in patients with primary chronic pain diagnoses (as defined by the ICD-11 classification) [39]. We excluded disease specific tools, such as those for children with sickle cell disease or cancer and parent proxy measures.

Our inclusion criteria for studies describing these tools included the following: 1) The population exclusively involved pediatric patients (ages 2-18) with primary idiopathic chronic pain diagnoses/locations. 2) The outcomes of the study focused on the relationship between pain intensity and the multidimensional biopsychosocial items captured by the tool under investigation. 3) We excluded systematic reviews, meta-analyses, case studies, abstracts, and qualitative studies that did not include a psychometric outcome, such as a Cronbach alpha. We also excluded studies where the participant group included 50% or more of youth with secondary pain diagnoses related to an organic disease process such as cancer, sickle cell disease, juvenile rheumatoid arthritis, neurofibromatosis, or post-surgical pain.

Search Strategy and Information Sources.

The search strategy included two phases. Phase 1 searching focused on tool identification and was conducted in two measurement databases: PsychTEST and Health and Psychosocial Instruments (HAPI). Phase 2 searching focused on study identification, which involved a measure-forward search through two citation databases: Scopus and Web of Science. After eligible tools were selected in Phase 1, a citation search of their development article was then conducted during Phase 2. This search strategy was led by a librarian employed at The Children's Hospital of Eastern Ontario, and was PRESS reviewed by a librarian employed at The Ottawa Hospital Research Institute. Both phases of this search were first conducted in February 2020 and repeated in February 2022. Details of the search strategy can be found in Supplementary File 3.

Study Selection

A detailed instruction manual was developed based on the study eligibility criteria to guide the screening and retrieval process for Phase 1 and Phase 2 searches. One reviewer screened all results from the Phase 1 search and a second reviewer confirmed inclusion or exclusion decisions made. All tools identified in the reference articles were listed in a Microsoft Excel document, which organized tools based on eligibility and included data on tool properties (i.e., tool name, development reference, biopsychosocial domains/ variables and how they mapped to the *Multidimensional Biobehavioral Model of Pediatric Pain*).

Following the citation analysis of the development articles for each included tool conducted in Phase 2, all articles were uploaded to Covidence software to their respective project (i.e., each tool represented its own project in Covidence). Two reviewers independently screened titles and abstracts. Full text citations that met eligibility were then independently reviewed by two reviewers who further searched the text for additional eligible tools that may have been

missed in the Phase 1 search. Reviewers met on a bi-weekly basis to discuss discrepancies in eligibility assessments. All discrepancies were considered minor and were resolved. Details justifying elimination for excluded tools are listed in Supplementary File 4, and for excluded citations in Supplementary File 5.

Data Collection

A detailed data extraction instruction manual and data collection form was developed based on the study outcomes and contextual data. The data extraction process and form were piloted by two reviewers on five studies to ensure reliability of the data extraction instructions. Minor revisions were made. Two reviewers independently extracted the data based on explicit reporting of the following:

1) Study characteristics, which included authors' names, year of publication, study purpose, population demographics and methods (i.e., study design)
2) Reliability evidence as defined by *The Standards for Educational and Psychological Testing* [1]. All reliability evidence per the Standards was possible for extraction.
3) Validity evidence (as defined by *The Standards for Educational and Psychological Testing*) [1]. All validity evidence per the Standards was possible for extraction.
4) Clinical utility, as defined by Smart, 2006 [34], which included data on tool appropriateness, accessibility, practicality, and acceptability.

Results from data extraction were compiled into summary tables, which were iteratively refined to best prepare for data synthesis and narrative description.

Methodological Quality

Methodological quality and bias of all studies were assessed by two reviewers independently based on their study design, and was guided respectively by the *Quality*

Assessment and Validity Tool for Cross-sectional Studies [9] the *Quality Assessment and Validity Tool for Before and After/ Cohort Design Studies* [35] and the *Revised Cochrane Risk of Bias Tool for Randomized Trials* [19]. Studies were concluded to be weak, moderate, or strong based on the quality assessment tools.

Synthesis

The results from this review were synthesized descriptively. A meta-analysis was not appropriate due to the heterogeneity of studies describing the psychometric qualities of included multidimensional tools. Our synthesis involved a description of the relationships between pain and the biopsychosocial domains and subsequent variables that were measured across multidimensional tools. Our analysis focused on the validity evidence of each tool as it related to other variables. Significant bivariate and multivariate relationships were highlighted and tabulated across each pain domain and subsequent variable defined by the *Multidimensional Biobehavioral Model of Pediatric Pain* [40]. Reported measures of tool reliability were tabulated in a descriptive form. Cronbach alphas were considered adequate if over and/or above 0.70 [13]. A sensitivity analysis was not appropriate since only one weak study was included in this review, and results were unlikely to change based on its removal.

3.3 Results

Tool and Study Selection

In the Phase 1 search, 614 reference articles were screened for eligible tools. From this, 14 of 93 identified tools met eligibility criteria. Five of those tools were excluded as we could not locate the tool despite attempts to contact original authors. Details justifying exclusion for all tools reviewed can be found in Supplementary File 4. In the Phase 2 search, 1029 titles and abstracts, and 973 full text articles were screened across nine tools. This led to further exclusion

of three tools that did not yield outcome data. Therefore, six tools were included in our synthesis, which generated a total of 64 eligible studies. Details of search results can be found in Figure 1. Details justifying exclusion of studies can be found in Supplementary File 5.

Included Tools

A summary of tool characteristics, including number of variables and domains as well as respective mapping to the *Multidimensional Biobehavioral Model of Pediatric Pain* [40] is shown in Table 1. Variables reflecting the precipitant pain experience domain were not included in any of the six included tools. Results did not generate significant outcomes regarding clinical utility of tools, and thus information pertaining to clinical utility are described narratively below.

Included Studies

Amongst the 64 included studies, 46 were cross-sectional studies, 9 were cohort studies, 5 were randomized controlled trials, 3 were nonrandomized before and after studies, and 1 was a qualitative study. Most studies were conducted in the setting of tertiary level outpatient pediatric chronic pain programs (n=39) and included intensive inpatient pediatric chronic pain programs (n=5), other speciality clinics (n=8), research clinics (n=1), schools (n=2) and a data registry (n=1). Nine studies did not specify their setting. Six studies were found to be secondary analyses of other included studies, and therefore sample characteristics were not duplicated in our synthesis. Across the 64 studies included a total of 19,429 participants between 6 to 19 years of age. Majority of participants across studies that reported sex and ethnicity were female (median 73%) and Caucasian (median 85%). Most participants in all studies had primary chronic pain diagnoses unrelated to an underlying condition, while 11 studies included less than 50% of participants with secondary chronic pain diagnoses and 7 studies included a description of co-morbid mental health diagnoses. Study characteristics are reported in Table 2.

Bath Adolescent Pain Questionnaire (BAPQ) (n=31studies)

The Bath Adolescent Pain Questionnaire (BAPQ) was developed in 2005 and was designed specifically for use in adolescents with chronic pain [7]. Development involved expert consultation and focus groups with adolescents with chronic pain [7]. Authors for all included BAPQ citations in this study referenced that the BAPQ as appropriate for use in adolescents with chronic pain, noting its reliability and validity. Eccleston et al. (2007) demonstrated clinical utility of the BAPQ parent proxy for use with populations who cannot complete the questionnaire [8]. A noted limitation of the BAPQ was that it does not address non-adolescent age groups [26].

PROMIS Pediatric Pain Interference Scale (PPPI) (n=16 studies)

The PROMIS Pediatric Pain Interference Scale (PPPI) was developed in 2010 through the National Institutes of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS) initiative, with the intention of developing item banks and Computerized Adaptive Tests (CAT) that are applicable for a wide variety of chronic pain disorders (29). Within this initiative, the PROMIS Pediatric Cooperative Group had developed the pediatric self-report item banks, which included the PPPI that was guided by Item Response Theory (IRT) to analyze scale dimensionality, item local dependence and differential item functioning [41]. Authors of five PPPI cited studies in this review emphasized its strengths related to CAT and IRT by means of improving precision (30-34). It has been highlighted that CAT is an approach by which items are selected based on responses to previously administered items, which ultimately reduces respondent burden and optimizes scale completion [11]. The PPPI has also been used in a variety of chronic pain conditions, widening its utility across a more generalized pain population [3]. No studies in this review noted PPPI limitations.

Child Activity Limitations Questionnaire (CALQ) (n=7 studies)

The Child Activity Limitations Questionnaire (CALQ) was adapted from the Child Activity Limitations Interview (CALI) in 2007 which was designed to assess functional impairment in children and adolescents with chronic pain [16]. Four studies referenced good reliability and validity of the tool in measuring functional interference in the pediatric chronic pain population [16,10,21,37]. The clinical utility of the tool was considered enhanced over the CALI as it includes a written self-report version rather than an interview, reducing the administration time to approximately two to three minutes [16]. CALQ-focused studies in this review did not discuss its limitations.

Pain Interference Index (PII) (n=6 studies)

The Pain Interference Index (PII) was developed in 2009 to evaluate the influence of pain on functioning in the pediatric chronic pain population in clinical assessments, treatment evaluations and research studies. The PII was shown to have good reliability and validity and excellent completion rates [27]. A cited strength of the PII is its focus on the impact of pain interference compared to more general functioning [45]. Citations included in the PII review did not discuss limitations of the tool, however it is important to recognize that only 6 of 240 citations screened for the PII met eligibility for this review.

Pain Experience Questionnaire (PEQ) (n=3 studies)

The Pain Experience Questionnaire (PEQ) was originally adapted from the German Multidimensional Pain Inventory for Adults [13] in 2008, intended to assess the psychosocial impact of chronic pain in children and adolescents [18]. All three studies included in the review for the PEQ emphasized its good reliability and validity, and appropriateness for use in the

pediatric chronic pain population. Limitations were not mentioned in studies included in the PEQ review.

Pain Related Problem List for Adolescents (PRBL-A) (n=1 study)

The Pain Related Problem List for Adolescents (PRBL-A) was developed in 2005 to measure personal pain-related problems in adolescents with chronic pain [46]. The only citation that met eligibility for this review showed high internal consistency, good convergent and divergent validity and good anticipated clinical utility, as it focuses on what patients believe are their main pain related problems [46].

Reliability and validity evidence captured through this review are presented in Table 3.

Reliability Evidence

The reliability evidence captured in this review included internal consistency coefficients and test-retest coefficients. Other reliability coefficients (e.g., alternate-form coefficients, generalizability coefficients) were not revealed in included studies. Most studies provided reliability evidence on the tool under study, including 43 studies that reported Cronbach alphas to be acceptable (i.e., over 0.70). Of those, 41 studies reported Cronbach alphas to be >0.80 across various domains and total values. Two studies reported inadequate Cronbach alphas for two domains within the BAPQ—namely 0.66 for the social domain [24] and 0.66 for the physical functioning variable [47]. Across all six tools, three studies reporting on the BAPQ [7,2,32] measured test-retest reliability and showed it to be adequate in all cases. Other reliability coefficients (e.g., alternate-form coefficients, generalizability coefficients) were not measured in included studies. The amount of reliability evidence found reflected the amount of eligibility articles found per tool. The BAPQ review contained most of the reliability evidence (n=26

studies), followed by the PPPI (n=7 studies), the PPI (6 studies), the CALQ (n=4 studies), the PEQ (n=3 studies) and the PRBL-A (n=1 study).

Validity Evidence

The validity evidence captured in this review included structural validity identified through confirmatory and exploratory factor analyses and convergent validity identified through relationships to other variables. Results focused mainly on relationships to other variables and were found through both bivariate and multivariate relationships between pain and biopsychosocial domains highlighted within tool items. This review did not yield results on response process, content validity or cross-cultural validity. Four studies across four tools (BAPQ, PII, PEQ, PRBL-A) reported validity evidence based on internal structure. These studies used exploratory and confirmatory factor analyses (n=2 studies), comparison with other measures (n=2 studies) and subgroup comparison (n=1 study), which all showed satisfactory results. No studies in the review assessed response process, content validity or cross-cultural validity. All studies offered validity evidence for the tools based on relationships to other pain-related variables, since this was a main outcome of the review. A total of 84 of 112 (75%) relationships measured between biopsychosocial variables and pain were found to be significant. Of those, 20 of 29 (69%) were multivariate relationships measured through unstandardized betas (n=16 relationships) and path coefficients (n=4 relationships); and 65 of 84 (77%) were bivariate relationships measured through correlation coefficients (n=61 relationships) and odds ratios (n=4 relationships).

Across all six tools, 30 studies measured 37 relationships between pain and *general functional interference*. Of those, 34 relationships were found to be significant that included 10 multivariate correlations and 24 bivariate correlations.

Intervening Variables

Four variables were mapped within the intervening variables domain across 13 studies. The BAPQ provided majority of the data within this domain, reporting on all four of the variables, followed by the PEQ reporting on one variable. Across the 13 studies, most significant relationships were between pain and *social functioning* (n=6/11, 55% significant relationships), followed by pain and *family functioning* (n=3/6, 50% significant relationships), pain and *pain catastrophizing/ adaptability* (n=3/3, 100% significant relationships), and pain and *developmental functioning* (n=1/5, 20% significant relationships).

Functional Variables

Seven variables were mapped within the functional variable domain across 18 studies, involving the BAPQ, the PEQ and the PRBL-A. Across the 18 studies, most (n=11/14, 78.5% significant relationships) were found between pain and *depression/ mood*, followed by pain and *physical functioning* (n=9/9, 100% significant relationships), pain and *pain related anxiety* (n=8/11, 73% significant relationships), pain and *anxiety* (n=5/10, 50% significant relationships), pain and *affective distress* (n=2/2, 100% significant relationships), pain and *concentration* (n=2/2, 100% significant relationships) and pain and *activity/ school functioning* (n=1/1, 50% significant relationships).

Methodological Quality

Table 4 presents the methodological quality of studies as it pertains to each included tool. Most studies received a quality rating of moderate or strong with only a single study being rated as weak.

3.4 Discussion

Through this review, we aimed to identify multidimensional tools that specifically measure the biopsychosocial impact of chronic pain in the pediatric population. Our strategy has guided a systematic analysis of the relationship between pain and biopsychosocial variables, which help to describe the significant effect that pain has on the pediatric chronic pain experience. Results from this review revealed six reliable and valid multidimensional biopsychosocial tools for use in children and adolescents living with chronic pain, described in 64 studies. Furthermore, our findings highlight 11 biopsychosocial variables across two domains of the pediatric chronic pain experience that feature the ways in which biopsychosocial variables may be interpreted and weighed in predicting patient complexity in the pediatric chronic pain population. This knowledge may ultimately empower pediatric chronic pain programs to better prioritize care and tailor interdisciplinary pain management according to individualized biopsychosocial needs.

Psychometric Relevance

Although several related tools used in the pediatric chronic pain population have been identified, only six offer a holistic biopsychosocial pain assessment in chronic pain not specific to an underlying disease. Our reliability evidence primarily demonstrated internal consistency data measured through Cronbach alphas, presenting the relationships among items or subsets of items within each tool [39]. Our findings provide confidence in the homogeneity among items within each tool, as all six tools have exhibited acceptable internal consistency. Our validity findings focused predominantly on validity evidence assessed as relationships between pain and other related variables, which revealed the degree to which these relationships are consistent with the construct (pain interference) underlying the proposed test score interpretations [39]. All six tools demonstrated good convergent validity, highlighting evidence of several multivariate and

bivariate relationships between pain and specific biopsychosocial variables, as well as pain and general functional interference. Further illuminating our findings, it is noteworthy that only one of 64 studies was considered weak, reflecting confidence in our synthesis and conclusions drawn.

Clinical Relevance

Our findings show that the biopsychosocial domains comprising intervening variables and functional variables are associated with chronic pain and are important to assess in children and adolescents. Further, our review simultaneously offers six reliable and valid multidimensional tools that specifically measure the impact of chronic pain in pediatrics. Although it was our intention to report on the clinical utility of selected tools, our review did not generate substantial data in that regard. The BAPQ and the PPPI are the most studied tools found within our review, however their usability and efficiency are limited. The BAPQ is lengthy with 61 items across seven domains and the PPPI, although brief in nature, poses scoring complexity by means of T-score metrics that is not clearly explained in the literature and may deter use. With regards to underrepresented tools in the literature, the PEQ offers biopsychosocial representation through 15 items, however its scoring instructions are not explicit. It is also important to note that only 30 studies were identified at the screening phase in the PEQ review, highlighting its limited psychometric evaluation in the literature. The CALQ offers an efficient and clear administration and scoring system by simple summation of the scoring on 21 items on a 5-point Likert scale and identifying the eight most bothersome activities. Similarly, the PRBL-A involves a total of 18 items across 4 relevant biopsychosocial domains and is scored by averaging the items within the domains and then summing the domain scores. Further research into the CALQ and PRBL-A in pediatric chronic pain practice is warranted to support

understanding of tool clinical utility and psychometric value. Of the six tools reviewed, the PII offers the shortest multidimensional assessment platform that inclusively captures pain interference in general activities, physical activities, friendships, school, and sleep in six short questions. Furthermore, the PII involves a simple scoring system that includes calculating the average of completed items. These usability advantages may be considered more appealing to referring providers who wish to offer a quick biopsychosocial assessment for patients being referred to interdisciplinary pediatric chronic pain programs. The multidimensional nature of the tool provides a holistic assessment that may efficiently guide prioritization of care and tailoring of pain interventions based on the biopsychosocial needs.

3.5 Limitations

Despite developing a comprehensive search strategy that was formally PRESS reviewed and involved two iterative phases including relevant psychometric databases, it is possible that not all eligible instruments were identified. The Phase 1 search strategy involved a tedious manual search of eligible tools within research articles where potential tools may have been missed during the review of articles. This risk was mitigated through use of two independent reviewers. An additional layer to this limitation includes the fact that several tools have been referenced using various names, causing confusion. For example, the terms CALQ and CALI, though distinct tools, were used interchangeably between articles. We intended for our study to be focused on pediatric patients with primary chronic pain diagnoses, however strictly limiting this criterion would have omitted significant findings. Therefore, a small number of articles including a small representation of secondary chronic pain diagnoses were included. The availability of multidimensional biopsychosocial tools measuring the impact of chronic pain in pediatrics is relatively scarce, and thus we felt including these studies would provide more

advantage than disadvantage when synthesizing the literature on this topic. Consequently, our synthesis cannot confirm generalizability to patients solely with primary chronic pain diagnoses. It is important to note that the definitions within the *Multidimensional Biobehavioral Model of Pediatric Pain* domains are ambiguous and there was an element of subjectivity in how the biopsychosocial variables within each tool were mapped to the model's domains.

3.6 Future Directions

At this time, the biopsychosocial variables identified through this review to be significantly impacted by chronic pain could be assessed at various time points across the pediatric chronic pain journey, which may ultimately inform clinical practice. Although this review offers promising multidimensional biopsychosocial pain tools that specifically measure the impact of chronic pain and are supported by reliability and validity evidence, further psychometric and clinical utility research is warranted to confidently make recommendations for tool use in guiding clinical decision making in pediatric interdisciplinary chronic pain programs. Research on these tools could be expanded specifically for use in a triage assessment to help prioritize access to interdisciplinary pediatric pain care, considering the current limited availability of interdisciplinary pediatric chronic pain programs worldwide. This would provide assurance of the most psychometrically robust, rapidly administered and clinically useful tools that can be easily administered by referring providers prior to the triage assessment. We believe this would enhance the validity and reliability of triage assessments and improve prioritization of interdisciplinary pain care for patients based on the holistic impact of their chronic pain experience. With recall bias in mind, the clinical use of such tools could be expanded further to assess baseline and ongoing patient needs during intake and follow up assessments. This could

help clinicians efficiently tailor the most appropriate interdisciplinary pain interventions and assess effectiveness of proposed interventions.

3.7 Conclusion

This review is the first of its kind to systematically retrieve pain focused, reliable and valid multidimensional tools that holistically measure biopsychosocial interference in children and adolescents with chronic pain. Furthermore, this review has capitalized on the psychometric strengths of the tools to robustly emphasize the significant relationships between pain and the biopsychosocial domains and subsequent variables of the pediatric chronic pain experience. Findings from this review emphasize the strength of the relationship between pain and functional interference and offer a categorized and objective overview of 11 biopsychosocial variables across two domains that are significantly impacted by chronic pain in children and adolescents. This review offers enhanced guidance regarding biopsychosocial assessments for children and adolescents referred to interdisciplinary chronic pain programs and details avenues for further psychometric and clinical utility research. We feel that the understudied tools found in this review are promising and could be easily adopted by both referring providers and chronic pain providers. Such tools may improve prioritization of access to interdisciplinary chronic pain programs worldwide, and tailor interdisciplinary care within such programs based on biopsychosocial needs.

Acknowledgements

Registration

This review was registered with PROSPERO (CRD42020166828) on April 28, 2020. Minor amendments were made to the original protocol, that involved more precise exclusion criteria of the population under study. Specifically, our patient population was further refined to

include a higher proportion of primary chronic pain diagnoses. We excluded studies focused on patients with secondary chronic pain diagnoses (e.g., Juvenile Idiopathic Arthritis, Cancer, Sickle Cell Disease, Fibromyalgia).

Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Author Contributions

MG was the primary author who developed the justification for and general objectives of the study. All authors offered feedback to several manuscript drafts. MG designed the study protocol, which was thoroughly reviewed and revised by JES, LJ, KL and TB. Data extraction and quality appraisal was completed by MG, MDV and AS. Organization of data synthesis was primarily developed by MG and was thoroughly reviewed and revised by JES. Study results were reviewed by JES, LJ, KL, TB and CL. LJ, JES, KL and TB offered extensive feedback on the impressions and conceptualization of study findings, while CL offered insight into the clinical relevance within the setting of interdisciplinary pediatric chronic pain programs.

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BATH Adolescent Pain Questionnaire

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Figure 3.1 Search Results

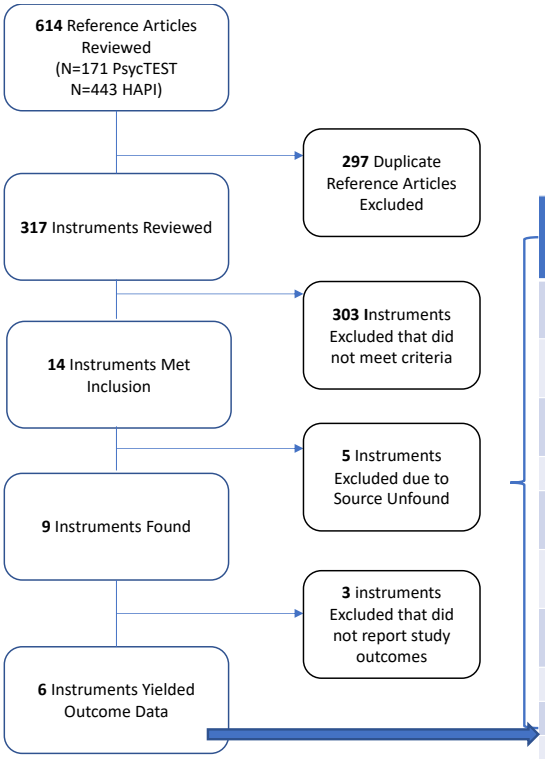

Figure 1 – Search Results

Phase 2 Search

Tool	Studies Screened	Full Text Studies Assessed	Studies Included
Bath Adolescent Pain Questionnaire	183	178	31
PROMIS Pediatric Pain Interference	181	158	16
Child Activity Limitations Questionnaire	34	33	7
Pain Interference Index	240	223	6
Pain Experience Questionnaire	30	30	3
Pain Related Problem List for Adolescents	30	6	1
Multidimensional Pain Inventory	194	188	0
Brief Pain Inventory	136	129	0
Recurrent Pain Measure	25	22	0
Total	1029	967	64

Table 3.1 Tool Characteristics

Tool	Development Article	Number of Items	Number of Domains	Scoring Method	Biopsychosocial Domains		
					Precipitant Variables	*Intervening Variables*	*Functional Variables*
BATH Adolescent Pain Questionnaire (BAPQ)	Eccleston et. Al. (2005)	61	7	5-Point Likert Scale	0	44 items across 5 domains	17 items across 3 domains
PROMIS Pediatric Pain Interference Scale (PPPI)	Varni et al. (2010)	8	N/A	4-Point Likert Scale	0	3 items	5 items
Child Activity Limitations Questionnaire (CALQ)	Hainsworth et al. (2007)	21	N/A	5-Point Likert Scale	0	4 items	18 items
Pain Interference Index (PII)	Wicksell et al. (2009)	6	N/A	7-Point Likert Scale	0	2 items	4 items
Pain Experience Questionnaire (PEQ)	Hermann et al. (2008)	15	N/A	7-Point Likert Scale	0	3 items	12 items
Pain Related Problem List for Adolescents (PRBL-A)	Weel et al. (2005)	18	4	3-Point Likert Scale	0	5 items across 1 domain	13 items across 3 domains

Table 3.2 Study Characteristics

Tool	Study Characteristics				Sample Characteristics							
	Article	**Study Type**	**Setting**	**Sample Size**	**Age (years) Mean (SD)**	**Age (years) Range**	**Female (%)**	**Male (%)**	**Ethnicity (%)**	**Chronic Pain Diagnoses/ Location of Pain (%)**	**Co-morbid Medical Diagnoses (%)**	**Co-morbid Mental Health Diagnoses (%)**
BATH Adolescent Pain Questionnaire (BAPQ)	Atikinson-Jones et al. (2021)	Cross-sectional	Outpatient Pain Program (1 site)	68	12 (2.03)	11-18	73	27	Caucasian (91) Pakistani (6) Asian (1.5) Indian (1.5)	Widespread (66) CRPS (15) Back (6) Knee (4) Headache (4) Foot/ leg (3) Hand/arm (1.5)	Hypermobility (33) Asthma (24) Spinal conditions (14) Cerebral Palsy (5) Congenital Heart Disease (5) Vascular Malformation (5)	Mental Health unspecified (33) Anxiety and Depression (36) ASD (9) ADHD (4.5) Tourette Syndrome (4.5)
	Benore et al. (2015)	Cohort	Outpatient Pain Program (1 site)	119	15.4 (2.67)	NR	75	25	Caucasian (94)	CRPS (34), Abdominal (21) Other (21) Headache (17) Back (7)	NR	NR
	Benore et al. (2018) (a)	Cohort	Outpatient Pain Programs (Registry)	135	15.2 (2.2)	NR	74	26	Caucasian (96) African American (2) Hispanic (1) Asian (1)	Headaches & Migraines (100)	NR	NR
	Caes et al. (2015)	Cohort	Research Clinic (1 site)	856	NR	17	65.5	34.5	NR	Back (54.5) Leg/Foot (34.5) Knee (32) Shoulder (28) Abdominal (24) Buttock (23) Hip (20.5) Arm/Hand (17) Headaches (14)	NR	NR

										Neck (13) Torso/Sternum (10)		
	Cohen et al. (2010) (a) & (b)	Cross-sectional	Outpatient Pain Program (2 sites)	222	14.8 (1.9)	10-18	75	25	Caucasian (99)	Whole-body (43) Limb (37) Back (8) Headaches (5) Abdominal pain (4) Hip (1) Chest (0.5)	NR	NR
	Connolly et al. (2019)	Cross-sectional	Various outpatient pain and specialty clinics (number of sites NR)	128	14.4 (1.4)	12-18	68	32	NR	Unspecified primary chronic pain	NR	NR
	Eccleston et al. (2005) & (2007)	Cross-sectional	Outpatient Pain Programs (2 sites)	222	14.8 (1.9)	11-19	75	25	NR	Widespread (41) Limb (38) Back (9) Head (5) Abdomen (4) Hip (1) Chest (0.5)	Juvenile idiopathic arthritis (21)	NR
	Eccleston et al. (2008)	Cross-sectional	Outpatient Pain Program (1 site)	110	15.1 (1.9)	11-18	73	27	NR	Widespread (55) Limb (20 Back (10) Head (10) Abdomen (9) Hip (1)	NR	NR
	Fales et al. (2014)	Cross-sectional	Various outpatient pain and	210	14.2 (1.6)	10-17	74	26	Caucasian (84) African American (5)	Musculoskeletal (81) Abdominal (32.5) Headaches (26)	NR	NR

			specialty clinics (number of sites NR)						Alaskan Native (3) Asian (1) Mixed (3) Other (3)			
	Fisher et al. (2016)	Cohort	Research Clinic (1 site)	855	13 & 17	NA	66	34	NR	Unspecified primary chronic pain (100%)	NR	NR
	Gagnon et al. (2020	Cross-sectional	Outpatient Pain Program (1 site)	202	14.1 (2.5)	8-18	77	23	NR	Headache (18) Central Sensitization (12) CRPS (12) Abdominal (9) Joint (8) Back (8) Other (2)	Fibromyalgia (6) Scoliosis (1) EDS (8)	Functional Neurological Disorder (5)
	Gauntlett-Gilbert et al. (2007)	Cross-sectional	Outpatient Pain Program (1 site)	110	15.1 (1.9)	NR	73	27	NR	Widespread (43) CRPS (37) Headache (8) Back (6) Abdominal (6)	NR	NR
	Gauntlett-Gilbert et al. (2019) (b)	Cross-sectional	Inpatient Pain Program (1 site)	355	15.6 (1.8)	10-19	77	23	NR	Widespread (34) CRPS (22) Back (13) Abdominal (10) Joint (8) Headaches (12)	Obesity (100) Hypermobility (8)	NR
	Harrison et al. (2016)	Cross-sectional	Research Database	196 (Pain Condition Group)	NR	NR	67	33	Caucasian (88) Other (12)	Chronic Primary pain Unspecified (100%)	NR	NR
	Jordan et al. (2020)	Qualitative	Inpatient Pain Program	14	NR	12-16	93	7	Caucasian (88) Indian (1)	Joint (21) Widespread (43) CRPS (29) Back (7)	Hypermobility (21)	NR

			(1 site)						African American (0.5)			
	Kemani et al. (2018)	Non-randomized Clinical Trial	Inpatient Pain Program (1 site)	164	15.5 (1.8)	11-18	77	22	NR	Widespread (66) CRPS (42) Back (17) Abdominal (13) Joint (10) Other (15)	Hypermobility (10)	NR
	Kersche et al. (2020)	Cross-sectional	Outpatient Pai program (1 site)	98	13.1 (2.4)	7-18	66	34	NR	Musculoskeletal (38) Visceral (30) CRPS (12) Widespread (12) Headache (8)	NR	NR
	Liam et al. (2017)	Cross-sectional	Outpatient Pain Program	60	13.3 (2.5)	6-19	80	20	NR	Abdominal (38) Limb (35) Head/Neck (22) Back (5)	NR	NR
	McCracken et al. (2010)	Cross-sectional	Outpatient Pain Program (1 site)	122	15.2 (2.0)	10-18	75	25	NR	Chronic primary pain unspecified	NR	NR
	McGarrigle et al. (2020)	Cross-sectional	Outpatient Pain Programs (multi-site, not reported)	129	14.5 (1.4)	12-18	68	32	NR	Musculoskeletal (47) Headache (34) Abdominal (12) Other (7)	NR	NR
	Murray et al. (2019) & (2020) &	RCT	Outpatient Pain Programs (15 sites)	273	14.7 (1.6)	11-17	75	25	Caucasian (85) African American (5) Hispanic (4) Other (5)	Widespread (40) Musculoskeletal (42) Abdominal (11) Headaches (7)	NR	NR

	Palermo et al. (2016) (a)								NR (1.5)			
	Palermo et al. (2016) (b)	RCT	Outpatient Pain Programs (2 sites)	61	14.3 (1.9)	10-17	80	20	Caucasian (90) African American (2) Asian (2) Other (6)	Musculoskeletal (39) Headache (29.5) Abdominal (29.5) Missing 92)	NR	NR
	Revivo et al. (2019)	Cohort	Intensive Pain Program (1 site)	30	14 (2.8)	9-18	90	10	NR	Diffuse Joint (100%)	Hypermobility (100%)	NR
	Robinson et al. (2019)	Cross-sectional	Inpatient Intensive Pain Program (1 site)	59	14.4 (2.6)	NR	73	27	Caucasian (86) African American (12) Other (2)	CRPS (32) Abdominal (22) Widespread (25)	EDS (15) Sickle Cell Disease (5) Concussion (3)	Conversion Disorder (8.5)
	Sinclair et al. (2019)	Cross-sectional	Outpatient Pain Program (site number not reported)	70	15.6 (1.2)	13-18	90	10	NR	Headache (30) Limb (24) Widespread (17) Back (14) Abdominal (8.5) Hip (3) CRPS (3)	NR	NR
	Vowles et al. (2010) (a)	Cross-sectional	Outpatient Pain Program	222	4.3 (4.1)	10-18	75	25	Caucasian (99)	Widespread (44) Limb (39) Back (8) Headaches (5) Abdominal/ Chest (5)	NR	NR
	Waldron et al. (2018)	Cross-sectional	Outpatient Pain Progra	148	14.6 (1.3)	13-17	72	28	Caucasian (94)	Chronic primary pain unspecified (100%)	NR	NR

			m (3 sites)									
PROMIS Pediatric Pain Questionnaire	Bhandari et al. (2022)	Cohort	Outpatient Pain Program (1 site)	328	14.7 (2.3)	8-17	72	28	Non-Hispanic (63) Hispanic (28) Unknown (12)	Musculoskeletal (22) Headache (21) Abdominal (14) CRPS (6) Fibromyalgia (4)	EDS (2) Rheumatological condition (1.5) Sickle Cell Disease (0.3)	Primary Psychological diagnosis (1.2)
	Birnie et al. (2020)	Cross-sectional	Outpatient Pain Program (1 site)	806	14.5 (2.4)	8-17	72	28	European American (60) Asian (9) African American (3) Alaskan (0.5) Native Hawaiian (0.4) Other (16) Declined to report (12)	Musculoskeletal (24) Headache (24) Abdominal (16) CRPS (7) Widespread (3)	EDS (1.7) Rheumatological condition (1)	NR
	Chan et al. (2017)	Cross-sectional	Outpatient Pain Clinic (1 site)	172	14.8 (1.7)	12-18	76	24	Caucasian (92) African American (4) Other (4)	Chronic pain including widespread pain, regional pain syndromes, headaches, abdominal pain (frequencies not provided)	NR	NR
	Dutta et al. (2020)	Cohort	Outpatient Pain program (1 site)	64	15 (1.7)	11-19	84	16	Caucasian (84) African American (6) Hispanic (2) Asian (2) Mixed (5) Other (2)	Chronic Pain Unspecified	NR	NR
	Feinstein et al. (2017)	Cross-sectional	Data Registry	325	15.5 (1.4)	8-17	74	26	Caucasian (67) Asian (7) African American (3) Alaskan (1)	Musculoskeletal (37) Headache (18) Abdominal (15) CRPS (10) Fibromyalgia (5.5) Other (9.5)	Rheumatological condition (0.9) EDS (0.9)	Primary Psychological Diagnosis (1)

									Other (11) Declined to state (2) Missing (6)	Missing (2)		
	Feinstein et al. (2018)	Cross-sectional	Outpatient Pain Program (1 site)	324	14.7 (2.1)	10-17	73	27	Hispanic (19) Non-Hispanic (69) Missing (39)	Musculoskeletal (39) Abdominal (19) Headache (24) CRPS (5) Fibromyalgia (1.5) Other (4) Missing (1)	EDS (0.3) Rheumatological condition (3)	Primary Psychological Diagnosis (2.5)
	Gamwell et al. (2021)	Cross-sectional	Gastroenterology Clinics (several, unspecified)	5281	13 (3)	8-18	60	40	Caucasian (91) African American (6) Asian (1) American Indian (0.1) Middle Eastern (0.04) Other (1.1) Not reported (0.8)	Abdominal (100)	Gastroesophageal Reflex (5) Irritable Bowel Syndrome (4)	NR
	Kersch et al. (2020)	Cross-sectional	Outpatient Pain Program (1 site)	98	13.1 (2.4)	7-18	66	34	NR	Musculoskeletal (42) Visceral (29) CRPS (12) Widespread (8) Headache (8)	NR	NR
	Morris et al. (2021)	RCT	Not specified	278	14.6 (2)	11-17	65	35	NR	Functional Abdominal Pain (100)	NR	NR
	Ross et al. (2018)	Cross-sectional	Outpatient Pain Program (1 site)	328	14.9 (1.5)	12-18	79	21	Caucasian (62) Hispanic (21) Asian (10) African American (4)	Headache (18) Abdominal (17) Joint (12.5) Back (12) CRPS (7) Fibromyalgia/ Pain Amplification (5)	NR	NR

										Lower extremity (5) Other (23)		
	Salamon et al. (2022)	Cohort	Outpatient Pain Program (1 site)	94	14.6 (1.8)	9-18	74	26	Caucasian (85) African American (7) Hispanic (3) Multiple (3) Asian (2)	Headache (44) Back (32) Joint (20) Abdominal (19)	Chronic Fatigue Syndrome (9) POTS (6) Sickle Cell Disease (1) Other unspecified (7)	NR
	Sánchez-Rodríguez et al. (2021)	Cross-sectional	Schools (3 sites)	218	14.4 (1.8)	12-18	62	38	NR	Headaches (73) Back (57) Abdominal/ Pelvis (57) Leg (44) Neck (39) Feet (31) Shoulder (28) Arm (20) Chest/ Breast (19)	NR	NR
	Soltani et al. (2018)	Cross-sectional	Outpatient Pain Program (1 site)	145	13.3 (2.6)	NR	67	33	Caucasian (81) Multiple (8) Asian (4) Latin American (3.5) Asian Other (3) Declined (0.7)	Headaches (61) Complex Pain (38) Abdominal (1)	NR	NR
	Stone et al. (2017)	Cross-sectional	Gastroenterology Clinic (1 site)	138	14.2 (1.8)	NR	68	32	NR	Abdominal (100)	NR	NR
	Stone et al. (2020)	Cohort	Gastroenterology Clinic (1 site)	278	NR	11-17	66	34	Caucasian (86)	Functional Abdominal Pain (100)	NR	NR

	Yoon et al. (2019)	Cross-sectional	Outpatient Pain Program (1 site)	285	13.9 (2.5)	8-17	71	29	Caucasian (58) Non-Hispanic (62)	Musculoskeletal (30) Headache (24) Abdominal (22) CRPS (5) Neuropathic (4) Fibromyalgia (2)	Rheumatological Conditions (1.8)	NR
Child Activity Limitations Questionnaire (CALQ)	Cunningham et al. (2019)	Cross-sectional	Study 1: Outpatient Pain Program (1 site)	959	14.0 (2.4)	NR	70	30	Caucasian (79) African American (8) Hispanic (5) Asian (0.2) Native American (0.03) Multiple (4) Other (1) Not reported (0.5)	Head (41) Extremities (17.5) Back (13) Abdominal (13) Joint (13) Generalized (8) Other (6)	NR	NR
			Study 2: Outpatient Pain Program (1 site)	207	14.2 (2.6)	NR	77	23	Caucasian (87) African American (4) Hispanic (1) Asian (1) Native American (1) Multiple (2) Other (0.5) Not reported (3)	Back (30) Abdominal (23) Joint (17) Generalized (11) Extremities (10) Head (3) Other (3.5)	NR	NR
	Evans et al. (2015)	Cross-sectional	Outpatient Pain Program (1 site)	310	15.2 (1.5)	12-18	68	32	Caucasian (78)	Headache (34) Back (18) Lower Extremity (15) Abdominal (12.5)	NR	NR
	Hainsworth et	Cross-sectional	Outpatient Pain	62	14.0 (2.7)	8-18	82	18	Caucasian (42)	Headaches (43) Migraines (10) Abdominal (17)	NR	NR

	al. (2007)		Program (1 site)						African American (7) Multiple (7) Latino (4)	Back (10) Neuropathic (10) Joint (7) Chest (2) Foot (2)		
	Jagpal et al. (2021)	Cross-sectional	Outpatient Pain Program (1 site)	770	14.2 (2.4)	8-18	70	30	Caucasian (80)	Headaches (41) Trunk (17) Extremities (17)	NR	NR
	Salamon et al. (2014)	Cross-sectional	Outpatient Pain Program (1 site)	278	14.1 (2.6)	8-18	69	31	Caucasian (77) African American (9) Multiple (4) Hispanic (5) American Indian (1) Missing (4)	Head (37) Abdomen (16) Back (16) Lower Extremity (12) Upper Extremity (6) Generalized (6) Other (6)	NR	NR
	Stoner et al. (2017)	Cross-sectional	Outpatient Pain Program (1 site)	461	13.9 (2.4)	8-18	73	27	Caucasian (84) African American (7) Multiple (4) Hispanic (3) Other (0.9) Native American (0.4) Middle Eastern (0.2) Asian (0.1)	Headaches (41) Extremities (17) Abdominal (15) Trunk (16) Other (12)	Obesity (24.5)	NR
	Tran et al. (2015)	Cross-sectional	Outpatient Pain Program (1 site)	725	14.1 (2.5)	8-18	69	31	Caucasian (75) African American (9) Latino (5)	Headaches (37) Abdominal (15) Lower Extremity (15) Back (14)	NR	NR

									Biracial/ Other (11)			
Pain Interference Index (PII)	Balter et al. (2021)	Noncontrolled Before & After Study	Outpatient Pain Program (1 site)	47	14.8 (2.2)	9-19	70	30	NR	Chronic pain unspecified	NR	Autistic Traits (81) ADHD Symptoms (85)
	Holmström et al. (2015)	Cross-sectional	Outpatient Pain Program (1 site)	163	14.1 (2.2)	7-18	74	26	NR	Chronic Pain Unspecified	NR	NR
	Lipsker et al. (2021)	Cross-sectional	Outpatient Pain Program (1 site)	146	14.5 (2.4)	NR	70	30	NR	Headache (80) Abdominal (60) Leg (60)	NR	NR
	Wickselll et al. (2011)	RCT (secondary analysis)	Behavior Medicine Treatment Service (1 site)	32	14.6 (SD NR)	10-18	77	23	NR	Back/ Neck (22) Headache (19) Widespread (19) CRPS (19) Visceral (6) Lower Extremity (6) Post-Herpetic (3)	NR	NR
	Wickselll et al. (2016)	Cross-sectional	Outpatient Pain Program (1 site)	163	14.1 (2.6)	NR	74	26	NR	Headache (66) Abdominal (41) Back (31) Joint (23) Widespread (12)	NR	NR
	Zetterqvist et al. (2020)	Nonrandomized Pilot Study	Outpatient Pain Program (1 site)	28	15.4 (1.3)	13-17	100	0	NR	Headache (75) Abdominal (39) Back (46) Leg (46) Throat (4) Chest (7)	NR	NR

										Arm/Hand (25) Teeth (7) Ear (7) Pelvis/Hip (14) Menstrual (36) Neck (7) Joint (7) Foot (7)		
Pain Experience Questionnaire (PEQ)	Calvano et al. (2016)	Cross-sectional	Gastroenterology Clinics (16 sites)	151	10.9 (2.6)	6-17	65	35	NR	Abdominal (100)	NR	NR
	Hermann et al. (2008)	Cross-sectional	NR	111	11.5 (1.8)	7-18	42	58	NR	Headache (66) Abdominal (22) Fibromyalgia (13)	NR	NR
	Offenbächer et al. (2016)	Cross-sectional	Rheumatology Clinic (1 site)	329	13.9 (2.5)	NR	81	19	NR	Musculoskeletal (100)	NR	NR
Pain Related Problem List for Adolescents (PRBL-A)	Weel et al. (2005)	Cross-sectional	School (1 site)	129	15.1 (1.6)	12-18	70	30	NR	Headaches (30) Limb (19) Back (13) Abdominal (12) Neck (5)	NR	NR

Legend:
NR = Not Reported
CRPS = Complex Regional Pain Syndrome
EDS= Ehler's Danlos Syndrome

Table 3.3 Reliability and Validity Evidence of Included Tools in the Pediatric Chronic Pain Populations

Tool	**Article**	**Reliability Evidence** *Cronbach (∝) Test Retest (r)*	**Validity Evidence**											
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/* ***Significance****)*										
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
Bath Adolescent Pain Questionnaire (BAPQ)	Atkinson-Jones et al. (2021)	∝ 0.85-0.92	-	-	-	-	-	-	-	-	-	-	-	-	-
	Benore et al. (2015)	test-retest r 0.64-0.81	-	-	-	-	-	-	-	-	-	**r 0.41**	**r 0.436**	-	-
		∝ 0.80-0.83		**β 0.568**	-	-	-	-	-	-		β 0.129	**β 0.443**	-	-
	Benore et al. (2018)	∝ 0.80 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-
	Caes et al. (2015)	∝ 0.87 (total)	-	-	**β (-) 0.165**	-	-	**β 0.193**	-	-	-	-	-	-	**β 0.349**
	Cohen et al. (2010) (a)	∝ 0.79-0.89	-	-	**r 0.31***	-	-	-	**r 0.46**	-	-	-	-	-	-
	Cohen et al. (2010) (b)	∝ 0.80-0.85	-	-	-	-	-	-	-	-	-	-	-	-	-
	Connolly et al. (2019)	∝ 0.80-0.87	-	-	-	-	-	-	-	-	-	-	-	-	-
	Eccleston et al. (2005)	∝ 0.80-0.85 test-retest r 0.64-1.00	EFA/ CFA $\chi 2$ 62.66 RMSEA 0.071 GFI 0.90	-	**r 0.26**	**r 0.22**	**r 0.40**	-	**r 0.34**	-	-	**r 0.22**	**r 0.28**	**r 0.40**	-
	Eccleston et al. (2007)	∝ 0.82-0.93	-	-	r 0.07	r 0.11	r 0.13	-	**r 0.21**	-	-	r 0.15	r 0.05	**r 0.18**	-

Tool	Article	Reliability Evidence *Cronbach (∝) Test Retest (r)*	Validity Evidence												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/ **Significance**)*										
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
	Eccleston et. Al. (2008)	-	-	-	**r 0.24**	**r 0.24**	-	-	-	-	-	**r 0.22**	**r 0.29**	**r 0.40**	
	Fales et al. (2014)	∝ 0.88 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-
	Fisher et al. (2016)	∝ 0.75-0.86	-	-	-	-	-	-	-	-	-	-	-	-	-
	Gagnon et al. (2020)	∝ 0.94 (total)	-	-	**r (-) 0.28**	**r (-) 0.26**	r (-) 0.11	-	**r (-) 0.30**	-	-	**r (-) 0.21**	**r (-) 0.33**	**r (-) 0.19**	-
	Gauntlett-Gilbert et al. (2007)	∝ >0.80 (all subscales)	-	-	-	-	-	-	-	-	-	-	-	-	-
	Gauntlett-Gilbert et al. (2019) (M)	-	-	-	β 0.00	β (-) 0.02	β 0.07	-	**β 0.18**	-	-	β 0.02	β 0.01	β 0.01	-
	Harrison et al. (2016)	∝ 0.87 (1 subscale)	-	-	-	-	-	-	-	**OR 1.79**	-	-	**OR 2.19**	**OR 2.04**	**OR 3.09**
	Jordan et al. (2020)	∝ 0.76-0.91	-	-	-	-	-	-	-	-	-	-	-	-	-
	Kermani et al. (2018)	∝ 0.64-0.85	-	-	-	-	-	-	-	-	-	-	-	-	-
	Kersch et al. (2020)	-	-	-	-	-	-	-	-	-	-	-	**r 0.388***	**r 0.308***	-
	Lim et al. (2017)	-	-	**β 0.313**	-	-	-	-	-	-	-	r 0.238	**r 0.327**	r 0.203 **β 0.501**	-
	McCracken et al. (2010)	-	-	-	r 0.049	r 0.12	r 0.13	-	**r 0.26**	-	-	r 0.12	r 0.063	**r 0.23**	-
	McGarrigle et al. (2020)	∝ 0.85-0.86	-	-	-	-	-	-	-	-	-	**r 0.42**	-	**r 0.49**	-

Tool	Article	Reliability Evidence *Cronbach (∝) Test Retest (r)*	Validity Evidence												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/ **Significance**)*											
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
	Murray et al. (2019)	∝ 0.83-0.84	-	-	-	-	-	-	-	-	-	-	-	-	-
	Murray et al. (2020)	∝ 0.83-0.84	-	-	-	-	-	-	-	-	-	-	-	-	-
	Palermo et al. (2016) (a)	∝ 0.83-0.84	-	-	-	-	-	-	-	-	-	-	-	-	-
	Palermo et al. (2016) (b)	∝ 0.85-0.88	-	-	-	-	-	-	-	-	-	-	-	-	-
	Revivo et al. (2019)	test-retest r 0.60-0.94	-	-	-	-	-	-	-	-	-	-	-	-	-
	Robinson et al. (2019)	∝ 0.82-0.84	-	-	-	-	-	-	-	-	-	-	-	-	-
	Sinclair et al. (2019)	-	**-**	**r 0.25**	**β (-) 2.01**	-	-	β (-) 1.97	**β (-) 5.79**	-	**-**	-	-	**β (-) 3.84**	**β 4.19**
	Vowles et al. (2010)	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	Waldron et al. (2018)	∝ >0.66	-	-	r 0.14	-	-	-	**r 0.35**	-	-	-	-	r 0.02	-
PROMIS Pediatric Pain Interference (PII) Scale	Bhandari et al. (2022)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.377**
	Birnie et al. (2020)	-	-	-	-	-	-	-	-	-	-	-	-	-	ß 0.02
	Chan et al. (2017)	∝ 0.88 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.39**
	Dutta et al. (2020)	∝ 0.73 (total)	-	-	-	-	-	-	-	-	-	-	-	-	r 0.21

Tool	Article	Reliability Evidence *Cronbach (∝) Test Retest (r)*	Validity Evidence												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/ **Significance**)*										
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
	Feinstein et al. (2017	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.448 (children)** **r 0.42 (adolescents)**
	Feinstein (2018)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.384**
	Gamwell et al. (2021)	∝ 0.92 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.501**
	Kersch et al. (2020)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.321**
	Morris et al. (2021)	-	-	-	-	-	-	-	-	-	-	-	-	-	ß 0.393 (baseline) **ß -0.108 (overtime)**
	Ross et al. (2018)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.38** **ß 0.33**
	Salamon et al. (2022)	∝ 0.84-0.90	-	-	-	-	-	-	-	-	-	-	-	-	-
	Sánchez-Rodríguez et al. (2021)	∝ 0.85 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 1.11** **β 0.32** **PC 1.10-1.13**
	Soltani et al. (2018)	∝ 0.84 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.54**

Tool	**Article**	**Reliability Evidence** *Cronbach (∝) Test Retest (r)*	**Validity Evidence**												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/ **Significance**)*											
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
	Stone et al. (2017)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.48**
	Stone et al. (2020)	∝ 0.85 (total)		-	-	-	-	-	-	-	-	-	-	-	-
	Yoon et al. (2019)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.283** **PC 0.105-0.116**
Child Activity Limitations Questionnaire (CALQ)	Cunningham et al. (2019)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.41 (study 1)** **r 0.41 (study 2)**
	Evans et al. (2015)	∝ 0.93 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-
	Hainsworth et al. (2007)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.31-0.40**
	Jagpal et al. (2021)	∝ 0.89 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**ß 4.74**
	Salamon et al. (2014)	∝ 0.96 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.23-0.40**
	Stoner et al. (2017)	∝ 0.95 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-
	Tran et al (2015)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.41**
Pain Interferenc	Balter et al. (2021)	∝ 0.83 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-

Tool	Article	Reliability Evidence *Cronbach (∝) Test Retest (r)*	Validity Evidence												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/ **Significance**)*										
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
e Index (PII)	Holmström 2015 et al. (2015)	∝ 0.86 (total)	Good construct validity (via comparison with FDI & CES-DC & hierarchical regression analyses)	-	-	-	-	-	-	-	-	-	-	-	**r 0.381**
	Lipsker et al. (2021)	∝ 0.86 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.267**
	Wicksell et al. (2011)	∝ 0.84 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**PC 0.52-0.60**
	Wicksell et al. (2016)	∝ 0.86 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.39** **PC 1.28-1.29**
	Zetterqvist et al. (2020)	∝ 0.81 (total)	-	-	-	-	-	-	-	-	-	-	-	-	-
Pain Experience Questionnaire (PEQ)	Calvano,& Warschburger, (2016)	∝ 0.89 (total)	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.302**
	Hermann et al. (2008)	∝ 0.71-0.87	EFA/CFA $\chi 2$ 603.34* GFI 0.90 CFI 0.96 RMSEA 0.06	-	r (-) 0.06 - 0.10	-	-	-	-	-	**r 0.28 -0.35**	-	-	-	**r 0.34-0.35**

Tool	**Article**	**Reliability Evidence** *Cronbach (∝) Test Retest (r)*	**Validity Evidence**												
			Evidence Based on Internal Structure *CFA/EFA Subgroup comparison Comparison with other measures*	**Evidence Based on Relationships to Other Variables Between Pain (intensity/ frequency/duration/modulation) and Biopsychosocial Domains** *(Correlation Measurement; Magnitude/* ***Significance****)*											
				Pain and Intervening Variables				**Pain and Functional Variables**							**Pain and General Interference**
				Pain Catastrophizing/ Adaptability	**Social Support/ Dysfunction**	**Family Support/ Dysfunction**	**Develop Mental Functioning**	**Activity / School Functioning**	**Physical Functioning**	**Concentration**	**Affective Distress**	**Anxiety**	**Pain Anxiety**	**Depression/ Mood**	
			External validity demonstrated through sub-group comparison												
	Offenbächer et al. (2016)	-	-	-	-	-	-	-	-	-	-	-	-	-	**r 0.50**
Pain Related Problem List for Adolescents (PRBL-A) (n=1 article)	Weel et al. (2005) Weel et al. (2005) (M)	∝ 0.71-0.86	Good construct validity vai comparison with CPDI, PedMIDAS and PAQoL-A	-	-	-	-	-	**r 0.28-0.43**	**r 0.03-0.37**	**r -0.03 – 0.24**	-	-	**r 0.03-0.21**	**r 0.08-0.48**

Legend:
(-)= Negative relationship
β= Unstandardized beta
α= Cronbach's alpha
r = Spearman correlation (via test-retest)
PC = Path co-efficient
OR = Odds ratio
EFA = Exploratory Factor Analysis
CFA = Confirmatory Factor Analysis
(bolded) = Significant

Table 3.4 Methodological Quality of Studies

Tool	Article	Methodological Quality
Bath Adolescent Pain Questionnaire (BAPQ)	Atkinson-Jones et al. (2021)	Moderate
	Benore et al. (2015)	Moderate
	Benore et al. (2018)	Moderate
	Caes et al. (2015)	Moderate
	Cohen et al. (2010) (a)	Moderate
	Cohen et al. (2010) (b)	Moderate
	Connolly et al. (2019)	Strong
	Eccleston et al. (2005)	Moderate
	Eccleston et al. (2007)	Moderate
	Eccleston et. Al. (2008)	Moderate
	Fales et al. (2014)	Strong
	Fisher et al. (2016)	Moderate
	Gagnon et al. (2020)	Moderate
	Gauntlett-Gilbert et al. (2007)	Moderate
	Gauntlett-Gilbert et al. (2019)	Moderate
	Harrison et al. (2016)	Moderate
	Jordan et al. (2020)	Moderate
	Kermani et al. (2018)	Moderate
	Kersch et al. (2020)	Moderate
	Lim et al. (2017)	Moderate
	McCracken et al. (2010)	Moderate
	McGarrigle et al. (2020)	Moderate
	Murray et al. (2019)	Moderate
	Murray et al. (2020)	Strong
	Palermo et al. (2016) (a)	Strong
	Palermo et al. (2016) (b)	Moderate
	Revivo et al. (2019)	Moderate
	Robinson et al. (2019)	Moderate
	Sinclair et al. (2019)	Moderate
	Vowles et al. (2010)	Moderate
	Waldron et al. (2018)	Strong
PROMIS Pediatric Pain Interference (PII) Scale	Bhandari et al. (2022)	Moderate
	Birnie et al. (2020)	Moderate
	Chan et al. (2017) (a)	Moderate
	Dutta et al. (2020)	Moderate
	Feinstein et al. (2017)	Moderate
	Feinstein (2018)	Moderate
	Gamwell et al. (2021)	Moderate
	Kersch et al. (2020)	Moderate
	Morris et al. (2021)	Moderate
	Ross et al. (2018)	Strong
	Salamon et al. (2022)	Strong

	Sánchez-Rodríguez et al. (2021)	Strong
	Soltani et al. (2018)	Moderate
	Stone et al. (2017)	Moderate
	Stone et al. (2020)	Moderate
	Yoon et al. (2019)	Moderate
Child Activity Limitations Questionnaire (CALQ)	Cunningham et al. (2019)	Strong
	Evans et al. (2015)	Moderate
	Hainsworth et al. (2007)	Moderate
	Jagpal et al. (2021)	Moderate
	Salamon et al. (2014)	Moderate
	Stoner et al. (2017)	Moderate
	Tran et al (2015)	Moderate
Pain Interference Index (PII)	Balter et al. (2021)	Moderate
	Holmström 2015 et al. (2015)	Moderate
	Lipsker et al. (2021)	Strong
	Wicksell et al. (2011)	Moderate
	Wicksell et al. (2016)	Moderate
	Zetterqvist et al. (2020)	Weak
Pain Experience Questionnaire (PEQ)	Calvano,& Warschburger, (2016)	Moderate
	Hermann et al. (2008)	Moderate
	Offenbächer et al. (2016)	Moderate
Pain Related Problem List for Adolescents (PRBL-A)	Weel et al. (2005)	Moderate

Chapter 4: Triage Decision-Making in Interdisciplinary Pediatric Chronic Pain Programs

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Keywords: Chronic pain. Pediatric. Triage. Interdisciplinary. Patient care team.

Abstract

Background: Interdisciplinary pediatric chronic pain programs are ideal treatment settings for youth with chronic pain who are complex from a biopsychosocial perspective. There is currently no evidence-based clinical decision support to guide nurses triaging patients to such programs, which increases the risk for haphazard triage decisions.

Aim: To explore and describe the decision-making practices of and contextual influences on nurses triaging patients to interdisciplinary pediatric chronic pain programs.

Design: A qualitative exploratory descriptive design.

Participants: 12 nurses across 11 different interdisciplinary pediatric chronic pain programs participated in this study.

Methods: Individual, semi-structured interviews were conducted, transcribed verbatim and analyzed using concurrent content analysis, guided by the Cognitive Continuum Theory and the Theoretical Domains Framework.

Results: Analysis generated three prominent themes: 1) Nurse-led triage determinants, 2) Process of triage decision-making, and 3) External influences on triage decision-making.

Conclusions: Triage decision making in the setting of interdisciplinary pediatric chronic pain programs is complex and often led by nurses. There is a desire amongst nurses to adopt an evidence-based Clinical Decision Support triage tool (CDS), which may streamline the referral and triage process and foster a system whereby patients in highest need for interdisciplinary care are best prioritized.

Key Practice Points: The following recommendations could be considered in developing clinical decision triage support: 1) Solidify expectations 2) Enhance diagnostic clarity 3)

Incorporate Patient Reported Outcome Measures 4) Accept that triage is an evolving decision and prepare for change and 5) Optimize communication and collaboration.

4.1 Introduction

Pediatric chronic pain is considered a significant problem worldwide (Tutelman et al., 2021). Chronic pain in children and adolescents not only increases risk of mobility issues, significant fatigue, poor sleep, school absenteeism, decreased cognitive function and worsening mental health (Miro et al., 2022), but also increases risk for opioid misuse in youth (Pielech et al., 2020). Interdisciplinary pediatric chronic pain programs are the gold standard for the treatment of chronic pain (Law et al., 2012); however the limited number of programs (Caes et al., 2018) may contribute to prolonged wait times. Lengthy wait times to access pain care in children and adolescents have been linked to increased frustration, anxiety, and feelings of hopelessness (Palermo et al., 2019). Due to the variability in complexity and disability between pediatric chronic pain patients (Wagner et al., 2014), it is essential to optimize triage decisions to chronic pain programs to accurately prioritize pain care for patients in highest need. Still there is no established model or framework for this purpose.

Without a methodological framework on which to base triage decisions, there is potential that they will be both unstructured and unsafe. In general, if triage decisions are made appropriately, there are many positive consequences, including resource efficiency, time savings and increased capacity (Aitken & FitzGerald, 2012), expedited access to treatment (Foley & Way, 2017), and improved care quality (Brown et al., 2012; Gertz & Bucknall, 1999). Triage assessments require accurate interpretations of clinical data, where observation and patient inclusion in the assessment allows the nurse to validate their clinical judgement (Noon, 2014). Given the lack of supplementary evidence to support the diagnosis of medically unexplained chronic pain in children (Konijenberg et al., 2004), triage-decision making in this patient population may be challenging.

Although the literature on patient triaging is abundant in acute care settings, there is very little empirical knowledge on triage processes within interdisciplinary chronic pain programs. One study investigated triage across 66 adult multidisciplinary chronic pain programs internationally and, although a need to develop best practice clinical guidelines for triage at tertiary pain clinics was identified, a description of the triage process was not provided (Page et al., 2017). Further, Zomahoun and colleagues (2021) suggest that there is no knowledge synthesis on Clinical Decision Support (CDS) systems for referral to chronic pain settings; however, several CDS system features have been correlated with success, including the need to justify the decision support with credible evidence and involve local users in the development process (Lobach et al., 2011). Such a system could facilitate the triage practices of nurses who work in interdisciplinary pediatric chronic pain programs.

4.2 Purpose and Objectives

Since nurses often assume the role of triage, the purpose of this study was to explore and describe the decision-making practices of and contextual influences on pediatric chronic pain nurses triaging patients to interdisciplinary chronic pain programs. Specific study objectives included:

1. Explore the types of decisions involved in triage.
2. Explore triage decision-making processes.
3. Explore the determinants (i.e., barriers, facilitators, and contextual factors) that influence triage decision making.
4. Explore current use of Clinical Decision Support (CDS) triage tools in making triage decisions.

5. Explore interest in using a Clinical Decision Support (CDS) triage tool in making future triage decisions.

4.3 Methods

Study Design

A qualitative exploratory descriptive design was used. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury & Craig, 2007) directed our approach for reporting of results, which is detailed in Supplementary File 1. This study was reviewed and approved by the Research Ethics Boards at both the University of Ottawa (REB #H-11-19-5122) and the Children's Hospital of Eastern Ontario (REB #2020058).

Participants

Eligible participants were licenced a) Registered Nurses (RNs), Advanced Practice Nurses (APNs), Clinical Nurse Specialists (CNSs) or Nurse Practitioners (NPs) who work within an interdisciplinary pediatric chronic pain team, b) have a minimum of one year of experience working with pediatric chronic pain patients and c) can read and write in English. We purposively recruited participants through the Pediatric Pain List Serve, which is an international internet forum maintained by Dalhousie University in Halifax, Nova Scotia. Recruitment also included snowball sampling as many interested participants shared the invitation with eligible colleagues. Interested participants contacted the Principal Investigator (MG) to confirm eligibility, share the study's Letter of Information and consent form and set up a time and date for the virtual interview. We informed participants both through the letter of information and prior to their interview that their participation in the study was voluntary. Participants were sent a small incentive as a token of appreciation for their participation in the study.

Procedures

We developed a semi-structured interview guide for data collection which was based broadly on the objectives listed above and can be found in Supplementary File 2. The interview guide was piloted with a local Nurse Practitioner who has worked with an interdisciplinary pediatric chronic pain service and has triaged referrals. No revisions were required. Two authors, (MG and JL) with experience in qualitative methodology independently coded the interviews.

Theoretical Frameworks

Two theoretical frameworks guided the analysis of this study. The revised Cognitive Continuum Theory (CCT) (Standing, 2008) provided the theoretical underpinnings to guide understanding of triage decision making. This framework was considered particularly suitable to guide the investigation of triage decision making because of its ability to explain the 'back and forth' or oscillation of triage decisions (Brown & Clark, 2014). One noted limitation of CCT is that it overlooks the importance of sociological perspectives and interdisciplinary factors (Reeves & Hean, 2013), thereby creating difficulty capturing those 'real life' factors beyond the control of the decision maker. The Theoretical Domains Framework (TDF) (Cane et al., 2012) was thus used to capture the determinants that influence nurses triaging practices, including interdisciplinary and other contextual factors.

Data Collection & Data Analysis

Individual interviews were conducted by Zoom due to geographical diversity of participants and were between 25 to 60 minutes in duration. Data saturation was reached after 12 interviews (Jiggins et al., 2016). All interviews were audio-recorded, transcribed verbatim by

Otter Transcribe software, and managed through NVivo (release 1.7.1). Interview transcripts were not shared with participants, and repeat interviews were not conducted. Concurrent content analysis was used to describe triage in a conceptual form (Elo & Kyngas, 2008) because it allows for both inductive and deductive forms of qualitative analysis. General nodes were derived from the interview guide and were further analysed to include sub-nodes. Prominent themes and sub-themes were generated based on the topic and how often themes and sub-themes were referenced. See Supplementary File 3 for a summary of the coding analysis, which outlines the nodes, their definitions and how they mapped to the theoretical frameworks and prominent themes. This summary chart, as well as the illustration of the triage process (Figure 1) was emailed to participants for a member check. Three of the 12 participants responded and highlighted the comprehensiveness of the analysis. No questions, concerns or suggestions for revisions were offered.

4.4 Results

Participant and Team Characteristics

This study included 12 nursing participants from 11 different interdisciplinary pediatric chronic pain programs across Canada (n=5), the United States of America (n=5) and Australia (n=1), seven of whom held an advanced practice role. One participant held a Nursing Doctorate degree, four held a Nursing Master's degrees and seven had a Bachelor of Science in Nursing degree. Participants had between two to 20 years of experience working within their interdisciplinary team and between two and 21 years of experience working with the pediatric chronic pain population. Half of participants indicated that they receive up to 40 patient referrals monthly and almost all participants utilized a structured referral form (n=11). One participant

reported working within an intensive inpatient chronic pain program, while all other participants (n=11) reported working in an outpatient chronic pain program, all of which had interdisciplinary team representation. No participants withdrew from the study. Details regarding participant and team characteristics are presented in Table 1.

Our analysis generated three major themes regarding triage decision-making within interdisciplinary pediatric chronic pain programs, including: 1) Nurse-led triage, 2) Process of triage decision-making and 3) External influences to triage decision-making. Details of themes and exemplar quotes are presented in Table 2.

Theme 1: Nurse-Led Triage Determinants

Our data emphasized the leading role nurses play in triage decision-making within interdisciplinary pediatric chronic pain programs. All 12 participants are involved in triaging within their teams, and most are the only member who triage within their team (n=7). Several participants (n=6) described how *smoothing the way* (n=7) and *ensuring a thorough triage process* (n=7) are significant aspects of their nursing role. Many participants (n=7) spoke to *triage development and adaptation*. One participant mentioned,

> "I had the time to do what I call a deeper dive. So we developed the new triage form, so there'd be more information on it… so that I could triage properly" (ID2).

Another participant spoke to their collaborative approach in developing a new triage form after compiling ideas for various data points and Patient Reported Outcome Measures (PROMS), who stated,

> "We were kind of just in the process of taking that data [to the team] and helping to differentiate what providers would like to see" (ID8).

In line with our original recognition of limited evidence regarding triage decisions in interdisciplinary pediatric chronic pain programs, many participants alluded to the fact that there is *limited evidence-based guidance* on how to make triage decisions within their work setting. Most participants (n=9) emphasized the need to have an evidence-based triage tool. This idea was expanded by one participant in relation to patient access to pain care, who explained,

> "(for) exclusion criteria, we need some like real evidence-based rationale for that, because if anyone's going to even counter that argument and complain or whatever, like we're on the line a little bit" (ID 7).

Participants also highlighted how limited evidence is a specific barrier to triage decision-making. One participant elaborated to say,

> "I was actually kind of frustrated that there really aren't some good guidelines to follow… it was really challenging to come into this role… there's so much variability with every referral that comes through" (ID1).

The unique complexity of triage specific to the pediatric chronic pain population was emphasized by many participants (n=9) and *managing complexity* is a part of their triage role. One participant explained,

> "I'm a very experienced nurse. I've had a short time in chronic pain, but I spent many years in a cardiac clinic. When a patient arrived to clinic we pretty much knew where the defect was in the heart, we're pretty confident … we knew there was something very

> specific and we had a pretty good idea of how we're going to help support the patient and the family through that journey. When a patient's referred to the chronic pain clinic, you never know what you're gonna get… what appears on paper and all this sort of thing you do and everything you read, you still can't predict how that's all going to go until it comes and they may not even have the pain diagnosis that they're thinking… so how can somebody triage that, it's impossible… it's a very different patient population because they haven't had that diagnosis yet" (ID1).

Multiple participants mentioned how 'getting it right', is not easy. One participant reported,

> "it's a really fine balance. We try our best, but we don't always get it right…I don't think we always get it right despite all this information" (ID5).

Another participant described a triage audit that was conducted within their team and emphasized that it took up to 38 days to make a triage decision on one patient, which they explain was related to the complexity of the referral and the "back and forth" communication with the referring provider (ID8). Progressive patient complexity was also mentioned, with one participant who stated,

> "It's definitely gotten a lot more complex over the years. I find its just each year it gets more complex, more referrals" (ID9).

Many participants (n=7) considered patient complexity a significant barrier in making a triage decision and emphasized how an evolving patient status can further complicate the triage decision. One participant mentioned,

> "A number of things can also happen in their life that I'm not even privy to because I accept the referral and I move onto other things. So when that patient shows up who would have been referred in January, they might have had surgery. They might have seen other specialists or emergency (services) because all of those things that transpire. I'm not getting that information as a triage nurse role, that's just added by that patient when they present in clinic… I don't keep track of all the patients once they've been triaged" (ID1).

Clinical instinct was described by participants as a "gut feeling" based on experience and was often (n=5) discussed as a factor contributing to triage decisions. Participants (n=5) also considered how *personal influences and bias*, or pre-existing values and perceptions, impact triage decisions. One participant described how,

> "…having misperceptions [about patient cases]… perceptions and biases come into play [when making triage decisions] and you know, those may not be correct" (ID8).

Triage Decision-Making

The focus of our analysis highlighted the process and influencing factors of the triage decision. There were several commonalities in how participants described the overarching triage process and determinants that are illustrated in Figure 1. The inner circle represents the individual nurse factors influencing the triage decision. Outside of the circle are the external influences on the decision-making of the nurse.

Theme 2: Process of Triage Decision-Making

The inner circle captures the influences on the process, which is thought to be more certain, involving the *gathering of patient information* that is considered important in formulating a triage decision, *assessing patient eligibility* to the program based on several patient factors, and *prioritizing* patients based on urgency who are in greatest need of interdisciplinary chronic pain care. Participants also spoke of the 'grey' components of the triage decision that are considered more intangible. *Anticipating patient needs* or predicting what patients will require as part of their pain care, was discussed in various ways by many participants (n=8) that can impact patient eligibility and prioritization decisions.

Diagnostic clarification, or clarity of pain etiology on the referral, was the most prominent sub-theme discussed about the triage process. Almost all participants mentioned diagnostic clarification as a facilitator to the triage decision (n=11), as an important eligibility requirement (n=10), and a factor that influences how patients are prioritized (n=11). One participant (ID3) described how a "straightforward diagnosis", such as Complex Regional Pain Syndrome simplifies the triage decision. Many participants recognized Complex Regional Pain Syndrome as an urgent diagnosis (n=8), followed by secondary pain from an underlying disease (e.g., cancer, inflammatory) (n=6) and persistent post-surgical pain (n=2). Almost all participants (n=10) emphasized the importance of a complete diagnostic work up prior to making a triage decision. One participant provided an example of the dangers of misdiagnosing chronic pain, reporting,

> "I had a kid with chronic leg pain for a long time. They called me and they were describing to me a pain that I thought was different. And it was in her calf. And it was just different. And I said, 'I just don't like how this sounds'. You know what I mean? And she had a DVT [Deep Vein Thrombosis]. So I think you have to have that mindset

that not everything is related to anxiety. Everything's related to your pain diagnosis. Someone has to make sure of that" (ID11).

Facilitators and *barriers* of the triage decision were pronounced topics when discussing the overarching triage process. *Completeness of referrals* was highlighted as an important aspect of the triage process, which involved inclusion of all diagnostic investigations done on the patient, all consultations they may have had with other specialty services, and a past medical and psychosocial history. Incomplete referrals were of the most frequently discussed barriers reported by participants (n=10), whereas complete referrals enabled an informed triage decision (n=9). Some participants consider *clear reasons for referral* (i.e., what referring providers are seeking from the referral) (n=4), *access to clinical documentation* (i.e., through an Electronic Medical Chart and/ or clinical reports included in the referral) (n=3) and *collaboration with referring providers* (n=2) be to be additional facilitators to the triage decision. Related to this, *use of standardized triage forms* was considered a facilitator in making triage decisions (n=4). One participant mentioned that the eligibility criteria their clinic followed had been outlined by a provincial committee as "*inadequate*" and considered not helpful in informing their triage decision (ID1). *Time and resources* were frequently discussed by participants as influencing triage. Lack of time and resources was considered by almost all participants (n=10) as a significant barrier to triage.

In terms of triage logistics, many participants (n=9) *review referrals for completeness* prior to triaging patients into their programs. Several participants (n=7) also *require patient intake forms to be complete* prior to making a triage decision. To this point, participants mention *patient and family buy-in* to a rehabilitative approach are important eligibility criteria for program entrance (n=5) and are facilitators to the triage decision (n=2). Prior to concluding a

triage decision, several participants (n=5) indicated that they *communicate directly to the referring provider* to gather missing information. Half of the sample (n=6) also comment that they *link patients with resources* (e.g., physiotherapy, psychology), while families are waiting for their chronic pain intake appointment.

Theme 3: External Influences on Triage Decision-Making

Many nurses spoke to factors outside of their personal judgement that can impact their triage decisions. All 12 participants discussed the *influence that patient and families* have on their triage decision in various ways. One participant described family influence as a challenge, stating,

> "I find it really difficult when parents get really angry, but the child is actually functioning, so I don't want to prioritize them" (ID 12).

Almost all participants (n=11) described the *influence that referring providers* have on their triage decision. One participant provided a challenging case with a referring provider, stating,

> "…someone referred for CRPS [Complex Regional Pain Syndrome]. And it really didn't meet the criteria. And so I sent her a letter and she was quite upset about it and didn't contact me directly but contacted one of our Doc's. And we brought in the patient" (ID2).

Organizational influence was also discussed by several participants (n=5), with one participant who described the undue pressure their organization places on wait times. They explained,

> "At this institution… we've been told that you're supposed to be getting an appointment within two weeks. Well, it's just it's just not feasible for our clinic…we kind of utilize

> that factor with administration and say, well, if that's the case, then you need to give us more support because we can't there's it's just impossible. We can't do that in our clinic. So we have tried to adjust that accordingly. But that would be one influence, which I wouldn't say it's very strong in our opinions" (ID7).

Although most participants (n=8) described the *influence from their interdisciplinary team* as positive, one participant explained that occasionally there is a "bone of contention" between themselves and team members, stating

> "…when the family shows up in clinic and a member of the time might be exasperated to say, 'why are we seeing this patient? They're clearly not ready for a three P (pain management) approach.' And the counter argument is until they come to clinic and they can be assessed by the multidisciplinary team, how does anybody determine that?" (ID1).

4.5 Discussion

The prominent nuance of the data highlighted the desire and need to adopt a structured triage practice grounded in evidence to better guide the triage process and decision-making for complex pediatric patients being referred to such settings. Although the function of pain programs varies, the general recommendations generated by our data may be clinically useful to consider and adopt for decision support across interdisciplinary pediatric chronic pain programs worldwide.

Solidify Expectations

Solidifying the expectations of the referring provider is essential to reducing the "back and forth" involved in gathering patient information, setting boundaries for the roles and

responsibilities between the referring provider and the pain team, and to protect and support the nurses' triage decision. In a systematic review protocol intending to synthesize the effectiveness and harms of clinical decision support systems for referral to chronic pain practices, authors highlight that appropriate triage decisions require exploration of a "massive" amount of clinical data, emphasizing that the interdisciplinary team must have clear eligibility guidelines for pain management to be effective (Zomahoun et al., 2021). A study conducted in Germany investigating the referral practices to specialized pain clinics contended that the one reason for extensive time delays to access pain care is because of 'unstructured' patient referral systems (Shulte et al., 2010). Furthermore, a qualitative study exploring the experience of patients with chronic back pain who are referred to physiotherapy clinics for pain management identified that when the referring provider did not suspect pain to be related to serious underlying pathology, referral patterns were less structured (Boyle et al., 2022). Solidifying and clarifying referral expectations may reduce disparities in referral practices which may lead to improved pain care and access equity between referred patients.

Enhance Diagnostic Clarity

Taking measures to enhance diagnostic clarity at point of referral is important to facilitate triage decisions, rule out secondary sources of pain, tailor treatment approaches based on pain conditions and improve patient and family buy-in to a self-management, rehabilitative approach. The notion that diagnostic clarity is imperative aligns with an international survey of 66 adult multidisciplinary pain clinics showing that pain etiology and pain type are the most important criterions for triage (Page et al., 2017). Diagnostic uncertainty is described as the perception that a patient's health problem is inaccurate and has been associated with heightened pain interference in the pediatric chronic pain population (Neville et al., 2020). There is also

qualitative evidence that pediatricians struggle in deciding when to stop investigating underlying causes of child and adolescent pain (Neville et al., 2020). A systematic classification for chronic primary and secondary pain diagnoses has been developed by an international, multidisciplinary task force through the International Association for the Study of Pain (IASP) for the International Classification for Diseases (ICD-11) (Treede et al., 2015). Although this taxonomy offers better accuracy in coding chronic pain conditions when compared to previous classification system (Barke et al., 2022), it does not outline the diagnostic investigations necessary to rule out secondary pain diagnoses. A recent Delphi study that investigated the diagnostic expectations of specialized pain physicians and advanced practice nurses generated a list of 72 important items to consider in diagnosing six common primary chronic pain disorders prior to referral to interdisciplinary pediatric chronic pain programs (Greenough et al., 2022). A combination of the ICD-11 categories with these important diagnostic items may enhance diagnostic clarity at patient referral or triage to chronic pain programs.

Incorporate Patient Reported Outcome Measures at Point of Referral

Due to the biopsychosocial complexity and wide spectrum of functional disability of the pediatric chronic pain population (Wagner et al., 2013), prioritizing referred patients to interdisciplinary pain programs is challenging. Further complicating this prioritization is the absence of the patient's report of symptoms while making the triage decision. Incorporating valid, reliable, and pragmatic multidimensional Patient Reported Outcome Measures (PROMs) at the point of referral may provide an efficient and objective measure of the biopsychosocial impact of the pain experience to ease triage decisions and increase the chance that patients in highest need have prompt access to care. Our data suggests many pain programs require patients

and families to complete PROMs prior to receiving their assessment appointment, which will elevate the patient and family voice in analysing how pain is impacting their life.

Accept that Triage is an Evolving Decision and Prepare for Change

Our data shows that triage decision-making in the setting of complex interdisciplinary pediatric chronic pain programs is an evolving process and decisions can change based on the several contextual factors—making room for error. We assert that there must be a level of acceptance and flexibility around the triage nurse' decision at point of referral. There is a foundation of ambiguity when it comes to the diagnostic approaches in pediatric patients with medically unexplained chronic pain (Konijnenberg et al., 2004; Neville et al., 2020). To this point, patient symptoms and trajectories inevitably change throughout their pain and health journey and additional details often arise during more in-depth, interdisciplinary assessments with the patient. Pediatric pain programs should therefore continuously assess patient eligibility, from acceptance to discharge, and re-direct their care to more appropriate providers should pain no longer be their primary problem.

Optimize Communication and Collaboration

Communication and collaboration between referring providers and chronic pain specialists is particularly vital at the point of triage, when the decision to accept or deny a patient is based on referral data that is not always complete. A best practice referral guideline was developed in Australia to improve communication and shared care arrangements between general practitioners referring patients to psychiatrists and psychologists. This guideline affirms that to support best practice communication between health providers, all clinicians must communicate with each other about the patient's clinical management (Bulletin of the Royal

Australian and New Zealand College of Psychiatrists, 2014). This principle supports our findings that positive and collaborative relationships between both referring providers and interdisciplinary team members facilitates the triage decision.

4.6 Strengths

This is the first study to explicitly explore the contextual determinants and triage decision-making practices of nurses who work in interdisciplinary pediatric chronic pain programs. Our data generated rich insights from the perspectives of 12 nurses across 11 different interdisciplinary pediatric chronic pain programs worldwide and has prompted five recommendations to consider in triage decision support development. Findings from this study will provide the foundation for our next user-centered design study in developing a CDS triage tool for interdisciplinary pediatric chronic pain clinics.

4.7 Limitations

Although the intention of this study was to focus on the nursing lens, we recognize the value of interdisciplinary perspectives on the topic of triage due to the biopsychosocial diversity of this patient population and setting. It is also important to acknowledge that the Principal Investigator of this study had prior working relationships with some of the participants. This, as well as her clinical experience, creates a risk of bias in how results were interpreted. This bias risk was mitigated by having other non-pain specialized members involved in the study design. We were transparent with participants about this potential bias, as well her research goals. We also conducted a member check to confirm the interpretation of findings (Creswell, 2014). Although there was fair participant representation within Canada and the United States, all but one participant was from North America, which limits generalizability of results. There is also an

element of selection bias, since only those subscribed to the Pain List Service or known to the investigator or other participants were recruited.

4.8 Conclusion

This study highlights the complexity of triage decision-making within the multifaceted setting of interdisciplinary pediatric chronic pain programs. Further investment into evidence-based triage guidance in this context is warranted and may streamline the referral and triage process. This may ultimately reduce time and workload on the nurse and enhance the rigor of the triage decision by basing it on justified eligibility and prioritization factors. We believe this will improve the equity of access to chronic pain care across the population, while fostering a system that best prioritize those in highest need for interdisciplinary care.

Declarations of Competing Interests

All authors declare that this research was conducted without any commercial or financial relationships as a potential conflict of interest.

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Table 4.1 Participant Demographics and Chronic Pain Team Context

PARTICIPANT DEMOGRAPHICS		
Item		**N=12 Participants (%)**
Geographical area of work	Ontario, Canada	3 (25)
	Quebec, Canada	2 (17)
	British Columbia, Canada	1 (8)
	Missouri, United States	2 (17)
	Ohio, United States	1 (8)
	California, United States	1 (8)
	Delaware, United States	1 (8)
	Sydney, Australia	1 (8)
Nursing Role	Nurse Practitioner	4 (33)
	Clinical Nurse Specialist	3 (25)
	Clinical Coordinator	3 (25)
	Case Manager	1 (8)
	Clinic Nurse	1 (8)
Nursing Education	Bachelor of Science in Nursing	7 (58)
	Master of Science in Nursing	4 (33)
	Doctorate in Nursing	1 (8)
Years of Experience with Interdisciplinary Chronic Pain Team	0-5 years	4 (33)
	6-10 years	5 (42)
	11-15 years	2 (17)
	16-20 years	1 (8)
Years of Experience working with the Pediatric Chronic Pain Population	0-5 years	3 (25)
	6-10 years	4 (33)
	11-15 years	1 (8)
	16-20 years	1 (8)
	21+ years	3 (25)
CHRONIC PAIN TEAM CONTEXT		
Item		**N=11 teams (%)**
Program Type	Outpatient	10 (91)
	Intensive Inpatient	1 (9)
Volume of Referrals	1-10 Monthly	2 (18)
	11-20 Monthly	1 (9)
	21-30 Monthly	2 (18)
	31-40 Monthly	6 (55)
Use of Standardized Referral Form	Yes	11 (100)
Use of Triage Categories	Yes	6 (50)
How Referrals are Received	Via Electronic Medical System	8 (67)
	Paper/ Fax	4 (33)
Interdisciplinary Roles	Nursing	11 (100)
	Medicine	11 (100)
	Psychology	11 (100)

	Physiotherapy	11 (100)
	Social Work	6 (55)
	Occupational Therapy	5 (42)
	Pharmacy	2 (18)
	Clinical Coordinator	2 (18)
	Recreational Therapy	1 (9)
	School Liaison	1 (9)
	Complementary Therapy	1 (9)
	Spiritual Care	1 (9)

Table 4.2 Themes and Exemplar Quotations

Theme	Sub-themes	Number of Participants (n=12)	Number of References	Exemplar Quote
Nurse-led Triage Determinants	Triage development and adaptation	7	14	"*We were kind of just in the process of taking that data [to the team] and helping to differentiate what providers would like to see*" (ID8).
	Ensuring a thorough triage process	7	10	*It's a matter of figuring out whether we need to go back and get more information, get more clarity on things. Going and looking at you know, other consults that might inform whether this is really the right time to see the patient. Looking at imaging. You know, flagging to the Fellow to say, you need to have a look at this. It's the facilitating and passing of information and making sure we're being thorough (ID3).*
	Smoothing the way	6	9	*My role is basically to advance things and make sure things go smoothly* (ID5).
	Limited evidence-based guidance	12	30	*… there is no evidence to show us how to make these complex decisions … there's just nothing out there. There's no guidance really* (ID3).
	Managing complexity	9	32	*…it's a really fine balance. We try our best, but we don't always get it right…I don't think we always get it right despite all this information* (ID5).
	Clinical instinct	5	8	*It's a mix of intuition, that nursing intuition, mixed with the experience and you've seen these other pain etiologies that are more acute. You can kind of have that gut instinct about it, and it's really valuable* (ID11).

	Personal bias and influence		5	7	*…having misperceptions… perceptions and biases come into play and you know, those may not be correct* (ID8).
Process of Triage Decision-Making	Triage logistics	Linking patients with resources	6	15	*When we have such a long wait list, and if people in quite distressed or sometimes get them going with some stuff and give them some of our resources and a little bit of education as well around chronic pain and how some of the mind movement strategies can start to be implemented. And sometimes we have a long wait list, which is what I'm hoping will happen early next year is a lot of these kids will have had sorted themselves out through just through that one phone call* (ID12).
		Communicating with referring providers	7	18	*We're basing that [triage decision] on the information you provided to us, and the patient is your responsibility until we see them…and if anything changes, let us know and we can look at this again* (ID1).
		Reviewing referrals for completeness	11	33	*And they don't they don't want to fill it [referral form] all in. We've put hard stops on some of the fields that require them to to actually answer those questions. When I first started, these questions, were not there and there was no forced entry so we modified the form to make them to at least answer the pertinent questions* (ID1).
	Gathering of patient information	Biological or medical data collected	12	26	*[We ask for] imaging you know, if we're talking about musculoskeletal pain, you know, has, do we have the imaging that we need before going in and treating the pain if there's any sort of, you know, joint pain, making sure that like their rheumatology has been involved, making sure that we have the information that the blood you know, the that we have the you know, sort of information on inflammatory markers, that sort of thing (ID3).*

		Psychological or psychiatric data	12	19	*[We request a] psychological history. If they're involved with a current counselor or any psychological diagnosis* (ID7).
		Social data	9	11	*We ask school involvement like if they're attending school, sports, any extracurriculars* (ID7).
		Services involved	8	14	*We'd want to sort of know who's been involved period, like not just like who we think needs to be involved. But if we see that multiple disciplines have been involved if we see that there have been multiple ER visits for pain or other I want to explore that a little bit (ID3).*
		Physical data	6	10	*…another thing on our form is or what I consider for triaging is if they're using how debilitating it is, like are they using mobility aids and that kind of thing? Because that bumps them right up* (ID2).
		Pharmacotherapy data	5	6	*…we can track down the medicine as well as sometimes just looking at the pharmacology of those patients* (ID4).
		Family dynamics data	3	4	*…we ask social situation who they live with, you know, whose is the main care providers?* (ID7).
		Patient/ family goals	2	2	*[We ask] what's the goal of the family for coming to the clinic, so that tells us a lot* (ID5).
		Interventional data/ treatments tried	1	1	*[We ask about] any injections. Like at the I mean, regional approaches in the past* (ID7).
	Identifying eligible patients	Diagnostic investigations complete	10	20	*I would say part of that question of has everything has all the medical workup been done to be able to be sure this is a*

					patient for our clinic or for us to really be able to see clearly what we need to do (ID3).
		When pain is not the primary concern	10	15	*…if pain is not the main problem, and you know, typically especially if they're very complex and have a lot of mental health issues, then we will decline* (ID2).
		Patient readiness and engagement	5	9	*If the readiness so like, are the medical investigations complete? Do you feel like you are ready to accept that they are complete and that you're moving on to this pain? Rehab model? Those are big decisions and important ones there* (ID9).
		Chronicity of pain	4	7	*…if they're having acute pain or like they haven't had pain for more than three months, then they're not ready to come? See me. Yeah. So they would go to either our chronic pain clinic, which has always has a three month wait, so everyone always has chronic pain, but they would be sent either there or to their primary care person because they're not chronic. I know this because I did it two weeks ago when the patient had to acute of pain to be in our clinic. At that point, they just weren't ready for our approach* (ID10).
		Patient must have a primary care provider	3	4	*They have a primary care provider who agrees to participate with the suggestions from CPS [Chronic Pain Service]* (ID5).
		Developmental and intellectual disabilities	2	2	*The ability to participate in cognitive behavioral therapy. So there has to be an acceptable mental capacity* (ID11).
		Foundational pain	1	1	*They must have been unresponsive to [foundational] treatment* (ID5).

		management strategies have been tried			
	Anticipating patient needs	N/A	8	27	*I have one [referral] right now that I've been delaying calling the family… She's a 26 weeker. Global Developmental Delay. Hearing impairment, behavioral concerns, disordered eating… the developmental pediatrician is referring her to us for head pain. And I just really question how we're going to benefit [her]* (ID9).
	Diagnostic clarification	N/A	10	36	*Diagnostics do matter. Not just for us, because sometimes we need to roll something out before we start proceeding with recommending them this kind of physiotherapy. Like what if they had a broken bone or something? There is a safety issue, but also for the families, they're not ready to move with that… I need to know the cause… so I think diagnostics helps the family* (ID5).
	Prioritization	Prioritization based on diagnosis	11	25	*If it if it's CRPS we want to see it as soon as possible* (ID3).
		Prioritization based on functional interference	9	17	*…one is severe level of pain related dysfunction regardless of the type of pain and so that's where those other factors that I described earlier would really play into it. They're not going to school, if they're not sleeping, if their mood is so disturbed, they can't get out of bed, you know, all those other factors would put them into that category a level two* (ID1)
		Prioritization based on age	6	7	*…age is kind of one of our first priorities* (ID7).
		Prioritization based on	6	9	*…if there's a really big mental health component, we might get to see them because wait lists to get into mental health services*

		mental health symptoms			*are quite long, so we might prioritize them in order to get them rather than waiting for us and then having a way to get into mental health as well* (ID12).
		Prioritization based on healthcare utilization	6	7	*If we see that multiple disciplines have been involved if we see that there have been multiple ER visits for pain or other I want to explore that a little bit* (ID3).
		Prioritization based on physical symptoms	3	5	*Mobility, even school attendance, because I think that says a lot. Yes, and no sports like a lot of our kids don't, you know, don't but I think mobility in general and school attendance is two big ones* (ID9).
		Prioritization based on referring provider impression/ opinion	3	6	*We have a section where if a provider wants a specific pain physician to evaluate the patient we have that you know as a checkmark, and then also if it's a an urgent referral or a routine referral* (ID6).
	Facilitators to triage	Diagnostic clarification	11	34	*If it was straightforward diagnosis like knowing that when the referral it's very, it seems very clearly that it's a CRPS. Yeah, so super straightforward diagnosis* (ID3).
		Completenes s of referrals	9	14	*if it's [referral form] filled out correctly, then we know what to focus on… that initial form just gives us some basic idea of why the patient is coming to see us so yes, it's helpful and that's why we want to have that form filled out* (ID6).
		Having clarity for reason of referral	4	4	*That intention or indication for referral* (ID8).

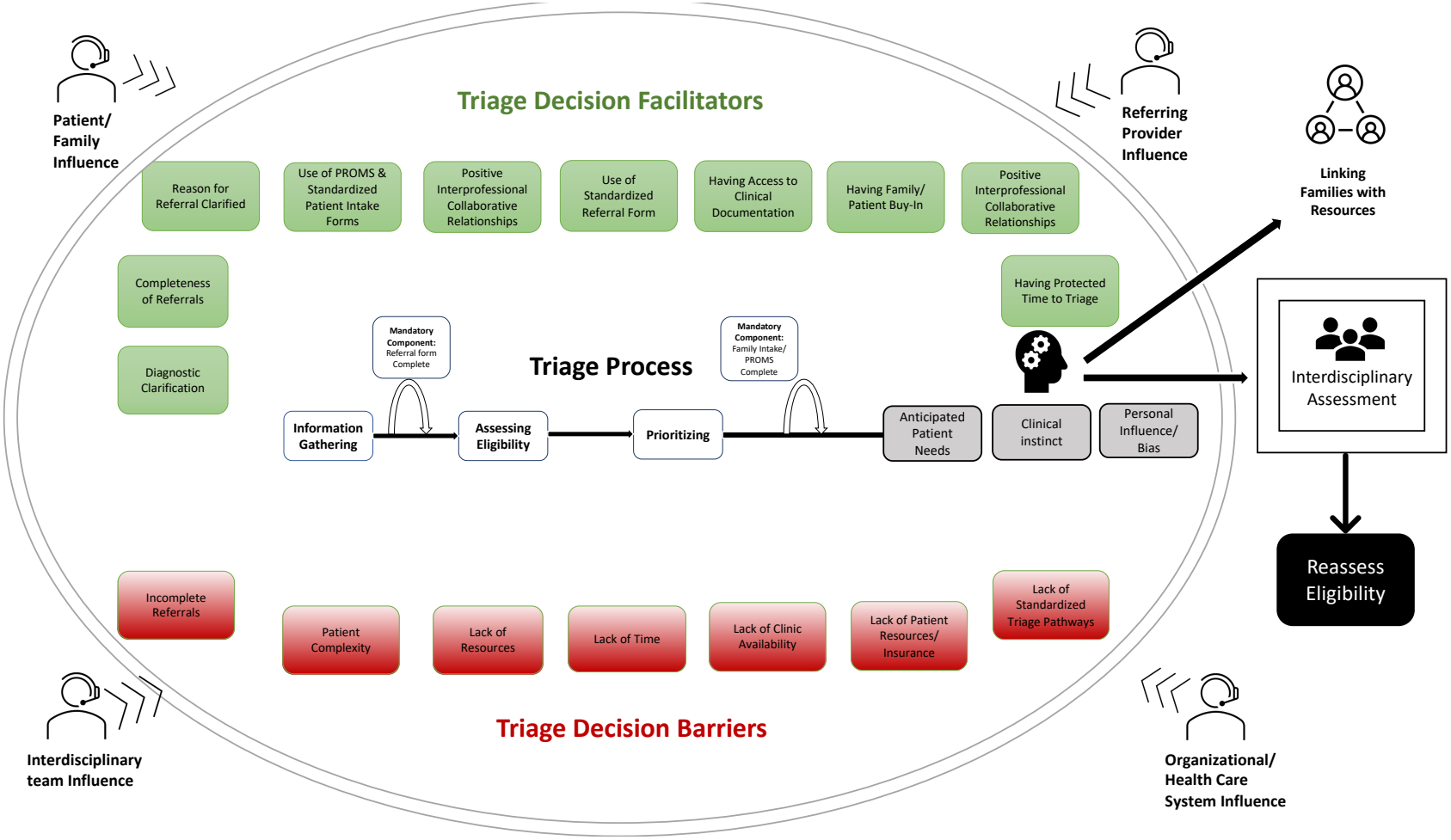
		Use of Patient Reported Outcome Measures (PROMS) and intake forms	3	4	*I think having some automation where that best fit is based on that diagnosis or those disability measures or whatever measures we're looking at* (ID8).
		Having positive interprofessional collaborative relationships	2	3	*So forming relationships, I think it really, really makes your job easier* (ID5).
		Use of a standardized referral form	2	3	*It [referral form] was something that we felt really was going to help us with this high number of referrals that continue to come through. And it also helped to guide us as we started evolving through the pandemic front, only virtual to them* (ID1).
		Having access to clinical documentation	2	2	*I would use Clinical Connect, I tried to use Clinical Connect and you know, just get more information so that I could triage appropriately* (ID2).
		Having family buy-in	2	2	*…having family buy in, even and, you know, sometimes we may get that referral, and the family ends up telling us you know, what, we're really not interested in this or we're not ready to go down that route* (ID8).
		Having clear eligibility criteria	1	1	*[Current eligibility is] really inadequate? Yeah, when I came on in 2018, this, this would have been developed. Probably around the same time. Yep. too big, not specific enough. And*

					again, that's why what I've just read out to you, we really needed to do and it also didn't give any indication of prioritizing, right? And as, as clinicians we know that this does not help us figure out who should be seeing in what order but it definitely helped. The acceptance criteria definitely helped us to decide if a patient was appropriate or not for our clinic, yeah, or should actually be moved, forwarded to the general pediatric clinic for further diagnostic assessment. Should it be rerouted to psychiatry to address the unmet mental health needs? So it has been helpful for that catch criteria to come to the clinic but it doesn't help us with that next level, but through triage (ID1).
		Having protected time for triage	1	1	*…having protected time designated to sit down and just focus on triage and having that as that time commitment for that task* (ID8).
	Barriers to triage	Incomplete referrals	10	22	*It's just a lack of accurate information. Because you get what people want to tell you… and then you do the appointment and think, 'oh, I really messed up on that one'… and we [interdisciplinary team] all look at each other like no, this wasn't how it was presented on paper…there's no way that I could really figure that out beforehand* (ID5).
		Patient complexity	7	9	*…probably 60% of our patients have comorbidities with psychological diagnoses, probably even higher than 60%. And so if they don't have really well-established care, that's really a challenge for us because you really can't treat someone we have our own pain psychologists but they can't take on significant mental health diagnoses and we don't have a psychiatrist on our staff, so who's managing their medications and we will not most of the time take on those medications. So I think that makes it super complicated* (ID7).

		Lack of resources	6	8	*I only have percentages of people [interdisciplinary team members]. I have to cram them into a couple days a week right now. Now, if I had a program where Monday through Friday we were seeing five days' worth of new patients, it would be so much easier* (ID 11).
		Lack of time	3	3	*I also would throw out maybe as an external contributor to that triage process is also time. Having other clinic responsibilities and setting aside time to do triage because that is just another task. That is part of the job. And so obviously, clinical duties take priority* (ID8).
		Lack of clinic availability	2	3	*Because I only have percentages of people. Yeah, you know, I have to cram them into a couple days a week right. Now, if I had a program where Monday through Friday, you know, we were seeing five days' worth of new patients, it would be it would be so much easier. You know because I could leave urgent spots open for those somewhat urgent kids. So I think resources are huge* (ID11).
		Lack of patient resources/ insurance	2	3	*…having went through a period where we were just one doctor, and there were we had patients who are waiting, you know, six to eight months six, we call past six months. And that was really upsetting to us. You know, we were just really trying to fix that, but we were so stuck with a lack of resources* (ID3).
		Lack of standardized triage pathways	1	3	*I was actually kind of frustrated that there, there really isn't some good guidelines to follow. And I think part of it comes from my own background as working in cardiology and we had very strict criteria for everything like it was all evidence. I wouldn't say it's all evidence base. We had a lot of evidence-based guidelines for our practice. Yeah. And so this this was really challenging to come into this role. And there's just so much variability with every referral that comes through* (ID1).
External Influences on Triage	Patient or family influences	N/A	12	43	*I find it really difficult when parents get really angry, but the child is actually functioning, so I don't want to prioritize them. I don't think it's fair to give appointments to those families, as*

Decision-Making					*like whoever shouts the loudest gets more, whereas those families that don't shout but are accepting of the system, they just sit there and wait on this list where they are actually in a worse situation… and then one parent recently wrote an email to the executive complaining about the waitlist. And then we're asked to prioritize them from the executive* (ID12).
	Referring provider influences	N/A	9	40	*Someone referred for CRPS [Complex Regional Pain Syndrome]. And it really didn't meet the criteria. And so I sent her a letter and she was quite upset about it and didn't contact me directly but contacted one of our Doc's. And we brought in the patient* (ID2).
	Interdisciplinary team influences	N/A	8	29	*…he [physician] would bring to us every week, consults that he felt were complex and he wanted to discuss and so there that influence, the team influence was really quite, quite significant. Now, I would say even if it's on our minds a little bit, I think because the team is bigger and the sort of opinions and impressions are probably a little more diverse in regards to any particular patient, you know, there's not that same influence* (ID3).
	Organizational influences	N/A	5	16	*At this institution… we've been told that you're supposed to be getting an appointment within two weeks. Well, it's just it's just not feasible for our clinic…we kind of utilize that factor with administration and say, well, if that's the case, then you need to give us more support because we can't there's it's just impossible. We can't do that in our clinic. So we have tried to adjust that accordingly. But that would be one influence, which I wouldn't say it's very strong in our opinions (ID7).*

Figure 4.1 Triage Decision Making – The Process and Influencers



Chapter 5 Integrated Discussion

My doctoral research concentrated on the investigation of triage decisions in the setting of interdisciplinary pediatric chronic pain programs, with the goal of developing a series of Clinical Decision Support (CDS) triage tools for this population. In this chapter, I highlight and integrate the findings of my three studies and discuss how they relate and contribute to the theoretical frameworks and models that guided the studies, as well as the clinical and academic field of pediatric chronic pain and the nursing profession. This chapter concludes with a description of how the CDS triage tool series was developed based on my study findings.

5.1 Summary of Dissertation Findings

5.1.1 Study 1 – Delphi Study

Detailed in Chapter 2, a modified Delphi study was conducted to attain expert consensus on the significant clinical indicators/ clinical red flags relevant to six common primary chronic pain diagnoses in pediatrics, as well as the diagnostic investigations required prior to referral to interdisciplinary chronic pain programs. Consensus was reached on 84% of diagnostic items, identifying 72 clinical red flags that were deemed important to assess for, as well as 85 diagnostic investigations that were considered not important to complete in the absence of clinical red flags. Study findings also highlighted the diagnostic role limitations of chronic pain providers and an idea of how participants approached patients referred to them without adequate diagnostics. A key finding of this study was the lack of evidence-based guidance to inform the diagnostic process in the pediatric chronic pain population. Ultimately, this study provided foundational support in understanding the general diagnostic expectations from the lens of pediatric chronic pain experts for patients referred to interdisciplinary pediatric chronic pain

programs. Findings from this study will help inform triage decisions of pediatric chronic pain nurses, based on diagnostic completeness.

5.1.2 Study 2 – Systematic Review

Described in Chapter 3, a systematic review was conducted to identify multidimensional biopsychosocial tools used in pediatric chronic pain, synthesize their reliability and validity evidence, and draw on the evidence to describe the relationships between chronic pain and biopsychosocial domains. Tool eligibility, based on their biopsychosocial description, was guided by the *Multidimensional Biobehavioral Model of Pediatric Pain*. Study eligibility was focused on primary chronic pain diagnoses unrelated to underlying disease. Results yielded six tools that included 64 eligible studies, highlighting 84 significant relationships between pain and functional interference across 11 biopsychosocial variables. Findings demonstrated good internal consistency and validity of all tools, highlighting that the Pain Interference Index (PII) offers the shortest multidimensional assessment that inclusively captures pain interference from a biopsychosocial perspective. Although this study did not generate substantial clinical utility data of the tools, inclusion of the PII in a triage assessment was promising since it appears brief and easy to use, while capturing a rapid screening of the biopsychosocial impact of chronic pain. Findings from this study will help shape how patients referred to interdisciplinary pediatric chronic pain programs could be prioritized based on biopsychosocial complexity and needs.

5.1.3 Study 3 – Exploratory Descriptive Qualitative Study

Presented in Chapter 4, an exploratory descriptive qualitative study was conducted to explore and describe the decision-making practices and contextual influences of nurses triaging patients to interdisciplinary pediatric chronic pain programs. The *Cognitive Continuum Theory (CCT)* and the *Theoretical Domains Framework (TDF)* informed the analysis to capture the

oscillation of triage decision-making as well as the determinant factors. Findings from this study provided rich descriptions of triage decision-making across 12 pediatric chronic pain nurses within 11 different interdisciplinary teams. This study highlighted three major themes, including 1) Nurse-led triage determinants, 2) Process of triage decision-making and 3) External influences of triage decision-making. I concluded from this study that nurses want to adopt a structured triage practice grounded in evidence to better guide the triage process and decision-making for complex pediatric patients being referred to interdisciplinary chronic pain programs. In doing so, five general recommendations evolved from the data that could be considered to enhance triage decision-making support in this setting, including: 1) Solidify expectations 2) Enhance diagnostic clarity 3) Incorporate Patient Reported Outcome Measures 4) Accept that triage is an evolving decision and prepare for change and 5) Optimize communication and collaboration.

5.2 Dissertation Findings in the Context of Theoretical Models and Frameworks

The foundation of this thesis was inspired by the *Knowledge to Action Framework (KTA)* and was guided by the *Multidimensional Biobehavioral Model of Pediatric Pain* (MBMPP), The *Cognitive Continuum Theory (CCT)* and the *Theoretical Domains Framework (TDF)* described in Chapter 1.

5.2.1 Knowledge to Action Framework (KTA)

The KTA framework (Graham & Tetroe, 2007) addressed the selection of knowledge (i.e., what is needed to make sound triage decisions) guided by the perspectives of pediatric chronic pain nurses interviewed in the qualitative study (Chapter 4). My research has outlined the importance of diagnostic clarity (Chapter 2 & Chapter 4) and biopsychosocial complexity (Chapter 3 & Chapter 4) in triage decision-making, and suggests such knowledge is required when making these decisions (Chapter 4). There is a desire amongst pediatric chronic pain

physicians and nurses to implement this knowledge into their interdisciplinary teams (Chapter 2 & Chapter 4). This knowledge can then be customized based on the barriers, facilitators, and contextual factors of triage decisions in a way that it will be clinically useful for interdisciplinary pediatric chronic pain programs. To optimize the clinical utility of this knowledge in the form of a CDS triage tool series, I plan to conduct a collaborative integrated KT approach with end-users (i.e., pediatric chronic pain patients and their families, pediatric chronic pain nurses and common referring providers) in the next phase of this research through a User-Centered Design (UCD) study. I will now highlight how the findings from my studies complement my theoretical and conceptual guidance.

5.2.2 Multidimensional Biobehavioral Model of Pediatric Chronic Pain

Findings from all three studies offer theoretical support for the *Multidimensional Biobehavioral Model of Pediatric Pain* (Varni, 1995) and its consideration of several adaptable precipitant and intervening factors that contribute to pain perception and functional interference in the pediatric chronic pain population (Varni et al., 1995). The systematic review offered evidence of 84 significant relationships between pain and functional interference across 11 biopsychosocial domains (Chapter 3). *Intervening variables*, including social functioning (perceived social support), family functioning (family environment), pain catastrophizing/ adaptability (cognitive appraisal and coping strategies) and developmental factors (biological predisposition) were found to be significantly associated with the chronic pain experience (Chapter 3). Similarly, significant relationships between chronic pain and *functional status variables*, including depression/ mood (depressive symptoms), physical functioning, pain related anxiety, general anxiety, and affective distress (anxious symptoms), concentration and activities/ school functioning were further proven to contribute to functional interference (Chapter 3). The

Delphi study supported the conceptualization of *precipitant variables* that encompass the biological components of the model, outlining a list of significant clinical indicators/ clinical red flags and the diagnostic investigations to consider that inform the pain related diagnosis (Chapter 2). The qualitative study provided rich insight into the biopsychosocial impact of the pediatric chronic pain experience from the perspectives of nurses who consider biopsychosocial complexity in guiding their triage decisions to interdisciplinary chronic pain programs (Chapter 4).

5.2.3 Cognitive Continuum Theory

Described in Chapter 1, the *Cognitive Continuum Theory (CCT)* (Standing, 2008) was selected to guide the analysis of triage decisions in the qualitative study. Results from my research provided supportive evidence of the oscillation of triage decisions, as pediatric chronic pain nurses waver between intuitive and analytical modes of reasoning (Chapter 4). *Experimental research* of triage decisions and *System-aided judgement*, or use of evidenced based clinical guidelines to inform triage decision-making, are greatly lacking in the setting on interdisciplinary pediatric chronic pain programs (Chapter 2 & Chapter 4). This further justifies my dissertation goal to develop an evidenced based clinical decision support triage tool grounded in evidence. My research suggests chronic pain nurses depend most on *patient and peer-aided judgement*, involving the review of patient specific data and the collaboration of patients/ families, interdisciplinary team members, and referring providers to influence their triage decision (Chapter 4). There is also evidence of *reflective judgement*, as many nurses indicated that they draw on previous experiences in making triage decisions and incorporate the anticipation of patient needs which impacts decisions on patient eligibility and prioritization (Chapter 4). *Intuitive judgement* was frequently referenced as a "gut feeling" and considered

valuable in informing triage decisions (Chapter 4). Conclusions drawn from my qualitative study may provide the groundwork of the *qualitative research* mode of reasoning to better understand triage processes and decision-making (Chapter 4). Findings from my Delphi study (Chapter 2) demonstrated consensus regarding the diagnostic expectations of referred patients, offering reasoning based on *survey research* that identifies attitudes, trends, and beliefs of pediatric chronic pain experts that can inform triage decisions based on diagnostic clarify. My systematic review findings will help to enhance the *critical review of experiential and research evidence* mode of reasoning, as it provides a rigorous synthesis of pain-related functional interference and offers valid and reliable ways to assess patients based on biopsychosocial complexity. Plans to conduct a UCD study to finalize and evaluate the CDS triage tool series may offer reasoning based on *action research and clinical audit*, through the identification of strengths and weakness of the tool to further enhance it.

5.2.4 Theoretical Domains Framework

The *Theoretical Domains Framework* (TDF) described in Chapter 1 also guided analysis of the qualitative study (Chapter 4) to feature the contextual influences and determinants of triaging (Atkins et al., 2017). Nurses considered *beliefs about consequences*, or outcome expectations, when describing their triage role, the complexity of triage, anticipation of patient needs, diagnostic clarification and the impact of personal influence and bias. *Beliefs about capabilities* and *social and professional role identity* were also captured through nuances of perceived competence in their involvement in triage development, how they manage triage complexity and interdisciplinary team influences. *Environmental context and resources* were discussed pertaining to triage logistics, when deciding on patient eligibility to the program and the influence of the organization on triage decisions. *Knowledge* of patient conditions,

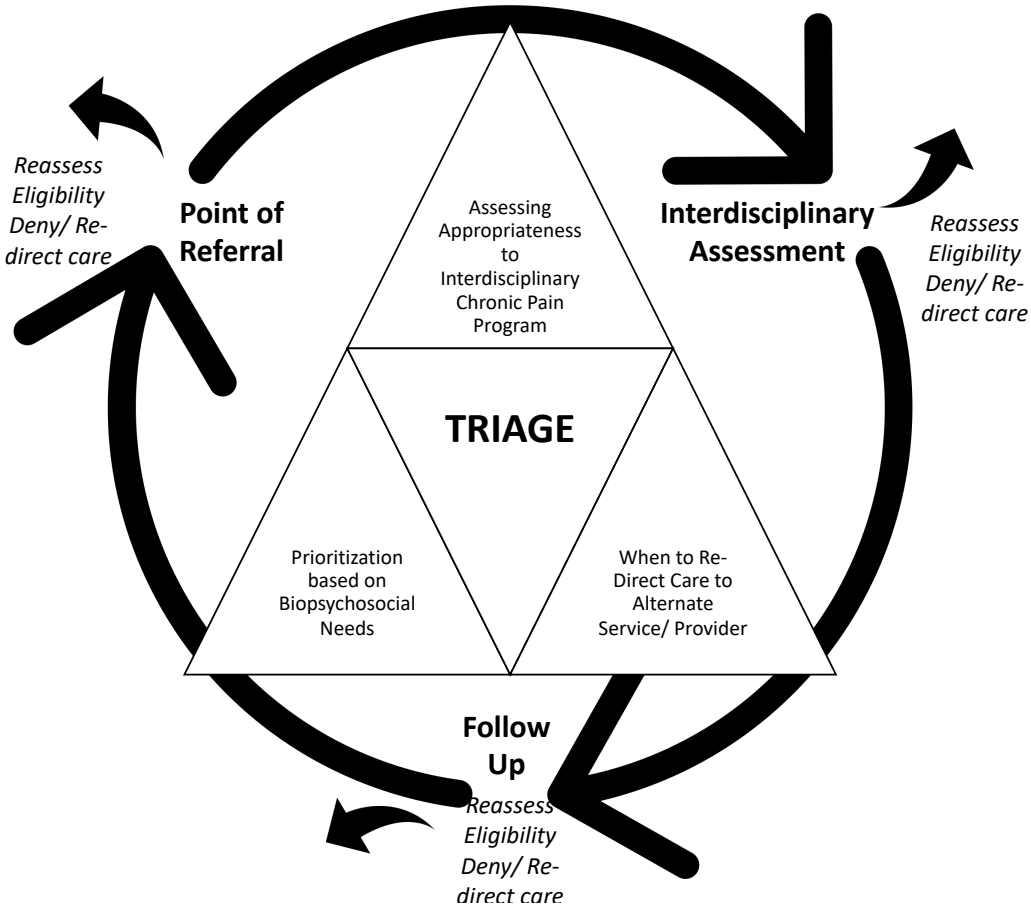
presentations and diagnostics were highlighted while discussing the triage process and the consideration of various patient characteristics (i.e., past medical and psychosocial history, diagnostics completed, treatments tried, etc.) that inform the triage decision. Nurses also consider patient and family functional goals when deciding on eligibility, which represents overall *motivation and goals* of patient and family participation in chronic pain programs. This was highlighted in discussions about patient and family readiness and buy in to a self-management, rehabilitative approach to chronic pain care, and how this may influence their appropriateness to the program. *Motivation and goals* were also captured through nurses' discussions of facilitators and barriers to triage decisions as intrinsic motivation. Dialogs on patient prioritization and decisions on patient eligibility focused on nursing *skills* and *memory, attention and decision processes* centered around nurses' ability to selectively focus on aspects of patient characteristics (i.e., biopsychosocial complexity, pain etiology, etc.) and choose between levels of urgency. This TDF domain was also captured through the influence of nurses' *intuition*, or "gut feeling" on triage decisions. *Social Influences* on triage decisions were identified through conversations of how referring providers, the organization and families sway triage decisions despite other patient factors considered. Lastly, *optimism*, or confidence that desired goals will be attained, was highlighted through talk about adopting an evidence based CDS triage tool in interdisciplinary pediatric chronic pain programs.

5.3 Integration of Dissertation Findings and Supportive Complementary Literature

In this section, I will discuss the integration of my dissertation findings and how this supports the overarching goal of developing a series of CDS triage tools for nurses triaging patients to interdisciplinary pediatric chronic pain programs. The figure below offers a visual conceptualization of the important elements of triage decision-making within this setting and has

been developed based on the union of my study findings and complementary literature described below. The triangle displays the prominent components of the triage decision, which includes 1) assessing patients based on appropriateness to the program, 2) deciding when to re-direct care to an alternate service or provider and 3) prioritize access to care based on biopsychosocial needs. The circle represents the evolution of the triage decision across various time points in the patient's chronic pain trajectory, and the smaller arrows demonstrate when the triage decision should be re-evaluated by the nurse and/ or the interdisciplinary chronic pain team.

Figure 5.1 The Conceptualization of Triage as an Evolving Decision in Interdisciplinary Pediatric Chronic Pain Programs



The next sections are organized according to the three components of the triage triangle: 1) assessing patient appropriateness based on diagnostic clarification, 2) deciding when to re-direct care to an alternate service or provider and 3) prioritize access to care based on biopsychosocial needs. There will then be a section explaining triage as an evolving decision along the pediatric chronic pain trajectory.

5.3.1 Assess Patient Appropriateness Based on Diagnostic Clarification

Assessing patient appropriateness and deciding on acceptance into interdisciplinary pediatric chronic pain programs based on diagnostic clarity is important to ensure secondary sources of pain have been ruled out (Chapter 2 & Chapter 4). This aligns with Page and colleagues' (2017) study considering pain etiology as one of the most important factors of the triage decision within adult multidisciplinary chronic pain programs. Since chronic pain providers typically do not assume a diagnostic role (Chapter 2), understanding pain etiology, or the underlying source of pain, relies heavily on the diagnostic data shared by referring providers (Chapter 4) which is often lacking (Chapter 2 and Chapter 4). My research indicates that chronic pain providers generally do not require extensive diagnostic investigations to be done prior to referral in the absence of clinical red flags (Chapter 2), yet many referring pediatricians find the decision to stop diagnostic testing for pediatric chronic pain patients ambiguous and complicated (Neville et al., 2020). There is evidence that practitioners order several diagnostic tests in fear of missing a secondary pain diagnosis (Squires et al., 2022), which if missed could cause harm. Supported by my Delphi study (Chapter 2) and qualitative study (Chapter 4) findings, this may be related to the diverse and complex spectrum of symptomatology reported by parents of children and adolescents with chronic pain (Heathcote et al., 2018), which may cloud the diagnostic process and possibly lead to referral delays.

My research also suggests that it is common for nurses to receive referrals that do not comprise ample diagnostic information needed to inform the triage decision (Chapter 2 and Chapter 4). Amongst several possible factors, minimal diagnostic guidance for pediatric chronic pain diagnoses possibly contributes to insufficient referrals. Explained by an Anesthesiologist who participated in my Delphi study,

> "Unfortunately, there are no pediatric specific diagnostic approaches for chronic pain syndromes. This is a need that would provide us with a standard for which to diagnose and allow other specialists to refer to pain physicians sooner if there were better discriminating tool" (Chapter 2).

Consequently, diagnosing primary chronic pain disorders take a substantial amount of time and knowledge considering the need to rule out possible secondary diagnoses (Carnago et al., 2021). It is plausible then that the triage decision based on diagnostic clarity also takes a great deal of time and knowledge. This assumption was supported by a pediatric chronic pain nurse, who stated,

> "I could spend a whole day triaging referrals based on complexity… there are patients who have pain everywhere, head to toe. They have lots of different conditions. They have a fatigue, they had a viral illness, they've had multimillion dollar workups, they've seen every specialist under the sun" (Chapter 4).

Further complicating the medical diagnostic process in pediatric chronic pain, involves the significant overlap with mental health disorders (Vinall et al., 2016), while many pediatricians assume the origin of chronic pain is often psychosomatic, or pain caused by psychological factors (Locher et al., 2023). Evidence generated by my systematic review highlights the significant associations between chronic pain and affective distress, mood, and

anxiety (Chapter 3); however the question remains, does pain cause anxiety and depression, or does anxiety and depression cause pain? High rates of chronic pain reports have been found in youth with persisting psychiatric disorders (Gardvik et al., 2020). It is therefore reasonable to assume that some patients referred to interdisciplinary pediatric chronic pain programs are suffering primarily from a psychiatric disorder that may have been missed and would be better treated by a primary mental health team. Although participants from my qualitative study assert that patients are not eligible for acceptance to their programs if pain is not their primary issue (Chapter 4), this is arbitrary at the point of triage in the milieu of frequent insufficient referrals highlighted in both my Delphi study (Chapter 2) and qualitative study (Chapter 4). This point leads to my next topic of discussion – when to re-direct care for referred patients who are not deemed appropriate to accept into interdisciplinary pediatric chronic pain programs.

5.3.2 Deciding When to Re-Direct Care

Deciding when to re-direct patient referrals based on diagnostic clarity and/ or when pain is not the primary issue is complicated. Despite best intentions of referring providers, the diagnostic process is at risk for error, particularly with complex youth who report chronic pain. Depending on the clinical setting, diagnostic errors including missed, delayed, or inaccurate diagnoses have been reported in up to 15% of patient encounters (Kliegman, et al., 2023). It has been estimated that adults with chronic pain are misdiagnosed 40 to 80% of the time which is related to inadequate history taking and ordering the wrong diagnostic tests (Hendler, 2016). However the nature, prevalence, and impact of diagnostic error in the pediatric chronic pain population has been largely overlooked (Carnago et al., 2020). Some participants in the Delphi study specified that they would re-direct referred pediatric patients with clinical red flags to an alternate, more appropriate specialty service such as the Emergency Department or Neurology

(Chapter 2). Furthermore, nurses from my qualitative study indicated that an important aspect of their triage decision involves the collection of diagnostic information and request for consultations by other speciality services when clinical red flags are identified or suspected (Chapter 4). For both actions to be possible, a comprehensive history and recording of clinical data on a referral form is necessary, however this is not frequently done (Chapter 2 and Chapter 4). This conceivably increases the risk that any potential diagnostic error made at point of referral will translate to a decision error at point of triage when deciding on patient appropriateness based on diagnostic clarity (Chapter 4). This helps to explain why a prominent finding of the Delphi study and qualitative study highlighted the importance of secondary sources of pain being ruled out prior to referral (Chapter 2 and Chapter 4). One nurse provided an example of this, stating,

> "I had a kid with chronic leg pain for a long time. They called me and they were describing to me a pain that I thought was different. And it was in her calf. And it was just different. And I said, I just don't like how this sounds. You know what I mean? And she had a DVT [Deep Vein Thrombosis]. So I think you have to have that mindset that not everything is related to anxiety. Everything's related to your pain diagnosis. Someone has to make sure of that" (Chapter 4).

In this case and supported by Kliegman and colleagues (2023), premature diagnostic closure occurred whereby the referring physician likely accepted the first plausible diagnosis (i.e., primary chronic pain) prior to obtaining confirmatory evidence for an acute underlying source of pain (i.e., DVT). This could have led to a catastrophic outcome if missed by the triage nurse. Supported by my findings (Chapter 2 and Chapter 4), transparency of the diagnostic process of referred patients is vital in deciding when care should be re-directed to ensure patient safety.

Aside from missed medical diagnoses, pediatric chronic pain nurses often re-direct patients with substantial medical complexities and developmental disabilities to more appropriate speciality services when they anticipate their chronic pain programs will fail in meeting their needs (Chapter 4).

Premature diagnostic closure is also possible in cases when psychiatric symptoms are predominant. The comorbidity of chronic pain with mental health conditions, including Post Traumatic Stress Disorder (PTSD), anxiety and depression is high and has been explained by shared neurobiology that maintain both conditions (Asmudson et al., 2002; Asmundson & Katz, 2009; Sharp & Harvey, 2001). My systematic review supports this by underlining the significant relationships between pain and mood, anxiety, affective distress, and pain catastrophizing (Chapter 3). Findings from my qualitative study stress the influence of co-existing mental health symptoms on the complexity of the triage decision (Chapter 4). It has been suggested that a chronic pain team, although interdisciplinary in nature, may not adequately meet the pain needs of youth with predominant mental health concerns without sufficiently addressing their psychiatric symptoms (Vinall et al., 2016). Since mental health comorbidities can interfere with chronic pain recovery in youth (Cunningham et al., 2016), it is appropriate to redirect patients who are referred to pediatric chronic pain programs with recent, active psychiatric symptoms to a primary mental health service.

Nonetheless, chronic pain in pediatrics is a complex and multidimensional experience and often requires interdisciplinary support through specialized pain teams. After concluding acceptance of patients into interdisciplinary pediatric chronic pain programs, the next multifaceted decision involves prioritization of patients who are in greatest need of pain care (Chapter 4).

5.3.3 Prioritize Patients Based on Biopsychosocial Complexity

The chronic pain experience in pediatrics is complex from a biopsychosocial perspective, involving a dynamic association with biological, psychological, environmental, and social factors (Liossi & Howard, 2016). My systematic review supports this by highlighting 84 significant relationships between chronic pain and functional interference across 11 biopsychosocial variables (Chapter 3). Since access to interdisciplinary pediatric chronic pain care is limited (Palermo et al., 2019), attention should be paid to the prioritization of pediatric patients requiring interdisciplinary chronic pain management. As youth with chronic pain wait for treatment, the risk of functional deterioration increases (Palermo et al., 2019). Thus, optimizing the effectiveness of triage would allow for identification of patients who are at highest risk for pain related disability in greatest need for interdisciplinary care. In the context of health care, triage involves the prioritization of patients that is usually based on a set of criteria that allocates a level of urgency for assessment and treatment (Iserson & Moskop, 2007). Data generated in my qualitative study points to the complexity involved in prioritizing patients (Chapter 4). One nurse explains,

> "When a patient's referred to the chronic pain clinic, you never know what you're gonna get… what appears on paper and all this sort of thing you do and everything you read, you still can't predict how that's all going to go… it's a very different patient population" (Chapter 4).

Patient prioritization is mainly based on level of functional interference from a biopsychosocial perspective, yet there were no objective measures identified to inform prioritization based on the biopsychosocial impact of pain at point of triage (Chapter 4). Although pediatric chronic pain nurses and physicians require referred patients to complete

Patient Reported Outcome Measures (PROMs) (Chapter 2 and Chapter 4), these measures are not evaluated until after the triage decision is made (Chapter 4). Suggested in my systematic review, limited use of PROMs at point of triage may be related to the shortage of brief, holistic, multidimensional tools that specifically measure the biopsychosocial impact of chronic pain in pediatrics (Chapter 3). Of the valid and reliable multidimensional tools available, the ones that have been heavily studied are limited in their usability (Chapter 3), making them challenging to adopt at point of referral and triage. The Pain Interference Index (PII) (Martin et al., 2015) was highlighted in my systematic review because it offers the shortest multidimensional assessment that inclusively captures pain interference in general activities, physical activities, friendships, school, and sleep in six short questions involving a simple scoring system (Chapter 3). Although psychometric evaluation of the PII in pediatric chronic pain is limited, its usability advantages cannot be ignored. Since nurses are faced with various external influences from patients and families, referring providers, interdisciplinary members, and organizational factors (Chapter 4), maintaining equity between patients by means of prioritization can be challenging. My research calls for a more psychometrically robust and objective measure of patient prioritization based on biopsychosocial complexity and needs.

5.4 Triage is an Ever-Evolving Decision Along the Pediatric Chronic Pain Trajectory

Triage decisions in the setting of interdisciplinary pediatric chronic pain programs are considered complex and difficult to "get right" (Chapter 4). This difficulty can be attributed to the degree of diagnostic uncertainty and the biopsychosocial complexity of the pediatric chronic pain population and exacerbated by the relative inadequacy of patient data provided on referrals (Chapter 2 and Chapter 4). Compounded by the significant lack of evidence-based triage guidance (Chapter 2 and Chapter 4) and limited availability of efficient, holistic,

multidimensional biopsychosocial measures (Chapter 3), guaranteeing triage accuracy at point of referral is not realistic in the current climate. My qualitative study poses that triage decision-making in this context is an evolving process and decisions can change based on the several contextual and patient factors (Chapter 4). One nurse explains,

> "A number of things can also happen in their life that I'm not even privy to because I accept the referral and I move onto other things. So when that patient shows up who would have been referred in January, they might have had surgery. They might have seen other specialists or emergency (services) because all of those things that transpire. I'm not getting that information as a triage nurse role, that's just added by that patient when they present in clinic… I don't keep track of all the patients once they've been triaged" (Chapter 4).

My research advocates that the triage decision is one that evolves and should be re-evaluated along various time points of patients' stay within interdisciplinary pediatric chronic pain programs. Patient symptoms and trajectories inevitably change throughout their pain and health journey and additional details often arise during more in-depth, interdisciplinary assessments with patients (Chapter 4). Thus, Pediatric pain programs should continuously assess patient eligibility, from acceptance to discharge, and re-direct their care to more appropriate providers should pain no longer be their primary problem.

5.5 Interdisciplinary Implications

I will now present the implications of my findings to interdisciplinary practice with a focus on nursing, leadership, policy, and research.

5.5.1 Practice

Pediatric chronic pain nurses and physicians yearn for a standardized triage assessment that is supported by evidence to facilitate and enrich their triage decisions (Chapter 2 and Chapter 4). My qualitative study demonstrated that nurses often make triage decisions independently in the setting of interdisciplinary pediatric chronic pain programs, and that it is a large part of their clinical role (Chapter 4). I have founded three principal clinical elements of the triage decision in this setting, including the establishment of diagnostic clarity to confirm patient appropriateness to the pain program, prioritizing patients based on biopsychosocial complexity and needs, and deciding when to re-direct care when pain is not the primary issue. My Delphi study offers support in streamlining the diagnostic processes for primary chronic pain diagnoses that cannot be better explained by secondary pathology (Chapter 2). This may enhance both referring providers and chronic pain providers clarity on the recognition of clinical red flags and the diagnostics required in the absence of clinical red flags at point of triage, which will support the nurse's decision to accept the patient into their pain program or re-direct them to an alternative specialty service based on diagnostic interpretation (Chapter 2). My systematic review features ways in which biopsychosocial variables may be interpreted and weighed in predicting patient complexity in the pediatric chronic pain population and has showcased an easy to use, holistic, multidimensional biopsychosocial tool that specifically measures the impact of chronic pain (Chapter 3). Acknowledgement of the significant associations synthesized between chronic pain and biopsychosocial variables (Chapter 3), may facilitate the nurse's decision to best prioritize patients in this setting. Furthermore, consideration of utilizing a psychometrically valid and reliable measure to objectively assess biopsychosocial needs at point of triage may minimize the force of external influences, personal misinterpretations and biases that may lead to patient inequities in accessing pain care.

5.5.2 Education

Triage accuracy has been linked to patient safety outcomes, and therefore nurses must be knowledgeable and skilled in making these decisions (Johannessen, 2017). In the setting of interdisciplinary chronic pain programs, nursing knowledge of diagnoses and biopsychosocial complexities, as well as skillset in prioritization are imperative to the triage decision (Chapter 2 and Chapter 4). Nurses who work in interdisciplinary pediatric chronic pain programs and assume the role of triage, come with varying educational backgrounds (Chapter 2 and Chapter 4), including those who have been trained to diagnose (i.e., Nurse Practitioners) and those who have advanced skills but have not been formally trained in the diagnostic process (i.e., Clinical Nurse Specialists, Advanced Practice Nurses, Registered Nurses) (College of Nurses of Ontario, 2021). Regardless, confirming diagnoses in this patient population can be challenging and requires extensive knowledge and experience (Carnago et al., 2021). Even pediatricians with extensive diagnostic training find the diagnostic process with pediatric primary chronic pain diagnoses vague and complicated (Neville et al., 2020).

The diagnostic clarification offered in the Delphi study (Chapter 2) may set the stage to increase nursing and interdisciplinary knowledge regarding the foundations of the diagnostic process and expectations for children and adolescents with common primary chronic pain disorders. Similarly, the systematic review enhances knowledge of the significant relationships between chronic pain and biopsychosocial aspects of life (Chapter 3). This knowledge, in combination with valued nursing experience and intuition (Chapter 4), may then transpire into an optimized skillset to adequately triage pediatric patients into interdisciplinary chronic pain programs.

5.5.3 Leadership and Policy

My research applauds nurses in their leadership around triage in the setting of interdisciplinary pediatric chronic pain programs (Chapter 4) and supports the notion that triage is an autonomous nursing role (Johannessen, 2017). Many nurses in my qualitative study discussed ways they have adapted the triage process in their respective settings when the original process fell short (Chapter 4). This may otherwise be known as a nurse workaround, which has been described in the literature as nurses devising alternative procedures to address a block in workflow (Rathert et al., 2012). Although there is risk for error with nurse workarounds, with the right foundation, they can also contribute to the evolution and refinement of a system (Rathert et al., 2012). Thus, my research has provided the foundation to understand nurses' triage workarounds (Chapter 4). My work also offers an avenue to affirm a standardized triage process that considers relevant determinants (Chapter 4), addresses knowledge gaps in diagnostic clarity (Chapter 2) and provides footing to better operationalize prioritization based on biopsychosocial needs (Chapter 3). In essence, the nurses who participated in my studies have contributed to the preliminary development of an evidence-based series of CDS triage tools that have potential to be integrated into the policies and procedures of various interdisciplinary pediatric chronic pain programs. In the next section, I will discuss the research implications of my dissertation and plans to move this work forward.

5.5.4 Research

My research is the first of its kind to generate data on the intricate and complex process, determinants, and decision-making of triage in the setting of interdisciplinary pediatric chronic pain programs. My studies have contributed to the diagnostic literature in the pediatric chronic pain population (Chapter 2) and have added to the psychometric knowledge specific to biopsychosocial multidimensional tools used in the pediatric chronic pain population.

Furthermore, my qualitative study contributed to the descriptive qualitative literature on nursing triage. Although my dissertation generated rich data from pediatric chronic pain nurses and physicians, it did not include perspectives of pediatric mental health providers, referring providers or patients and their families. Understanding the influence that mental health symptoms have on the diagnostic process for this patient population and the determinants of the referral process, will be valuable in developing an evidence-based tool to guide nurses' triage decisions in this setting.

5.6 Tool Development

My dissertation findings have been amalgamated to develop the prototype of a CDS triage tool series, which involves a standardized referral form and triage decision algorithm for five of the six primary chronic pain diagnoses investigated in the Delphi Study. The series includes CDS triage tools for: 1) CRPS type 1 (Figure 5.2), 2) chronic headaches (Figure 5.3), 3) chronic musculoskeletal and/ or joint pain (Figure 5.4), 4) chronic back pain (Figure 5.5) and 5) chronic abdominal pain (Figure 5.6). Chronic pelvic pain was omitted from the series due to the low consensus reached in the Delphi study (Chapter 2). The triage decision algorithm can be found in Figure 5.7. This CDS triage tool series includes diagnostic information learned from the Delphi study (Chapter 2), a platform to conduct an efficient and holistic biopsychosocial assessment gained through the systematic review (Chapter 3), and process features that consider facilitators and barriers to the triage decision, which were identified in the qualitative study (Chapter 4). Each referral form includes an eligibility checklist accompanied by a disclaimer that patient eligibility will be re-evaluated at various time points during the patient's stay in the program. They also list the mandatory components required prior to making a triage decision (i.e., referral form must be complete, etc.) and a condition that it is the referring provider's

responsibility to send updated clinical information as it arises. Eligibility and mandatory components were acquired through the qualitative study (Chapter 4) and supported by the Delphi study (Chapter 2) that delineated the diagnostic role and responsibilities of the referring provider. Each referral form includes a list of clinical red flags for each respective pain diagnosis paired with a cue to the referring provider to attach all relevant diagnostics and consultations if any red flags are present. If no diagnostics or consultations have been done for patients with clinical red flags, there is an alert to the referring provider to first rule out secondary pain sources prior to the referral. These diagnostic components were gained through the Delphi Study (Chapter 2) and supported by the qualitative study (Chapter 4) that emphasized the importance of diagnostic clarification in triage decision-making. The CRPS Type 1 Referral Form (Figure 5.2) also includes *Budapest criteria*, which is a diagnostic tool that several participants referenced in the Delphi study (Chapter 2). Each referral form also includes the PII found through the systematic review (Chapter 3), which prompts the referring provider to conduct a brief biopsychosocial screening assessment with the patient prior to referral. The importance of triaging patients based on function and biopsychosocial complexity was reinforced through the qualitative study (Chapter 4).

The Triage Decision Algorithm (Figure 5.7) involves a simple and structured decision tree that indicates when the referral should be denied or re-directed to an alternate service, based on eligibility criteria and mandatory referral components. These factors were generated by the Delphi study (Chapter 2) and qualitative study (Chapter 4). After the decision to accept the patient has been established, there is a decision-tree that guides prioritization (i.e., urgent, semi-urgent, non-urgent) based on pain diagnosis and biopsychosocial complexity. Participants in the qualitative study (Chapter 4) highlighted CRPS and post-surgical pain as “urgent” diagnoses and

are therefore highlighted in the Triage Decision Algorithm. Prioritization categories have been based on PII scores (i.e., PII score of six identifies patient as urgent, whereas PII score of zero to two identifies the patient has non-urgent).

Adoption of this CDS triage tool series by interdisciplinary pediatric chronic pain programs may offer a more efficient and evidence-based platform to support nurses' triage decisions for referred patients who are complex from a biopsychosocial perspective. It is important to recognize that the intention of this series is to guide triage decisions and not over-rule other important decision-making factors including clinical instinct and specific team and/ or organizational priorities. It is also important to note that this series is at the preliminary development phase and requires further investigation and testing.

5.7 Future Directions

My next step will be to conduct a User-Centered Design (USD) study with a team of referring providers and interdisciplinary chronic pain providers based on the first draft of the CDS triage tool series displayed below. User-Centered Design is considered a system development methodology that focuses on examining end-users' needs, mental processes, limitations, and preferences, with the goal of designing a system that meets end-users' requirements (Kilsdonk et al., 2013). UCD approaches facilitate CDS systems that are more effective and easier to use (Yen & Bakken, 2012), and may enhance the uptake of the CDS triage tool series by pediatric chronic pain nurses. The objectives of the study will be based on the processes outlined by Romer and Bruder (2015), to iteratively design, develop and evaluate the tool series. The USD study will further specify context and user requirements with an extended lens of additional pediatric chronic pain nurses, chronic pain patients and their families, interdisciplinary chronic pain providers and referring providers. The potential outcomes of this

study will include solidifying referral expectations, enhancing diagnostic clarity and offering a brief biopsychosocial screening assessment to augment nurses' triage decisions.

5.8 Conclusion

My research supports the literature that the pediatric chronic pain population is complex from a symptomatology (Chapter 2) and biopsychosocial perspective (Chapter 3 & Chapter 4), which influences the complexity of triage decision-making in interdisciplinary pediatric chronic pain programs (Chapter 4). To my knowledge and supported by the Delphi study (Chapter 2) and qualitative study (Chapter 4), there is no evidence-based guidance to inform such decisions, yet nurses often make these multifaceted decisions alone (Chapter 4). Furthermore, my systematic review revealed the relative lack of efficient multidimensional biopsychosocial tools that provide holistic and multifaceted chronic pain screening assessments in pediatrics (Chapter 3), which could be clinically useful at point of referral and triage. Pediatric chronic pain nurses and physicians aspire to adopt a streamlined and evidence-based referral and triage process that may enhance access of appropriate pain care based on patient needs (Chapter 2 & Chapter 4). My dissertation illuminates the nursing leadership role in triage processes and development in this setting. Furthermore, my studies provide the groundwork to launch a USD study that will enhance the rigour, usability, and uptake of the CDS triage tool series that have potential to ease nurses' triage decisions and optimize patient equity in accessing interdisciplinary chronic pain care.

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Figure 5.2 CRPS Type 1 Referral Form

Interdisciplinary Pediatric Chronic Pain Program

Referral Form for Primary CRPS Type 1

Date of Referral: _____
Referral Completed By: _____
Duration of Pain: _____

Patient Demographics

***If patient has additional pain locations, please complete additional relevant referral form**

Patient Eligibility

- ❑ Pain >3 months
- ❑ Patient/ Family understand their pain diagnosis and have agreed to this referral
- ❑ All relevant diagnostic investigations are complete
- ❑ All relevant consultations are complete
- ❑ Foundational pain management strategies have been tried (i.e., basic pharmacotherapy, physiotherapy, psychotherapy, etc.)

NOTE: patient eligibility will be re-evaluated at various points throughout our program.

Prior to accepting and triaging the patient into our Chronic Pain Program, the following MUST be included:

- ❑ This referral must be complete for a triage decision to be made
- ❑ All clinical documentation supporting the pain diagnosis and eligibility criteria MUST be attached
- ❑ A detailed medication reconciliation report
- ❑ A list of current health care providers involved (e.g., physicians, therapists, health programs)
- ❑ Our Patient Intake Form (*see attached)

NOTE: The referring provider will be responsible for sending updated clinical information, as it arises

Does your patient have any of the following Clinical Red Flags?

- ❑ Suspicion of active bone and/ or soft tissue damage
- ❑ Suspicion of neuropathies
- ❑ Fever and/ or chills
- ❑ Neurovascular changes
- ❑ History of pulselessness
- ❑ History of trauma
- ❑ History of surgery

If yes, has your patient had any relevant diagnostic investigations done/ any consultations completed?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant diagnostic reports

If no, please conduct all necessary diagnostic investigations/ consultations to rule out secondary sources of pain before referring this patient to our Chronic Pain Program

BUDAPEST CRITERIA
****Adapted from Harden et al., 2010***

All of the following criteria must be met:

- ❑ Continuing pain that is disproportionate to the inciting event
- ❑ 1 sign in 2 or more of the categories below
- ❑ 1 symptom in 3 or more of the categories below
- ❑ No other diagnosis can better explain signs and symptoms

Sensory

- ❑ Allodynia
- ❑ Hyperalgesia

Vasomotor

- ❑ Temperature asymmetry
- ❑ Skin color changes
- ❑ Skin color asymmetry

Sudomotor/ Edema

- ❑ Edema
- ❑ Sweating changes
- ❑ Sweating asymmetry

Motor/ Trophic

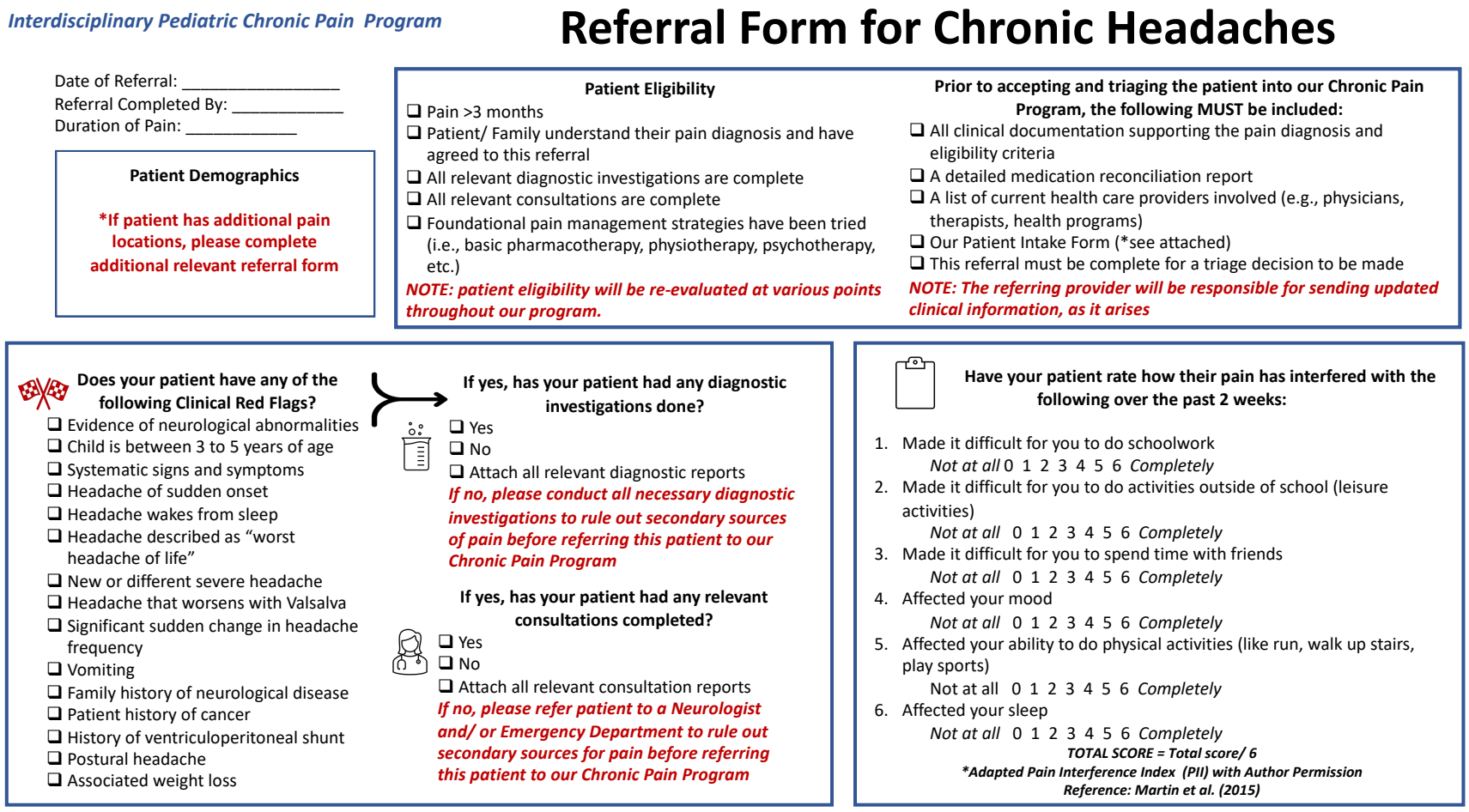
- ❑ Decreased ROM
- ❑ Motor dysfunction (weakness, tremor, dystonia)
- ❑ Trophic changes (hair, nail, skin)

Have your patient rate how their pain has interfered with the following over the past 2 weeks:

1. Made it difficult for you to do schoolwork
   Not at all 0 1 2 3 4 5 6 *Completely*
2. Made it difficult for you to do activities outside of school (leisure activities)
   Not at all 0 1 2 3 4 5 6 *Completely*
3. Made it difficult for you to spend time with friends
   Not at all 0 1 2 3 4 5 6 *Completely*
4. Affected your mood
   Not at all 0 1 2 3 4 5 6 *Completely*
5. Affected your ability to do physical activities (like run, walk up stairs, play sports)
   Not at all 0 1 2 3 4 5 6 *Completely*
6. Affected your sleep
   Not at all 0 1 2 3 4 5 6 *Completely*

TOTAL SCORE = Total score/ 6
****Adapted Pain Interference Index (PII) with Author Permission***
Reference: Martin et al. (2015)

Figure 5.3 Chronic Headaches Referral Form



Interdisciplinary Pediatric Chronic Pain Program

Referral Form for Chronic Headaches

Date of Referral: _____
Referral Completed By: _____
Duration of Pain: _____

Patient Demographics

***If patient has additional pain locations, please complete additional relevant referral form**

Patient Eligibility

- ❑ Pain >3 months
- ❑ Patient/ Family understand their pain diagnosis and have agreed to this referral
- ❑ All relevant diagnostic investigations are complete
- ❑ All relevant consultations are complete
- ❑ Foundational pain management strategies have been tried (i.e., basic pharmacotherapy, physiotherapy, psychotherapy, etc.)

NOTE: patient eligibility will be re-evaluated at various points throughout our program.

Prior to accepting and triaging the patient into our Chronic Pain Program, the following MUST be included:

- ❑ All clinical documentation supporting the pain diagnosis and eligibility criteria
- ❑ A detailed medication reconciliation report
- ❑ A list of current health care providers involved (e.g., physicians, therapists, health programs)
- ❑ Our Patient Intake Form (*see attached)
- ❑ This referral must be complete for a triage decision to be made

NOTE: The referring provider will be responsible for sending updated clinical information, as it arises

Does your patient have any of the following Clinical Red Flags?

- ❑ Evidence of neurological abnormalities
- ❑ Child is between 3 to 5 years of age
- ❑ Systematic signs and symptoms
- ❑ Headache of sudden onset
- ❑ Headache wakes from sleep
- ❑ Headache described as "worst headache of life"
- ❑ New or different severe headache
- ❑ Headache that worsens with Valsalva
- ❑ Significant sudden change in headache frequency
- ❑ Vomiting
- ❑ Family history of neurological disease
- ❑ Patient history of cancer
- ❑ History of ventriculoperitoneal shunt
- ❑ Postural headache
- ❑ Associated weight loss

If yes, has your patient had any diagnostic investigations done?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant diagnostic reports

If no, please conduct all necessary diagnostic investigations to rule out secondary sources of pain before referring this patient to our Chronic Pain Program

If yes, has your patient had any relevant consultations completed?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant consultation reports

If no, please refer patient to a Neurologist and/ or Emergency Department to rule out secondary sources for pain before referring this patient to our Chronic Pain Program

Have your patient rate how their pain has interfered with the following over the past 2 weeks:

1. Made it difficult for you to do schoolwork
   Not at all 0 1 2 3 4 5 6 *Completely*
2. Made it difficult for you to do activities outside of school (leisure activities)
   Not at all 0 1 2 3 4 5 6 *Completely*
3. Made it difficult for you to spend time with friends
   Not at all 0 1 2 3 4 5 6 *Completely*
4. Affected your mood
   Not at all 0 1 2 3 4 5 6 *Completely*
5. Affected your ability to do physical activities (like run, walk up stairs, play sports)
   Not at all 0 1 2 3 4 5 6 *Completely*
6. Affected your sleep
   Not at all 0 1 2 3 4 5 6 *Completely*

TOTAL SCORE = Total score/ 6

****Adapted Pain Interference Index (PII) with Author Permission***
Reference: Martin et al. (2015)

Figure 5.4 Musculoskeletal and/ or Joint Pain Referral Form

Interdisciplinary Pediatric Chronic Pain Program

Referral Form for Musculoskeletal and Joint Pain

Date of Referral: _____
Referral Completed By: _____
Duration of Pain: _____

Patient Demographics

***If patient has additional pain locations, please complete additional relevant referral form**

Patient Eligibility

- ❑ Pain >3 months
- ❑ Patient/ Family understand their pain diagnosis and have agreed to this referral
- ❑ All relevant diagnostic investigations are complete
- ❑ All relevant consultations are complete
- ❑ Foundational pain management strategies have been tried (i.e., basic pharmacotherapy, physiotherapy, psychotherapy, etc.)

NOTE: patient eligibility will be re-evaluated at various points throughout our program.

Prior to accepting and triaging the patient into our Chronic Pain Program, the following MUST be included:

- ❑ This referral must be complete for a triage decision to be made
- ❑ All clinical documentation supporting the pain diagnosis and eligibility criteria MUST be attached
- ❑ A detailed medication reconciliation report
- ❑ A list of current health care providers involved (e.g., physicians, therapists, health programs)
- ❑ Our Patient Intake Form (*see attached)

NOTE: The referring provider will be responsible for sending updated clinical information, as it arises

Does your patient have any of the following Clinical Red Flags?

- ❑ Unexplained weight loss
- ❑ Systemic signs and symptoms
- ❑ Pain and stiffness in the morning
- ❑ Arthralgia with redness and edema
- ❑ History of significant physical trauma
- ❑ Radiculopathy
- ❑ Bony tenderness
- ❑ History of congenital anomalies
- ❑ Pain at night
- ❑ History of cancer
- ❑ Positive trigger points

If yes, has your patient had any diagnostic investigations done?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant diagnostic reports

If no, please conduct all necessary diagnostic investigations to rule out secondary sources of pain before referring this patient to our Chronic Pain Program

If yes, has your patient had any relevant consultations completed?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant consultation reports

If no, please refer patient to a relevant specialty service and/ or the Emergency Department

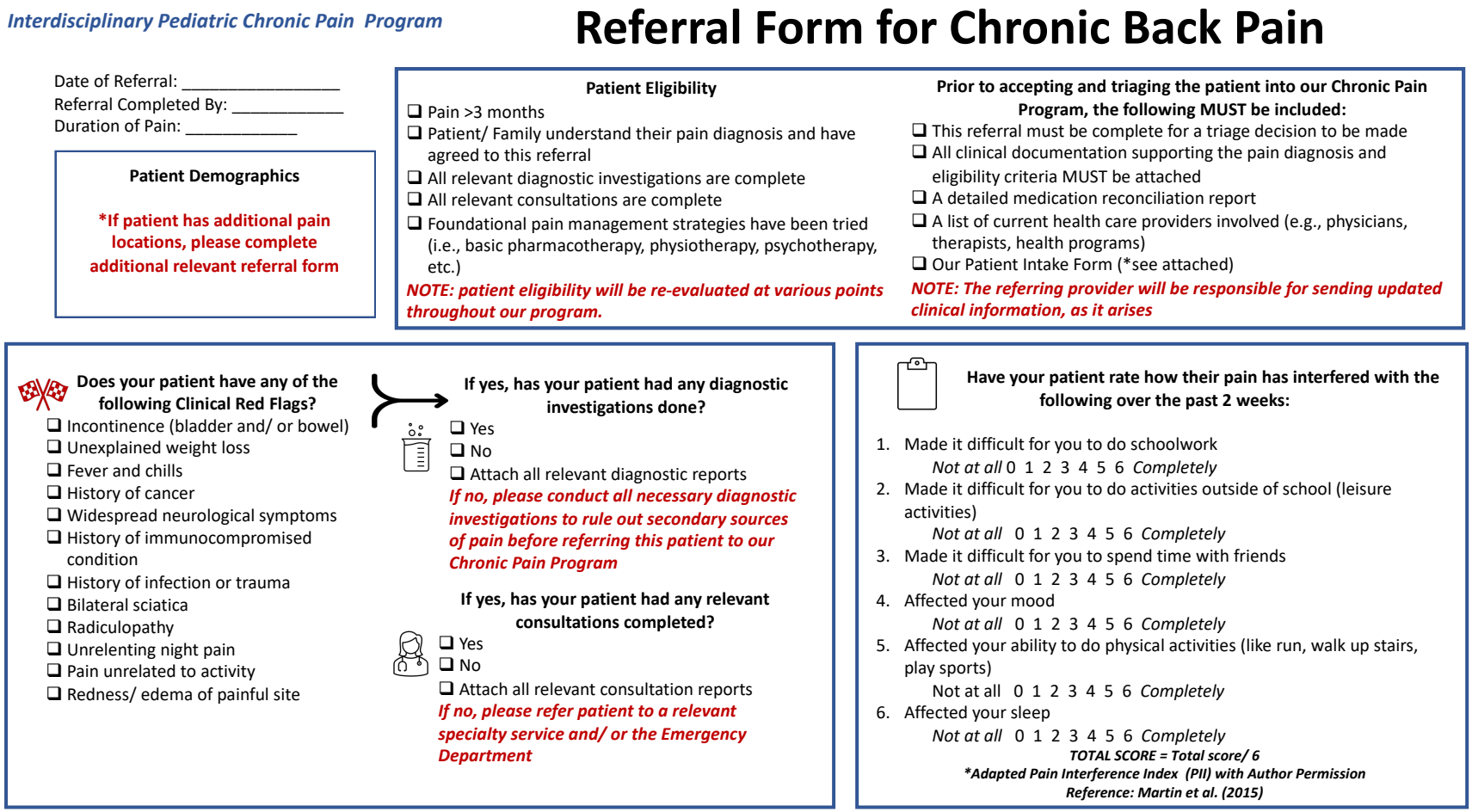
Have your patient rate how their pain has interfered with the following over the past 2 weeks:

1. Made it difficult for you to do schoolwork
   Not at all 0 1 2 3 4 5 6 *Completely*
2. Made it difficult for you to do activities outside of school (leisure activities)
   Not at all 0 1 2 3 4 5 6 *Completely*
3. Made it difficult for you to spend time with friends
   Not at all 0 1 2 3 4 5 6 *Completely*
4. Affected your mood
   Not at all 0 1 2 3 4 5 6 *Completely*
5. Affected your ability to do physical activities (like run, walk up stairs, play sports)
   Not at all 0 1 2 3 4 5 6 *Completely*
6. Affected your sleep
   Not at all 0 1 2 3 4 5 6 *Completely*

TOTAL SCORE = Total score/ 6

Adapted Pain Interference Index (PII) with Author Permission
Reference: Martin et al. (2015)

Figure 5.5 Chronic Back Pain Referral Form



Interdisciplinary Pediatric Chronic Pain Program

Referral Form for Chronic Back Pain

Date of Referral: _____
Referral Completed By: _____
Duration of Pain: _____

Patient Demographics

***If patient has additional pain locations, please complete additional relevant referral form**

Patient Eligibility

- ❑ Pain >3 months
- ❑ Patient/ Family understand their pain diagnosis and have agreed to this referral
- ❑ All relevant diagnostic investigations are complete
- ❑ All relevant consultations are complete
- ❑ Foundational pain management strategies have been tried (i.e., basic pharmacotherapy, physiotherapy, psychotherapy, etc.)

NOTE: patient eligibility will be re-evaluated at various points throughout our program.

Prior to accepting and triaging the patient into our Chronic Pain Program, the following MUST be included:

- ❑ This referral must be complete for a triage decision to be made
- ❑ All clinical documentation supporting the pain diagnosis and eligibility criteria MUST be attached
- ❑ A detailed medication reconciliation report
- ❑ A list of current health care providers involved (e.g., physicians, therapists, health programs)
- ❑ Our Patient Intake Form (*see attached)

NOTE: The referring provider will be responsible for sending updated clinical information, as it arises

Does your patient have any of the following Clinical Red Flags?

- ❑ Incontinence (bladder and/ or bowel)
- ❑ Unexplained weight loss
- ❑ Fever and chills
- ❑ History of cancer
- ❑ Widespread neurological symptoms
- ❑ History of immunocompromised condition
- ❑ History of infection or trauma
- ❑ Bilateral sciatica
- ❑ Radiculopathy
- ❑ Unrelenting night pain
- ❑ Pain unrelated to activity
- ❑ Redness/ edema of painful site

If yes, has your patient had any diagnostic investigations done?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant diagnostic reports

If no, please conduct all necessary diagnostic investigations to rule out secondary sources of pain before referring this patient to our Chronic Pain Program

If yes, has your patient had any relevant consultations completed?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant consultation reports

If no, please refer patient to a relevant specialty service and/ or the Emergency Department

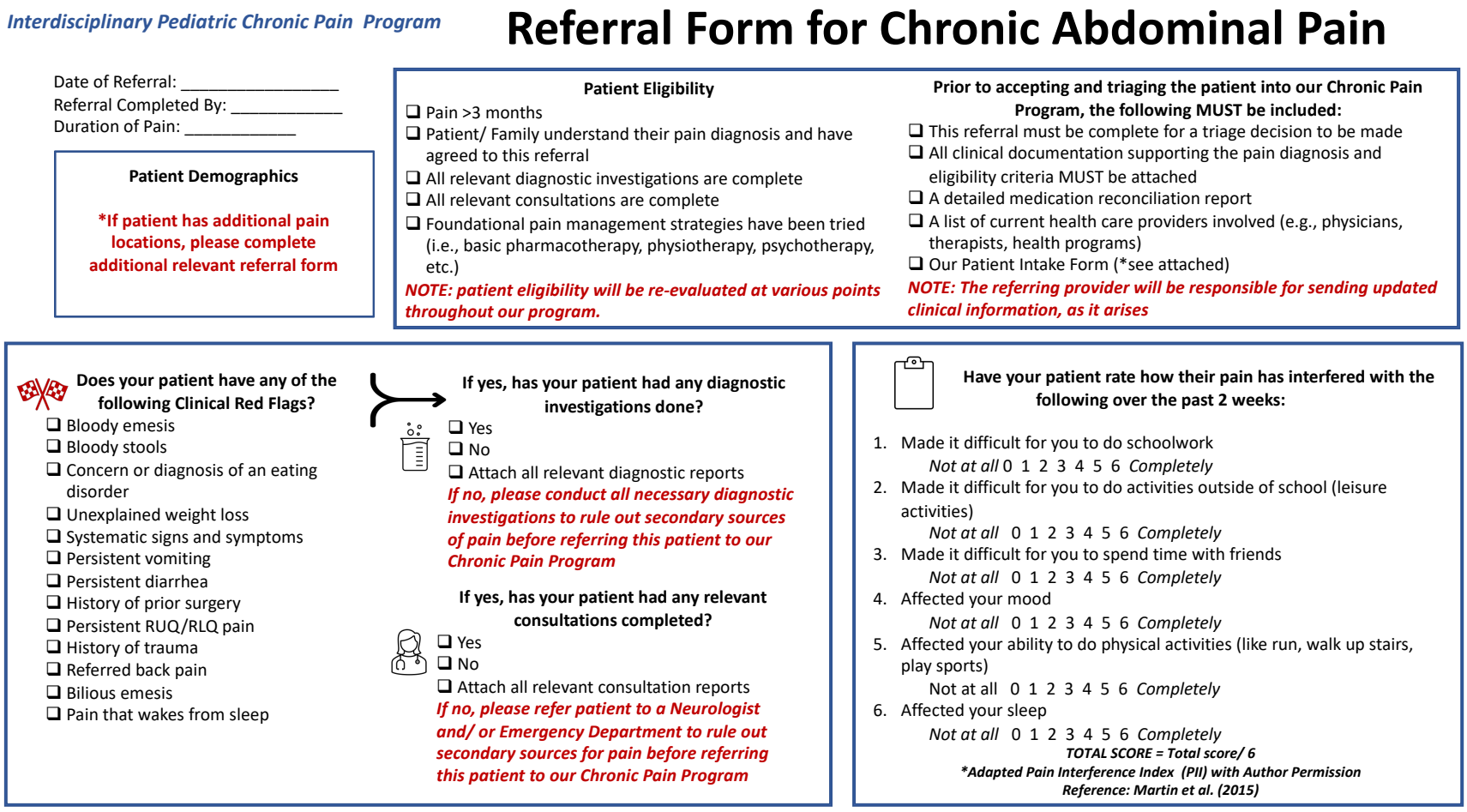
Have your patient rate how their pain has interfered with the following over the past 2 weeks:

1. Made it difficult for you to do schoolwork
   Not at all 0 1 2 3 4 5 6 *Completely*
2. Made it difficult for you to do activities outside of school (leisure activities)
   Not at all 0 1 2 3 4 5 6 *Completely*
3. Made it difficult for you to spend time with friends
   Not at all 0 1 2 3 4 5 6 *Completely*
4. Affected your mood
   Not at all 0 1 2 3 4 5 6 *Completely*
5. Affected your ability to do physical activities (like run, walk up stairs, play sports)
   Not at all 0 1 2 3 4 5 6 *Completely*
6. Affected your sleep
   Not at all 0 1 2 3 4 5 6 *Completely*

TOTAL SCORE = Total score/ 6

****Adapted Pain Interference Index (PII) with Author Permission***
Reference: Martin et al. (2015)

Figure 5.6 Chronic Abdominal Pain Referral Form



Interdisciplinary Pediatric Chronic Pain Program

Referral Form for Chronic Abdominal Pain

Date of Referral: _____
Referral Completed By: _____
Duration of Pain: _____

Patient Demographics

***If patient has additional pain locations, please complete additional relevant referral form**

Patient Eligibility

- ❑ Pain >3 months
- ❑ Patient/ Family understand their pain diagnosis and have agreed to this referral
- ❑ All relevant diagnostic investigations are complete
- ❑ All relevant consultations are complete
- ❑ Foundational pain management strategies have been tried (i.e., basic pharmacotherapy, physiotherapy, psychotherapy, etc.)

NOTE: patient eligibility will be re-evaluated at various points throughout our program.

Prior to accepting and triaging the patient into our Chronic Pain Program, the following MUST be included:

- ❑ This referral must be complete for a triage decision to be made
- ❑ All clinical documentation supporting the pain diagnosis and eligibility criteria MUST be attached
- ❑ A detailed medication reconciliation report
- ❑ A list of current health care providers involved (e.g., physicians, therapists, health programs)
- ❑ Our Patient Intake Form (*see attached)

NOTE: The referring provider will be responsible for sending updated clinical information, as it arises

Does your patient have any of the following Clinical Red Flags?

- ❑ Bloody emesis
- ❑ Bloody stools
- ❑ Concern or diagnosis of an eating disorder
- ❑ Unexplained weight loss
- ❑ Systematic signs and symptoms
- ❑ Persistent vomiting
- ❑ Persistent diarrhea
- ❑ History of prior surgery
- ❑ Persistent RUQ/RLQ pain
- ❑ History of trauma
- ❑ Referred back pain
- ❑ Bilious emesis
- ❑ Pain that wakes from sleep

If yes, has your patient had any diagnostic investigations done?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant diagnostic reports

If no, please conduct all necessary diagnostic investigations to rule out secondary sources of pain before referring this patient to our Chronic Pain Program

If yes, has your patient had any relevant consultations completed?

- ❑ Yes
- ❑ No
- ❑ Attach all relevant consultation reports

If no, please refer patient to a Neurologist and/ or Emergency Department to rule out secondary sources for pain before referring this patient to our Chronic Pain Program

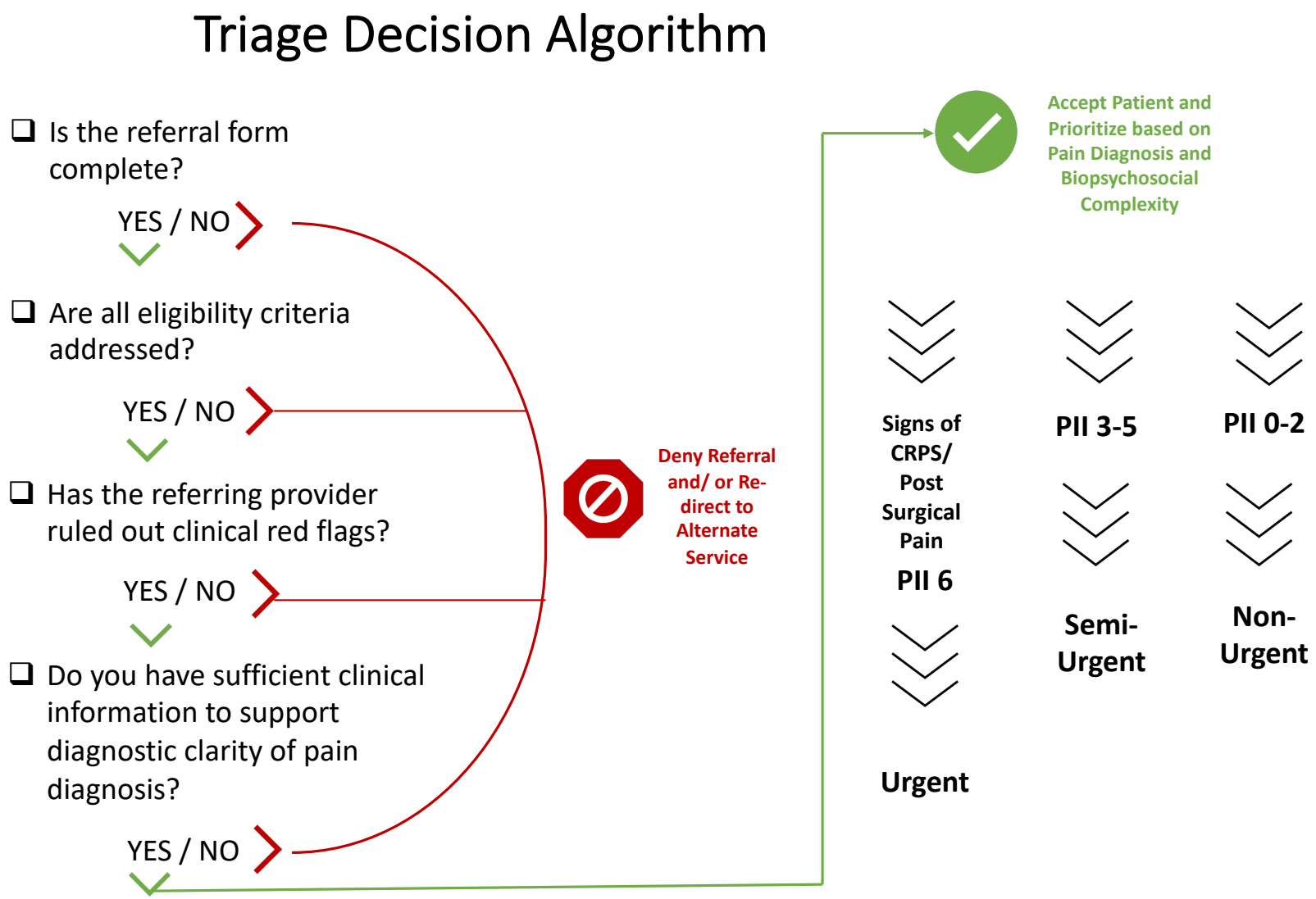
Have your patient rate how their pain has interfered with the following over the past 2 weeks:

1. Made it difficult for you to do schoolwork
   Not at all 0 1 2 3 4 5 6 *Completely*
2. Made it difficult for you to do activities outside of school (leisure activities)
   Not at all 0 1 2 3 4 5 6 *Completely*
3. Made it difficult for you to spend time with friends
   Not at all 0 1 2 3 4 5 6 *Completely*
4. Affected your mood
   Not at all 0 1 2 3 4 5 6 *Completely*
5. Affected your ability to do physical activities (like run, walk up stairs, play sports)
   Not at all 0 1 2 3 4 5 6 *Completely*
6. Affected your sleep
   Not at all 0 1 2 3 4 5 6 *Completely*

TOTAL SCORE = Total score/ 6

****Adapted Pain Interference Index (PII) with Author Permission***
Reference: Martin et al. (2015)

Figure 5.7 Triage Decision Algorithm



Supplementary Files

Systematic Review Supplementary File 1: PRISMA-P Checklist

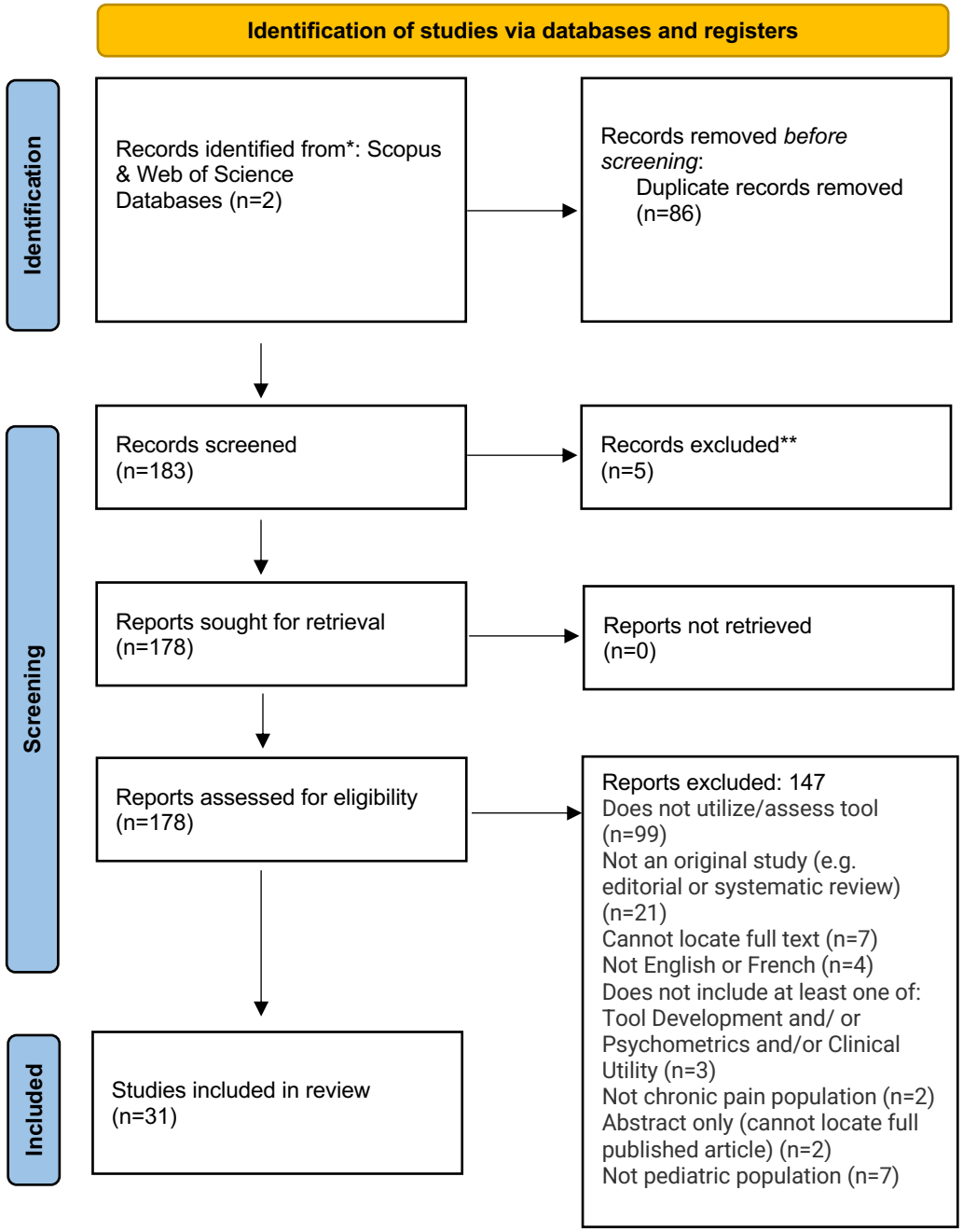
Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title page
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg 3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg 4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg 5
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Pg 5-6 Supplementary File 2
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg 5-6 Supplementary File 2
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Pg 6-7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pg 6-7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pg 7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pg 7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Pg 7-8

Section and Topic	Item #	Checklist item	Location where item is reported
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Pg 8
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Pg 8
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pg 8
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg 8
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pg 8
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A, addressed on Pg 8
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A, addressed on Pg 8
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Pg 7
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Pg 7
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Pg 8-9 Fig 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Supplementary Files 3 & 4
Study characteristics	17	Cite each included study and present its characteristics.	Citation List Pg 27-38 Table 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 4
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Table 2 & 4
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Table 3

Section and Topic	Item #	Checklist item	Location where item is reported
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Table 4
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 4
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg 15-19
	23b	Discuss any limitations of the evidence included in the review.	Pg 17-18
	23c	Discuss any limitations of the review processes used.	Pg 17-18
	23d	Discuss implications of the results for practice, policy, and future research.	Pg 18-19
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pg 19
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Not prepared
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Pg 19-20
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg 20
Competing interests	26	Declare any competing interests of review authors.	Pg 20
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Not yet publically available

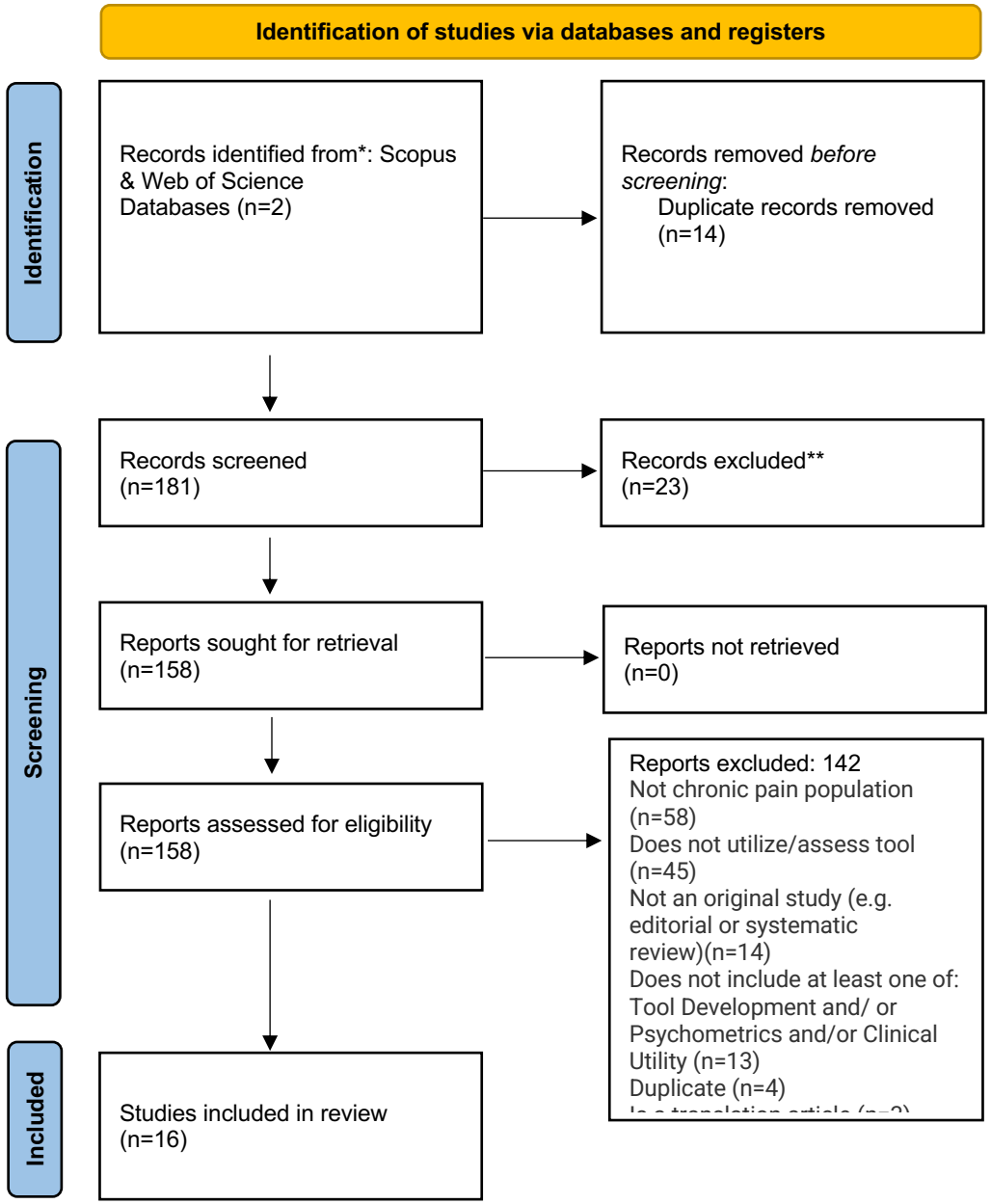
Systematic Review Supplementary File 2: PRISMA P Flow Diagrams

BATH Adolescent Pain Questionnaire

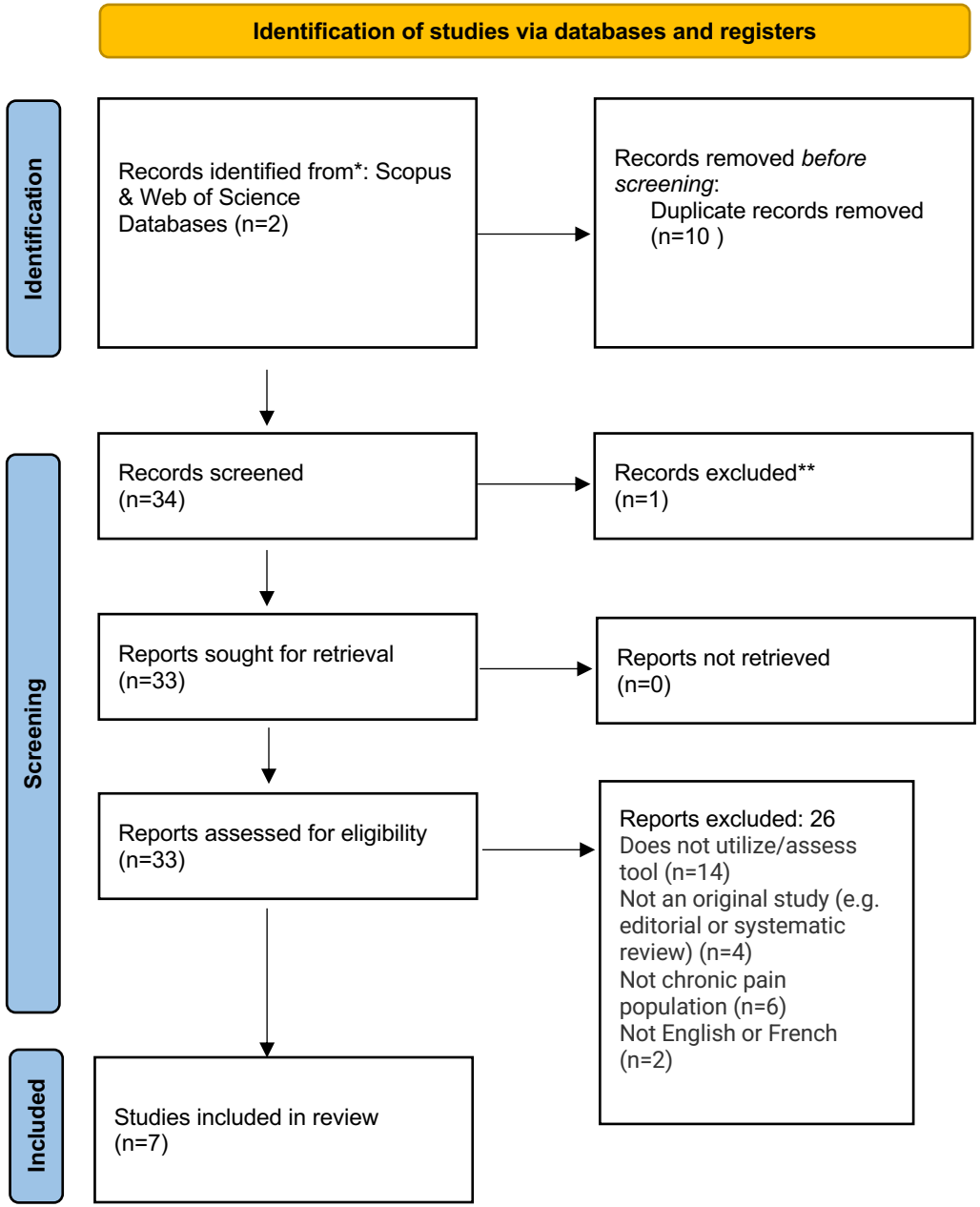


From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

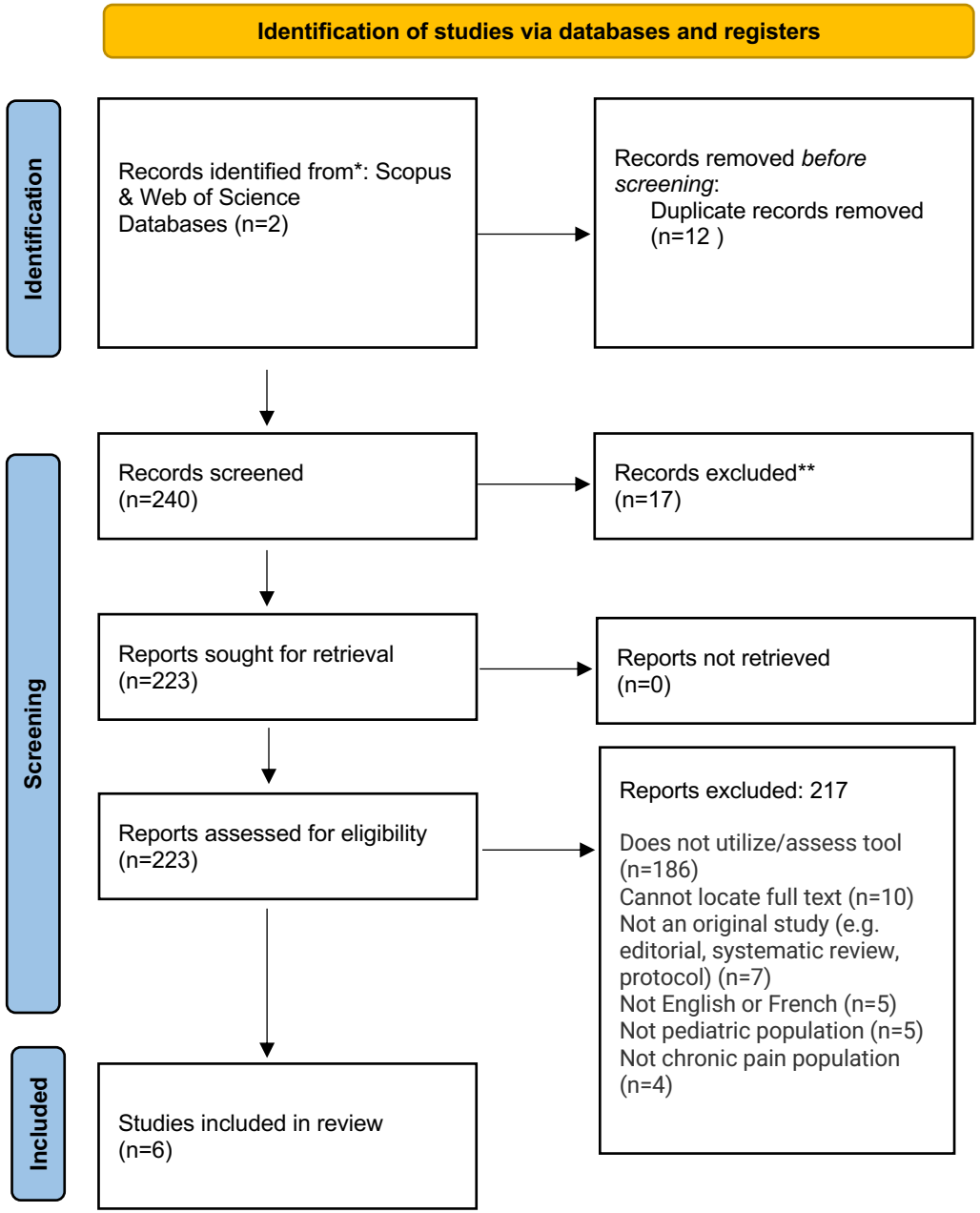
PROMIS Pain Interference Scale



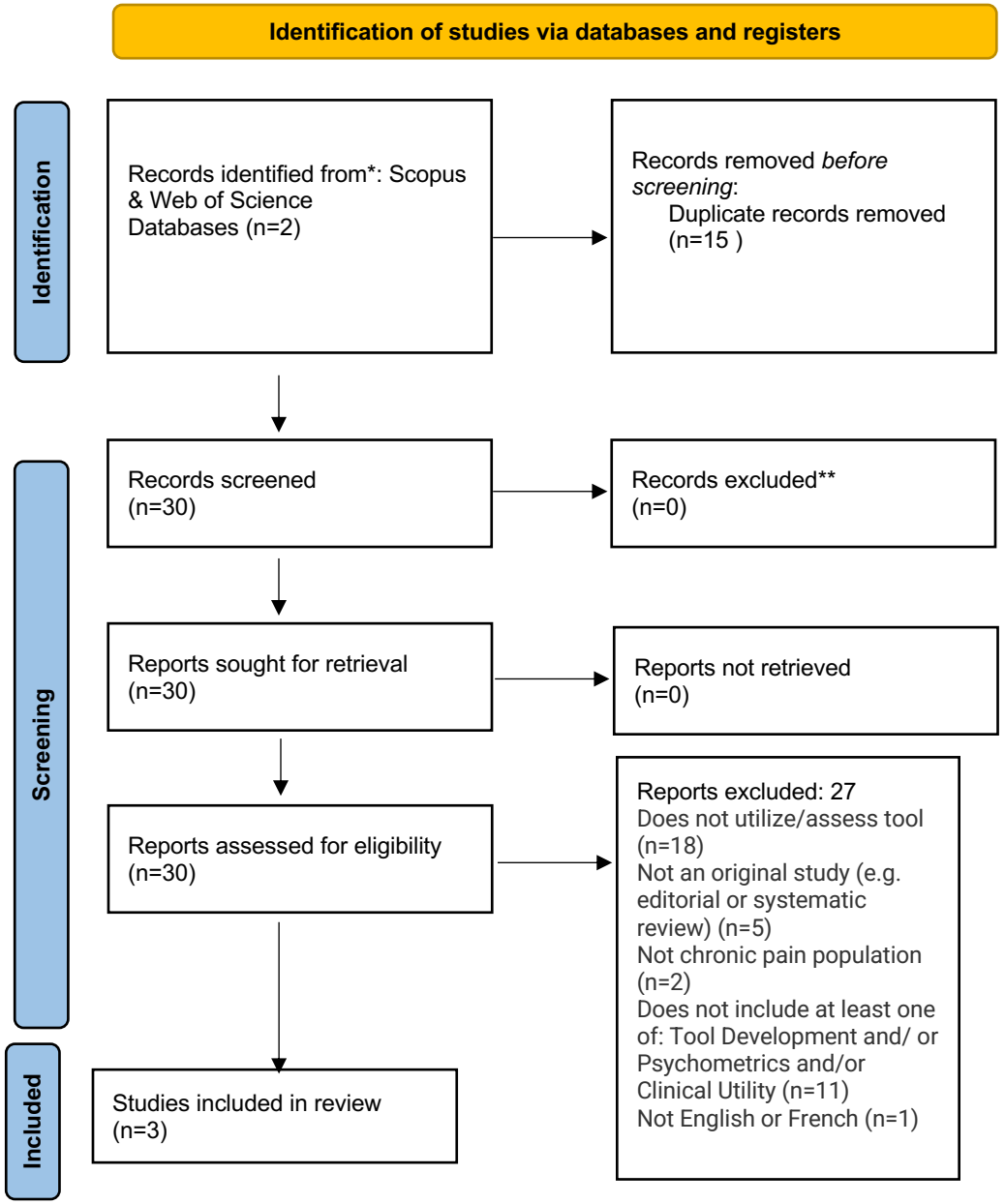
Child Activities Limitations Questionnaire (CALQ)



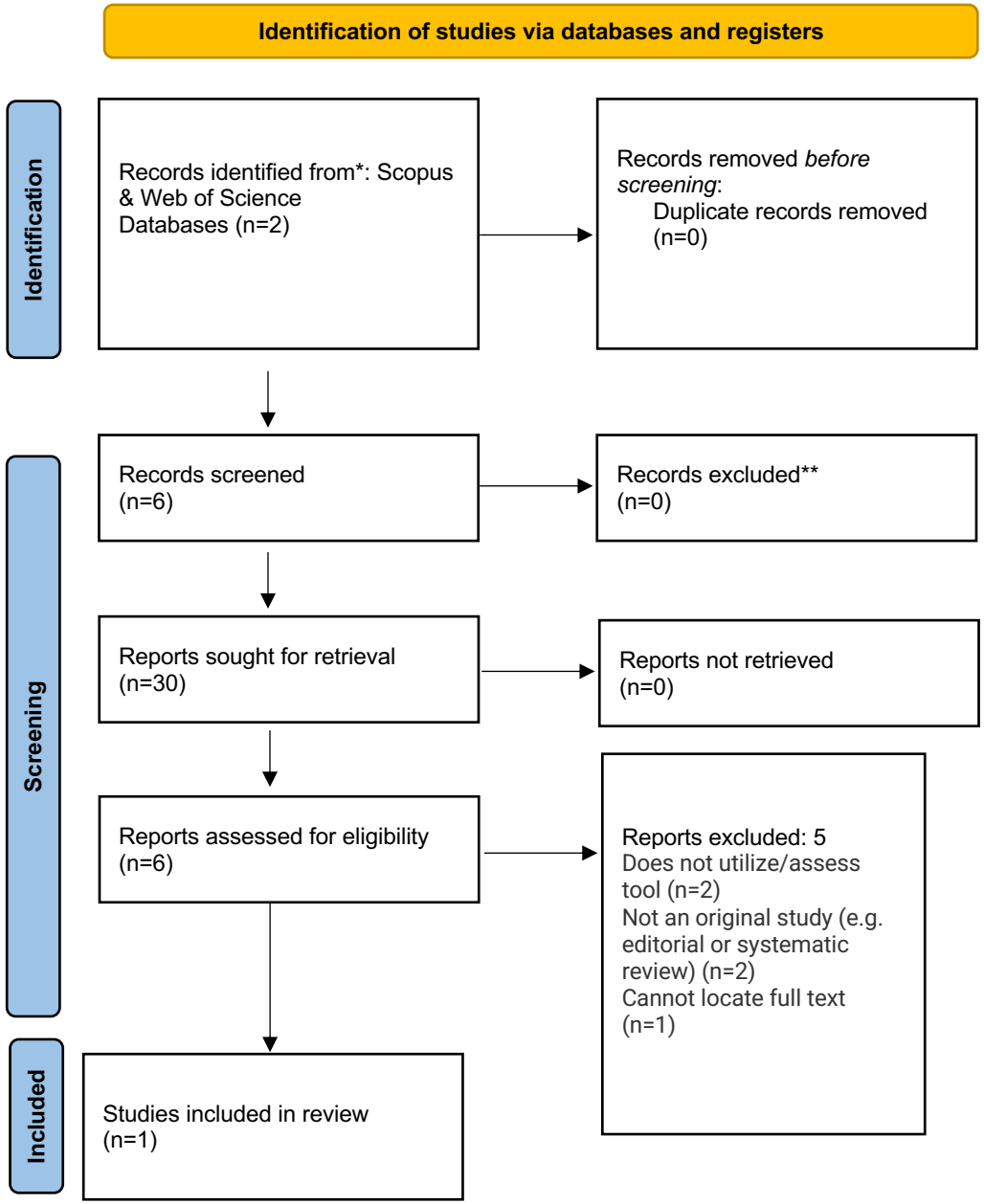
Pain Interference Index (PII)



Pain Experience Questionnaire (PEQ)



Pain Related Problem List for Adolescents (PRBL-A)



Systematic Review Supplementary File 3: Search Strategy and PRESS Review

PEER REVIEW ASSESSMENT: THIS SECTION TO BE FILLED IN BY THE REVIEWER (Tamara R)

1. PsycTEST

(results need to be reviewed online)
Suggested search;

pain
and
biopsychosocial* or bio-psycho-social* or biobehav* or bio-behav* or psychosocial* or psycho-social* or multidimension* or dimension* or interdisciplin* or multidisciplin* or multi-disciplin* or function* or dysfunction* or distress or coping or experience or burden or limitation*
And from the pulldowns:
Age Group: Childhood (birth-12 yrs) OR Adolescence (13-17 yrs)

This yields 142 records. If you just search Pain and the age group filter, omitting the biopsychosocial terms, you will get 228 records

PychTEST does not seem to have a way limit by language.

2. Health and Psychosocial Instruments (HAPI)

Results can be exported to a citation manager, but you typically lose a lot of detail on the test as there are many fields beyond the normal fields in a citation database.
Note that if you change the first line from pain.mp. (where *mp* means search all fields) to pain.ti. (where *ti* means search in the title) your final numbers drop from 406 to 73. Omit the last row if you want to consider all languages.

1	pain.mp.	8699
2	(biopsychosocial* or bio-psycho-social* or biobehav* or bio-behav* or psychosocial* or psycho-social* or multidimension* or dimension* or interdisciplin*	37253

	or multidisciplin* or multi-disciplin* or function* or dysfunction* or distress or coping or experience or burden or limitation*).mp.	
3	(toddler* or child* or school* or adolescen* or juvenil* or youth* or teen* or pubescen* or pediatric* or paediatric* or peadiatric*).mp.	60875
4	1 and 2 and 3	523
5	limit 4 to english language	406

Biopsychosocial terms:
biopsychosocial* or bio-psycho-social* or biobehav* or bio-behav* or psychosocial* or psycho-social* or multidimension* or dimension* or interdisciplin* or multidiscipline* or multi-disciplin* or function* or dysfunction* or distress or coping or experience or burden or limitation*

Child term – (add or omit the shaded terms, depending on your lower age of interest):
Infan* OR newborn* OR new-born* OR perinat* OR neonat* OR baby OR baby* OR babies OR toddler* or child* or school* or adolescen* or juvenil* or youth* or teen* or pubescen* or pediatric* or paediatric* or peadiatric*

Reviewer:	Date completed: 5 Oct 2020

1. TRANSLATION

A ---No revisions	X
B --- Revision(s) suggested	
C --- Revision(s) required	

2. BOOLEAN AND PROXIMITY OPERATORS

A --- No revisions	X
B --- Revision(s) suggested	
C --- Revision(s) required	

3. SUBJECT HEADINGS

A ---No revisions	X
B --- Revision(s) suggested	
C --- Revision(s) required	

4. TEXT WORD SEARCHING

A ---No revisions	
B --- Revision(s)suggested	X
C --- Revision(s) required	

5. SPELLING, SYNTAX, AND LINE NUMBERS

A ---No revisions	X
B --- Revision(s)suggested	
C --- Revision(s) required	

6. LIMITS AND FILTERS

A ---No revisions	X
B --- Revision(s) suggested	
C --- Revision(s) required	

OVERALL EVALUATION (Note: If one or more "revision required" is noted above, the response below must be "revisions required".)

A ---No revisions	

B --- Revision(s) suggested	X
C --- Revision(s) required	

Systematic Review Supplementary File 5: Reasons for Tool Exclusion

Tool	**Tool Not Intended to Measure Impact of Chronic Pain Interference**	**Tool Focused on Specific Disease Process or Pain Location**	**Unidimensional**	**No evidence for use in pediatrics**	**Does not Provide Quantitative Measure**	**Insufficient Details Available**
	(i.e., general health status tools, tools focused on pain coping/ perception/ focus on acute pain)	(i.e., Headache specific tools, Sickle Cell specific tool, etc.)	(i.e., did not fit criteria defined by the Multidimensional Biobehavioral Model of Pediatric Pain)	(i.e., within the ages of 2-18 years, neonatal/ infant tools excluded)	(i.e., interviews, etc.)	Cannot Locate Tool PDF/ Insufficient Description of Tool
Pain Discomfort Scale (Jensen, Turner, Romano & Strom, 1995)			X			
Pain Impairment and Relationship Scale (Slater, Hall, Atkinson & Garfin, 1991)	X		X			
Chronic Pain Values Inventory (McCracken & Yang, 2006)	X		X			
Recurrent Pain Measure (Vaalamo et al., 2002)						X
Varni/ Thompson Pediatric Pain Questionnaire (Varni, Wilcox, Handon & Birk, 1988)			X			
Biopsychosocial Perspective of Pain Measure (Guite et al., 2014)						X
Structured Pain Interview (Gil, Abrams, Phillips & Williams, 1992)					X	
Daily Pain and Activity Diary (Powers et al., 2002)					X	
Psychosocial Pain Inventory (Heaton et al., 1982)						X

Pain and Discomfort Module (Mason, Skevington & Obsnorn, 2004)						X
Pain Status Form (Lester, Lefebvre & Keefe, 1996)						X
Chronic Pain Grade Questionnaire (Smith et al., 1997)				X		
Comprehensive Pain Evaluation Questionnaire (Birch & Jamison, 1998)				X		
Dartmouth Pain Questionnaire (Corson & Schneider, 1984)				X		
Wisconsin Brief Pain Questionnaire (Daut, Cleeland & Flanery, 1983)				X		
Euro-QOL 5D (Strong et al., 2008)				X		
SF-Health Survey (Ware et al., 1993)	X			X		
Pain Coping Questionnaire (Kleinke, 1992)	X		X			
Pediatric Quality of Life Cancer Module (Varni et al., 2002)		X				
Oxford Ankle Foot Questionnaire for Children (Morris et al., 2010)		X				
Pain Catastrophizing Scale for Children (Crombez et al., 2003)	X		X			
Self-Assessment of Role Performance and ADLs (Watkins, Lounsbury & Fleming-Castaldy, 2016)	X					X
Functional Disability Inventory (Walker & Greene, 1991)	X		X			
Parent Fear of Pain Questionnaire (Simons, LE, Smith, Kaczynski & Basch 2015)	X		X			
Scoliosis Research Society-7 Questionnaire (Almarani et al., 2021)		X				
Youth Acute Pain Functional Ability Questionnaire (Zempsky et al., 2014)	X					
Sickle Cell Disease Pain Burden Interview for Youth (Zempsky et al., 2013)		X				

Pain Stages of Change Questionnaire for Adolescents (Lorig et al., 2014)	X		X			
Fear of Pain Questionnaire – Child Report (MacNeil & Rainwater, 1998)	X		X			
Pain Reactivity Scale (Wicksell, Olsson & Hayes, 2011)	X		X			
Batten's Observational Pain Scale (Breau, Camfield & Camfield, 2010)	X					
Pain-Related Parent Behavior Inventory (Hermann, Zohsel, Hohmesiter & Flor, 2008)			X			
The Inventory of Parent Responses to Child's Pain (Huguet, Miro & Nieto, 2008)	X		X			
Pain Expression Scale (Kuttner & LePage, 1989)	X		X			
Pain-Related Cognitions Questionnaire for Children (Hermann et al., 2007)	X		X			
Child Self-Efficacy Scale (Bandura, 2006)	X		X			
Adolescent Duke Health Profile (Guillemin et al., 1997)	X					
Pain Response Inventory for Children (Walker et al, 1997)	X		X			
Waldron/ Varni Pedatric Pain Coping Inventory (Varni et al., 1996)	X		X			
Children's Somatization Inventory (Walker & Greene, 1989)	X		X			
Abu-Saad Pediatric Pain Assessment Tool (Abu-Saad, Kroonen & Halfens, 1990)			X			
Observational Scale of Behavioral Distress (Elliott, Jay & Woody, 1987)	X		X			
International Pain Outcomes Questionnaire (Rothaug et al., 2013)	X					
Quality of Life Instrument for Chronic Diseases (Megari, 2013)	X					

The Children's Hospital of Eastern Ontario Pain Scale (Crellin et al., 2007)			X			
Ways of Coping Questionnaire (Folkman & Lazarus, 1988)	X		X			
Child Pain Scale (Gauvin-Piquard et al., 1987)			X			
Symptom Experience Index (Fu, McDaniel & Rhodes, 2007)	X					
Functional Status II Revised (Stein & Jessop, 1990)	X					
Migraine Specific Quality of Life Questionnaire (Jhingran et al., 1988)		X				
Arthritis Impact Measurement Scales (Meenan, Gertman & Mason, 1980)			X			
Clinical Outcome Variables Scale (Seaby & Torrance, 1989)	X		X			
Childhood Health Assessment Questionnaire (Singh et al., 1994)	X					
MOS 36-Item Short Form Health Survey (Ware JE & Sherbourne, 1992)	X					
Child Activities of Daily Living Scale (Fries et al., 1980)	X					
Menstrual Distress Questionnaire (Moos, 1968)		X				
Karnofsky Performance Status (Karnofsky & Burchenal, 1949)	X					
Brief Symptom Inventory (Derogatis & Melisaratos, 1983)	X					
Abdominal Pain Measure (Walker et al., 1997)		X				
Adolescent Pediatric Pain Tool (Savedra et al., 1992)			X			
Pain Response Inventory (Walker et al., 1997)	X		X			
Pain Beliefs Questionnaire (Edwards & Pearce, 1994)	X		X			
Health Utilities Index (Torrance et al., 1996)	X					
Headache Questionnaire (Raieli et al., 1995)		X				

McGill Pain Questionnaire (Melzack, 1975)			X			
Child Reported Pain Measure (Williamson, Walters & Shaffer, 2002)			X			
Headache Impact Questionnaire (Steward et al., 1998)		X				
Pain Experience History (Hester & Barcus, 1986)						X
Pain Related Control Scale (Flor & Turk, 1988)	X		X			
Pain Related Self-Statements Scale (Flor, Behle & Birbaumer, 1993)	X		X			
Nottingham Health Profile (Hunt et al., 1980)	X					
Roland Morris Disability Questionnaire (Roland & Morris, 1983)		X				

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Systematic Review Supplementary File 5: Reasons for Citation Exclusion

Tool 1: The Bath Adolescent Pain Questionnaire (n=140 citations excluded)

Citation Excluded	Reason for Exclusion
Double-blind, placebo-controlled randomized trial with adalimumab for treatment of juvenile onset ankylosing spondylitis (JoAS): Significant short term improvement Horneff, G; Fitter, S; Foeldvari, I; Minden, K; Kuemmerle-Deschner, J; Tzaribacev, N; Thon, A; Borte, M; Ganser, G; Trauzeddel, R; Huppertz, H.-I. Arthritis Research and Therapy // 2012;14(5): General Pediatrics, Asklepios Clinics, Arnold Janssen Str. 29, Sankt Augustin, 53757, Germany 2012 // DOI: 10.1186/ar4072	Does not utilize or assess tool
Clinical aspects of itch in adult atopic dermatitis patients Chrostowska-Plak, D; Salomon, J; Reich, A; Szepietowski, J C Acta Dermato-Venereologica // 2009;89(4):379-383 Department of Dermatology, Venereology and Allergology, Wroclaw Medical University, Wroclaw, Poland 2009 // DOI: 10.2340/00015555-0676	Does not utilize or assess tool Not pediatric population Not chronic pain population
Psychological effects of chronic pain: An overview McCracken, L M Clinical Pain Management: Chronic Pain, Second Edition // 2008;():169-177 2008 //	Cannot locate full text Not an original study
Patients with chronic pain exhibit a complex relationship triad between pain, resilience, and within- and cross-network functional connectivity of the default mode network Hemington, K S; Rogachov, A; Cheng, J C; Bosma, R L; Kim, J A; Osborne, N R; Inman, R D; Davis, K D Pain // 2018;159(8):1621-1630 Institute of Medical Science, University of Toronto, Toronto, ON, Canada Lippincott Williams and Wilkins 2018 // DOI: 10.1097/j.pain.0000000000001252	Does not utilize or assess tool
The prevalence, impact and cost of chronic non-cancer pain in Irish primary schoolchildren (PRIME-C): Protocol for a longitudinal school-based survey O'Higgins, S; Doherty, E; NicGabhainn, S; Murphy, A; Hogan, M; O'Neill, C; McGuire, B E BMJ Open // 2015;5(5): Centre for Pain Research, School of Psychology, National University of Ireland, Galway, Ireland BMJ Publishing Group 2015 // DOI: 10.1136/bmjopen-2014-007426	Not original study
Pediatric Pain Measurement, Assessment, and Evaluation Manworren, R C B; Stinson, J	Not an original study

Seminars in Pediatric Neurology // 2016;23(3):189-200 Acute Pain Management Program, Ann & Robert H. Lurie Children's Hospital of Chicago, Northwestern University, Chicago, IL, United States W.B. Saunders 2016 // DOI: 10.1016/j.spen.2016.10.001	
Validation of a self-report questionnaire version of the Child Activity Limitations Interview (CALI): The CALI-21 Palermo, T M; Lewandowski, A S; Long, A C; Burant, C J Pain // 2008;139(3):644-652 Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, United States 2008 // DOI: 10.1016/j.pain.2008.06.022	Does not utilize or assess tool
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Accelerating the drug delivery pipeline for acute and chronic pancreatitis-knowledge gaps and research opportunities: Overview summary of a National Institute of Diabetes and Digestive and Kidney Diseases workshop Uc, A; Andersen, D K; Borowitz, D; Glesby, M J; Mayerle, J; Sutton, R; Pandol, S J	Does not utilize or assess tool Not chronic pain population

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Effects of Multidisciplinary Team-Based Nurse-led Transitional Care on Clinical Outcomes and Quality of Life in Patients With Ankylosing Spondylitis Liang, L; Pan, Y; Wu, D; Pang, Y; Xie, Y; Fang, H Asian Nursing Research // 2019;13(2):107-114 Department of Nursing, The Third Affiliated Hospital of Sun Yat-sen University, Guangzhou, China Korean Society of Nursing Science 2019 // DOI: 10.1016/j.anr.2019.02.004	Does not utilize or assess tool
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The mechanisms of pain tolerance and pain-related anxiety in acute pain Cimpean, A; David, D Health Psychology Open // 2019;6(2): Doctoral School Evidence-Based Assesment and Psychological Interventions, Babes-Bolyai University, Romania SAGE Publications Inc. 2019 // DOI: 10.1177/2055102919865161	Does not utilize or assess tool
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Department of Physical Medicine and Rehabilitation, Medical Faculty, Ondokuz Mayis University, Samsun, Turkey W.B. Saunders 2015 // DOI: 10.1016/j.comppsych.2015.07.016	
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Quality of life and correlation with clinical and radiographic variables in patients with ankylosing spondylitis: A retrospective case series study Huang, J.-C.; Qian, B.-P.; Qiu, Y; Wang, B; Yu, Y; Zhu, Z.-Z.; Hu, J; Qu, Z BMC Musculoskeletal Disorders // 2017;18(1): Department of Spine Surgery, Drum Tower Hospital, Affiliated Hospital of Nanjing, University Medical School, Zhongshan Road 321, Nanjing, 210008, China BioMed Central Ltd. 2017 // DOI: 10.1186/s12891-017-1711-1	Does not utilize or assess tool

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Clinical utility and validity of the Functional Disability Inventory among a multicenter sample of youth with chronic pain Kashikar-Zuck, S; Flowers, S R; Claar, R L; Guite, J W; Logan, D E; Lynch-Jordan, A M; Palermo, T M; Wilson, A C Pain // 2011;152(7):1600-1607 Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, United States 2011 // DOI: 10.1016/j.pain.2011.02.050	Does not utilize or assess tool
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A short-term efficacy and safety study of infliximab in active ankylosing spondylitis Huang, F; Zhang, L Y; Zhang, J L; Zhang, F C; Liang, D F; Deng, X H; Guo, J H; Zhu, J; Zhao, W; Li, X F; Hou, Y Zhonghua nei ke za zhi [Chinese journal of internal medicine] // 2006;45(2):122-126 Department of Rheumatology, Chinese PLA General Hospital, Beijing, 100853, China 2006 //	Not English or French
Development and psychometric evaluation of the Bath Adolescent Pain Questionnaire (BAPQ) Jordan, A; Eccleston, C; McCracken, L; Connell, H; Clinch, J RHEUMATOLOGY 04// 2006;45(1):I107-I107 GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND OXFORD UNIV PRESS 2006 04//	Cannot locate full text
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DOI: 10.3233/ZMP-2012-210012	
Pain Amplification Syndrome: A Biopsychosocial Approach Namerow, L B; Kutner, E C; Wakefield, E C; Rzepski, B R; Sahl, R A Seminars in Pediatric Neurology // 2016;23(3):224-230 Department of Pediatrics, University of Connecticut School of Medicine, Farmington, CT, United States W.B. Saunders 2016 // DOI: 10.1016/j.spen.2016.10.006	Does not utilize or assess tool
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Enhancing daily functioning with exposure and acceptance strategies: An important stride in the development of psychological therapies for pediatric chronic pain Palermo, T M Pain // 2009;141(3):189-190 Division of Clinical Pain and Regional Anesthesia Research, Dept. of Anesthesiology and Peri-Operative Medicine, Oregon Health and Science University, 3181 SW Sam Jackson Park Rd., UHN-2, Portland, OR 97239, United States 2009 // DOI: 10.1016/j.pain.2008.12.012	Does not utilize or assess tool
Characterizing the pain narratives of parents of youth with chronic pain Noel, M; Beals-Erickson, S E; Law, E F; Alberts, N M; Palermo, T M Clinical Journal of Pain // 2016;32(10):849-858 Department of Psychology, University of Calgary, 2500 University Dr., N.W., Calgary, AB T2N 1N4, Canada Lippincott Williams and Wilkins 2016 // DOI: 10.1097/AJP.0000000000000346	Does not include at least one of: Tool Development or Psychometric Evaluation
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German Pain Questionnaire for Children, Adolescents and Parents (DSF-KJ): A multimodal questionnaire for diagnosis and treatment of children and adolescents suffering from chronic pain Schroeder, S; Hechler, T; Denecke, H; Müller-Busch, M; Martin, A; Menke, A; Zernikow, B	Not English or French

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Chronic pain problems in children and young people Howard, R F Continuing Education in Anaesthesia, Critical Care and Pain // 2011;11(6):219-223 Paediatric Anaesthesia and Pain Medicine, Clinical Lead for Pain Management, Great Ormond Street Hospital for Children, London WC1N 3JHUK, United Kingdom Oxford University Press 2011 // DOI: 10.1093/bjaceaccp/mkr042	Does not utilize or assess tool
Neuroimaging of paediatric pain Hartley, C; Slater, R Neuroimaging of Pain // 2017;():485-506 Department of Paediatrics, Level 2 Children's Hospital, John Radcliffe, University of Oxford, Oxford, OX3 9DU, United Kingdom Springer International Publishing 2017 // DOI: 10.1007/978-3-319-48046-6_18	Does not utilize or assess tool
The Role of the Mental Health Practitioner in the Assessment and Treatment of Child and Adolescent Chronic Pain Leo, R J; Srinivasan, S P; Parekh, S Child and Adolescent Mental Health // 2011;16(1):2-8 Department of Psychiatry, State University of New York at Buffalo, School of Medicine and Biomedical Sciences, Erie County Medical Center, 462 Grider Street, Buffalo, NY 14215, United States 2011 // DOI: 10.1111/j.1475-3588.2010.00578.x	Does not utilize or assess tool
Development of a Functional and Emotional Measure of Dysmenorrhea (FEMD) in Chinese University Women Li, L; Huangfu, L; Chai, H; He, W; Song, H; Zou, X; Wang, W Health Care for Women International // 2012;33(2):97-108 Department of Clinical Psychology and Psychiatry, Zhejiang University School of Medicine, Zijingang Campus, Yuhangtang Road 866, Hangzhou, Zhejiang 310058, China 2012 // DOI: 10.1080/07399332.2011.603863	Not pediatric population
Assessment of chronic pain in children: Current status and emerging topics Palermo, T M Pain Research and Management // 2009;14(1):21-26 Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239, United States Hindawi Limited 2009 //	Does not utilize or assess tool

DOI: 10.1155/2009/236426	
Efficacy of Internet-delivered cognitive-behavioral therapy for the management of chronic pain in children and adolescents: A systematic review and meta-analysis Tang, W.-X.; Zhang, L.-F.; Ai, Y.-Q.; Li, Z.-S. Medicine (United States) // 2018;97(36): Department of Anaesthesiology, First Affiliated Hospital of Zhengzhou University, Longhu Road and Longxiang Seven Street Intersection, Zhengdong New District, Zhengzhou, 450000, China Lippincott Williams and Wilkins 2018	Does not utilize or assess tool
Relationship between sleep quality and nocturnal pain in ankylosing spondylitis Zhang, S.-L.; Li, Y; Zhu, J; Huang, Z.-F.; Zhang, J.-L.; Huang, F National Medical Journal of China // 2013;93(13):970-972 Department of Rheumatology, Chinese PLA General Hospital, Beijing 100853, China 2013 // DOI: 10.3760/cma.j.issn.0376-2491.2013.13.004	Not English or French
Efficacy assessment in paediatric studies Wang, S; Laitinen-Parkkonen, P Handbook of Experimental Pharmacology // 2011;205():149-168 Norwegian Medicines Agency, Tønsberg Hospital Pharmacy, Sven Oftedalsvei 6, Oslo N-0950, Norway 2011 // DOI: 10.1007/978-3-642-20195-0_7	Not an original study
Physical and social functioning in adolescents with rheumatological conditions: A study of predictors Gauntlett-Gilbert, J; Kavirayani, A; Clinch, J Acta Paediatrica, International Journal of Paediatrics // 2013;102(3):e131-e136 Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases, Bath BA1 1RL, United Kingdom 2013 // DOI: 10.1111/apa.12094	Not exclusive chronic pain population
The Young Disability Questionnaire-Spine: Item development, pilot testing and conceptualisation of a questionnaire to measure consequences of spinal pain in children Meldgaard, Emilie; Lauridsen, Henrik Hein; Hestbaek, Lise BMJ Open 2021;11(5): BMJ Publishing Group 2021 DOI: 10.1136/bmjopen-2020-045580	Does not utilize or assess tool
Psychometric Properties of the Abdominal Pain Index (API) in the Iranian Adolescent Population Hoseini, Sepideh; Jafari, Mahdi; Asl Soleimani, Zahra; Qaderi Bagajan, Kaveh; Sadeghi, Meysam; Zolfaghari, Shadi Pain Research and Management 2020;2020(): Hindawi Limited 2020 DOI: 10.1155/2020/2632139	Does not utilize or assess tool

The Pediatric American Pain Society Patient Outcomes Questionnaire (Pediatric APS-POQ): Development and Initial Psychometric Evaluation of a Brief and Comprehensive Measure of Pain and Pain Outcomes in Hospitalized Youth Kaczynski, Karen; Ely, Elizabeth; Gordon, Debra; Vincent, Catherine; Waddell, Kristi; Wittmayer, Kimberly; Bernhofer, Esther Journal of Pain 2020;21(5-6):633-647 Churchill Livingstone Inc. 2020 DOI: 10.1016/j.jpain.2019.10.003	Not chronic pain population
Feasibility of a randomized controlled trial of paediatric interdisciplinary pain management using home-based telehealth Hilyard, Anna; Kingsley, Julia; Sommerfield, David; Taylor, Susan; Bear, Natasha; Gibson, Noula Journal of Pain Research 2020;13():897-908 Dove Medical Press Ltd. 2020 DOI: 10.2147/JPR.S217022	Does not include at least one of: Tool Development or Psychometric Evaluation
Achievement goals, fear of failure and self-handicapping in young elite athletes with and without chronic pain Molenaar, Bodile; Willems, Charlotte; Verbunt, Jeanine; Goossens, Mariëlle Children 2021;8(7): MDPI AG 2021 DOI: 10.3390/children8070591	Does not utilize or assess tool
The Bath Adolescent Pain - Parental Impact Questionnaire (BAP-PIQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of parenting an adolescent with chronic pain Jordan, A; Eccleston, C; McCracken, L M; Connell, H; Clinch, J Pain // 2008;137(3):478-487 Pain Management Unit, University of Bath, Bath, BA2 7AY, United Kingdom 2008 // DOI: 10.1016/j.pain.2007.10.007	Didn't include measure on children/ youth

Tool 2: PROMIS Pediatric Pain Interference Scale (n=139 excluded citations)

Citation Excluded	**Reason for Exclusion**
Concurrent validity of the PROMIS® pediatric global health measure Forrest, C B; Tucker, C A; Ravens-Sieberer, U; Pratiwadi, R; Moon, J H; Teneralli, R E; Becker, B; Bevans, K B Quality of Life Research // 2016;25(3):739-751 2016 //	Did not utilize or asses tool

DOI: 10.1007/s11136-015-1111-7	
Psychometric Evaluation of the PROMIS (R) Pediatric Psychological and Physical Stress Experiences Measures Bevans, Katherine B; Gardner, William; Pajer, Kathleen A; Becker, Brandon; Carle, Adam; Tucker, Carole A; Forrest, Christopher B JOURNAL OF PEDIATRIC PSYCHOLOGY 07// 2018;43(6):678-692 JOURNALS DEPT, 2001 EVANS RD, CARY, NC 27513 USA OXFORD UNIV PRESS INC 2018 07// DOI: 10.1093/jpepsy/jsy010	Not chronic pain population
From the Child's Word to Clinical Intervention: Novel, New, and Innovative Approaches to Symptoms in Pediatric Palliative Care Brock, Katharine E; Wolfe, Joanne; Ullrich, Christina CHILDREN-BASEL 04// 2018;5(4): ST ALBAN-ANLAGE 66, CH-4052 BASEL, SWITZERLAND MDPI 2018 04// DOI: 10.3390/children5040045	Did not utilize or assess tool
Risk and Resilience in Pediatric Pain: The Roles of Parent and Adolescent Catastrophizing and Acceptance Feinstein, Amanda B; Sturgeon, John A; Bhandari, Rashmi P; Yoon, Isabel A; Ross, Alexandra C; Huestis, Samantha E; Griffin, Anya T; Simons, Laura E CLINICAL JOURNAL OF PAIN 12// 2018;34(12):1096-1105 TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA LIPPINCOTT WILLIAMS & WILKINS 2018 12// DOI: 10.1097/AJP.0000000000000639	Not original study
Pediatric analgesic clinical trial designs, measures, and extrapolation: Report of an FDA Scientific Workshop Berde, C B; Walco, G A; Krane, E J; Anand, K J S; Aranda, J V; Craig, K D; Dampier, C D; Finkel, J C; Grabois, M; Johnston, C; Lantos, J; Lebel, A; Maxwell, L G; McGrath, P; Oberlander, T F; Schanberg, L E; Stevens, B; Taddio, A; Von Baeyer, C L; Yaster, M; Zempsky, W T Pediatrics // 2012;129(2):354-364 2012 // DOI: 10.1542/peds.2010-3591	Did not utilize or assess tool
Pain catastrophizing is associated with poorer health-related quality of life in pediatric patients with sickle cell disease Bakshi, N; Lukombo, I; Belfer, I; Krishnamurti, L Journal of Pain Research // 2018;11():947-953 2018 //	Did not include at least one of: Tool Development or Psychometric Evaluation

DOI: 10.2147/JPR.S151198	
Psychometric evaluation of the ProMISVR pediatric psychological and physical stress experiences measures Bevans, K B; Gardner, W; Pajer, K A; Becker, B; Carle, A; Tucker, C A; Forrest, C B Journal of Pediatric Psychology // 2018;43(6):678-692 2018 // DOI: 10.1093/jpepsy/jsy010	Not chronic pain population
The PROMIS initiative: Involvement of rehabilitation stakeholders in development and examples of applications in rehabilitation research Amtmann, D; Cook, K F; Johnson, K L; Cella, D Archives of Physical Medicine and Rehabilitation // 2011;92(10 SUPPL.):S12-S19 2011 // DOI: 10.1016/j.apmr.2011.04.025	Not pediatric population
Implementation of electronic patient reported outcomes in pediatric daily clinical practice: The KLIK experience Haverman, L; Van Oers, H A; Limperg, P F; Hijmans, C T; Schepers, S A; Sint Nicolaas, S M; Verhaak, C M; Bouts, A H M; Fijnvandraat, K; Peters, M; Van Rossum, M A; Van Goudoever, J B; Maurice-Stam, H; Grootenhuis, M A Clinical Practice in Pediatric Psychology // 2014;2(1):50-67 2014 // DOI: 10.1037/cpp0000043	Did not utilize or assess tool
Implementation of a Mental Health Screening Program in a Pediatric Tertiary Care Setting Herbert, L; Hardy, S Clinical Pediatrics // 2019;58(10):1078-1084 2019 // DOI: 10.1177/0009922819862613	Did not utilize or assess tool
Responsiveness to Change in PROMIS® Measures among Children with Asthma: A Report from the PROMIS® Pediatric Asthma Study Howell, C R; Thompson, L A; Gross, H E; Reeve, B B; Dewalt, D A; Huang, I.-C. Value in Health // 2016;19(2):192-201 2016 // DOI: 10.1016/j.jval.2015.12.004	Not chronic pain population
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Gipson, D S; Selewski, D T; Massengill, S F; Wickman, L; Messer, K L; Herreshoff, E; Corinna, B; Ferris, M E; Mahan, J D; Greenbaum, L A; MacHardy, J; Kapur, G; Chand, D H; Goebel, J; Barletta, G M; Geary, D; Kershaw, D B; Pan, C G; Gbadegesin, R; Hidalgo, G; Lane, J C; Leiser, J D; Plattner, B W; Song, P X; Thissen, D; Liu, Y; Gross, H E; DeWalt, D A Health and Quality of Life Outcomes // 2013;11(1): 2013 // DOI: 10.1186/1477-7525-11-30	
Evaluating PROMIS® instruments and methods for patient-centered outcomes research: Patient and provider voices in a substance use treatment setting Johnston, K L; Lawrence, S M; Dodds, N E; Yu, L; Daley, D C; Pilkonis, P A Quality of Life Research // 2016;25(3):615-624 2016 // DOI: 10.1007/s11136-015-1131-3	Did not utilize or assess tool
Pain as a quality of care measure in juvenile idiopathic arthritis: One step forward, but is it the best foot? Comment on the article by Lovell et al Connelly, M; Von Baeyer, C L; Stinson, J; Schanberg, L E Arthritis Care and Research // 2011;63(9):1352-1353 2011 // DOI: 10.1002/acr.20515	Not an original study
Importance ratings on patient-reported outcome items for survivorship care: comparison between pediatric cancer survivors, parents, and clinicians Jones, C M; Baker, J N; Keesey, R M; Eliason, R J; Lanctot, J Q; Clegg, J L; Mandrell, B N; Ness, K K; Krull, K R; Srivastava, D; Forrest, C B; Hudson, M M; Robison, L L; Huang, I.-C. Quality of Life Research // 2018;27(7):1877-1884 2018 // DOI: 10.1007/s11136-018-1854-z	Does not include at least one of: Tool Development or Psychometric Evaluation
Impaired Patient-Reported Outcomes Predict Poor School Functioning and Daytime Sleepiness: The PROMIS Pediatric Asthma Study Jones, C M; DeWalt, D A; Huang, I.-C. Academic Pediatrics // 2017;17(8):850-854 2017 // DOI: 10.1016/j.acap.2017.07.010	Not chronic pain population
Patient Reported Outcomes Measurement Information System and Quality of Life in Neurological Disorders Measurement System to Evaluate Quality of Life for Children and Adolescents with Neurofibromatosis Type 1 Associated Plexiform Neurofibroma	Does not include at least one of: Tool Development or Psychometric Evaluation

Lai, J.-S.; Jensen, S E; Charrow, J; Listernick, R Journal of Pediatrics // 2019;206():190-196 2019 // DOI: 10.1016/j.jpeds.2018.10.019	
A ResearchKit app to deliver paediatric electronic consent: Protocol of an observational study in adolescents with arthritis Lalloo, C; Pham, Q; Cafazzo, J; Stephenson, E; Stinson, J Contemporary Clinical Trials Communications // 2020;17(): 2020 // DOI: 10.1016/j.conctc.2020.100525	Not an original study
Construction of the eight-item patient-reported outcomes measurement information system pediatric physical function scales: Built using item response theory Dewitt, E M; Stucky, B D; Thissen, D; Irwin, D E; Langer, M; Varni, J W; Lai, J.-S.; Yeatts, K B; Dewalt, D A Journal of Clinical Epidemiology // 2011;64(7):794-804 2011 // DOI: 10.1016/j.jclinepi.2010.10.012	Does not utilize or assess tool
PROMIS pediatric Anger scale: An item response theory analysis Irwin, D E; Stucky, B D; Langer, M M; Thissen, D; DeWitt, E M; Lai, J.-S.; Yeatts, K B; Varni, J W; De Walt, D A Quality of Life Research // 2012;21(4):697-706 2012 // DOI: 10.1007/s11136-011-9969-5	Does not utilize or assess tool
PedsQL gastrointestinal symptoms module item development: Qualitative methods Varni, J W; Kay, M T; Limbers, C A; Franciosi, J P; Pohl, J F Journal of Pediatric Gastroenterology and Nutrition // 2012;54(5):664-671 2012 // DOI: 10.1097/MPG.0b013e31823c9b88	Does not utilize or assess tool
Promoting psychological flexibility in parents of adolescents with chronic pain: Pilot study of an 8-week group intervention Wallace, D P; Woodford, B; Connelly, M Clinical Practice in Pediatric Psychology // 2016;4(4):405-416 2016 // DOI: 10.1037/cpp0000160	Does not include at least one of: Tool Development or Psychometric Evaluation

A systematic review of pediatric self-report symptom measures: Congruence with the theory of unpleasant symptoms von Sadovszky, V; Christensen, E; Jennings, B M; Miller, S; Hosley, S; Drought, L; Lenz, E R Journal for Specialists in Pediatric Nursing // 2018;23(2): 2018 // DOI: 10.1111/jspn.12215	Not an original study
Integrating the Concept of Pain Interference into Pain Management Wilson, M Pain Management Nursing // 2014;15(2):499-505 2014 // DOI: 10.1016/j.pmn.2011.06.004	Not an original study
Psychometric properties of the brief pain inventory modified for proxy report of pain interference in children with cerebral palsy with and without cognitive impairment Barney, C C; Stibb, S M; Merbler, A M; Summers, R L S; Deshpande, S; Krach, L E; Symons, F J Pain Reports // 2018;3(4): 2018 // DOI: 10.1097/PR9.0000000000000666	Does not utilize or assess tool
Quantitative sensory testing is feasible and is well-tolerated in patients with sickle cell disease following a vaso-occlusive episode Bakshi, N; Lukombo, I; Belfer, I; Krishnamurti, L Journal of Pain Research // 2018;11():435-443 2018 // DOI: 10.2147/JPR.S150066	Does not include at least one of: Tool Development or Psychometric Evaluation
Psychological Characteristics and Pain Frequency Are Associated With Experimental Pain Sensitivity in Pediatric Patients With Sickle Cell Disease Bakshi, N; Lukombo, I; Shnol, H; Belfer, I; Krishnamurti, L Journal of Pain // 2017;18(10):1216-1228 2017 // DOI: 10.1016/j.jpain.2017.05.005	Does not include at least one of: Tool Development or Psychometric Evaluation
The CALI-9: A brief measure for assessing activity limitations in children and adolescents with chronic pain Holley, A L; Zhou, C; Wilson, A C; Hainsworth, K; Palermo, T M Pain // 2018;159(1):48-56 2018 //	Does not utilize or assess tool

DOI: 10.1097/j.pain.0000000000001063	
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Maternal Protective Parenting Accounts for the Relationship between Pain Behaviors and Functional Disability in Adolescents Lynch-Jordan, A M; Peugh, J; Cunningham, N R; Trygier, J R; Kashikar-Zuck, S Clinical Journal of Pain // 2018;34(12):1089-1095 2018 // DOI: 10.1097/AJP.0000000000000638	Does not utilize or assess tool
Measuring musculoskeletal pain in infants, children, and adolescents Michaleff, Z A; Kamper, S J; Stinson, J N; Hestbaek, L; Williams, C M; Campbell, P; Dunn, K M Journal of Orthopaedic and Sports Physical Therapy // 2017;47(10):712-730 2017 // DOI: 10.2519/jospt.2017.7469	Not an original study
Development of a computer-adaptive physical function instrument for social security administration disability determination Ni, P; McDonough, C M; Jette, A M; Bogusz, K; Marfeo, E E; Rasch, E K; Brandt, D E; Meterko, M; Haley, S M; Chan, L Archives of Physical Medicine and Rehabilitation // 2013;94(9):1661-1669 2013 // DOI: 10.1016/j.apmr.2013.03.021	Did not utilize or assess tool
PedsQL™ sickle cell disease module: Feasibility, reliability, and validity Panepinto, J A; Torres, S; Bendo, C B; Mccavit, T L; Dinu, B; Sherman-Bien, S; Bemrich-Stolz, C; Varni, J W Pediatric Blood and Cancer // 2013;60(8):1338-1344 2013 // DOI: 10.1002/pbc.24491	Did not utilize or assess tool
The emotional distress of children with cancer in China: an item response analysis of C-Ped-PROMIS Anxiety and Depression short forms Liu, Y; Wang, J; Hinds, P S; Shen, N; Zhao, X; Ding, J; Yuan, C Quality of Life Research // 2015;24(6):1491-1501	Did not utilize or assess tool

2015 // DOI: 10.1007/s11136-014-0870-x	
Late Effects Screening Guidelines after Hematopoietic Cell Transplantation (HCT) for Hemoglobinopathy: Consensus Statement from the Second Pediatric Blood and Marrow Transplant Consortium International Conference on Late Effects after Pediatric HCT Shenoy, S; Gaziev, J; Angelucci, E; King, A; Bhatia, M; Smith, A; Bresters, D; Haight, A E; Duncan, C N; de la Fuente, J; Dietz, A C; Baker, K S; Pulsipher, M A; Walters, M C Biology of Blood and Marrow Transplantation // 2018;24(7):1313-1321 2018 // DOI: 10.1016/j.bbmt.2018.04.002	Did not utilize or assess tool
IACT - An interactive mHealth monitoring system to enhance psychotherapy for adolescents with sickle cell disease Cheng, C; Brown, R C; Cohen, L L; Venugopalan, J; Stokes, T H; Wang, M D Proceedings of the Annual International Conference of the IEEE Engineering in Medicine and Biology Society, EMBS // 2013;():2279-2282 2013 // DOI: 10.1109/EMBC.2013.6609992	Does not include at least one of: Tool Development or Psychometric Evaluation
SickleREMOTE: A two-way text messaging system for pediatric sickle cell disease patients Cheng, C; Brown, C; New, T; Stokes, T H; Dampier, C; Wang, M D Proceedings - IEEE-EMBS International Conference on Biomedical and Health Informatics: Global Grand Challenge of Health Informatics, BHI 2012 // 2012;():408-411 2012 // DOI: 10.1109/BHI.2012.6211602	Does not include at least one of: Tool Development or Psychometric Evaluation
Health-Related Quality of Life Components in Children With Neonatal Brachial Plexus Palsy: A Qualitative Study Chang, K.W.-C.; Austin, A; Yeaman, J; Phillips, L; Kratz, A; Yang, L.J.-S.; Carlozzi, N E PM and R // 2017;9(4):383-391 2017 // DOI: 10.1016/j.pmrj.2016.08.002	Does not utilize or assess tool
Safety of Active Rehabilitation for Persistent Symptoms After Pediatric Sport-Related Concussion: A Randomized Controlled Trial Chan, C; Iverson, G L; Purtzki, J; Wong, K; Kwan, V; Gagnon, I; Silverberg, N D Archives of Physical Medicine and Rehabilitation // 2018;99(2):242-249 2018 //	Does not utilize or assess tool

DOI: 10.1016/j.apmr.2017.09.108	
Availability of researcher-led eHealth tools for pain assessment and management: Barriers, facilitators, costs, and design Higgins, K S; Tutelman, P R; Chambers, C T; Witteman, H O; Barwick, M; Corkum, P; Grant, D; Stinson, J N; Lalloo, C; Robins, S; Orji, R; Jordan, I Pain Reports // 2018;3(7): 2018 // DOI: 10.1097/PR9.0000000000000686	Not an original study
Testing the Feasibility and Psychometric Properties of a Mobile Diary (myWHI) in Adolescents and Young Adults With Headaches Huguet, Anna; McGrath, Patrick J; Wheaton, Michael; Mackinnon, Sean P; Rozario, Sharlene; Tougas, Michelle E; Stinson, Jennifer N; MacLean, Cathy JMIR MHEALTH AND UHEALTH // 2015;3(2): 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA JMIR PUBLICATIONS, INC 2015 // DOI: 10.2196/mhealth.3879	Does not utilize or assess tool
Using Rasch rating scale model to reassess the psychometric properties of the Persian version of the PedsQL TM 4.0 Generic Core Scales in school children Jafari, P; Bagheri, Z; Ayatollahi, S M T; Soltani, Z Health and Quality of Life Outcomes // 2012;10(): 2012 // DOI: 10.1186/1477-7525-10-27	Does not utilize or assess tool
Development and Evaluation of the PROMISA (R) Pediatric Positive Affect Item Bank, Child-Report and Parent-Proxy Editions Forrest, Christopher B; Ravens-Sieberer, Ulrike; Devine, Janine; Becker, Brandon D; Teneralli, Rachel E; Moon, JeanHee; Carle, Adam C; Tucker, Carole A; Bevans, Katherine B JOURNAL OF HAPPINESS STUDIES 03// 2018;19(3):699-718 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2018 03// DOI: 10.1007/s10902-016-9843-9	Duplicate
No Title ;():	Cannot locate full text
Pain assessment using the NIH Toolbox Cook, Karon F; Dunn, Winnie; Griffith, James W; Morrison, M Tracy; Tanquary, Jennifer; Sabata, Dory; Victorson, David; Carey, Leeanne M; MacDermid, Joy C; Dudgeon, Brian J; Gershon, Richard C NEUROLOGY 03// 2013;80(3):S49-S53	Not an original study

TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA LIPPINCOTT WILLIAMS & WILKINS 2013 03// DOI: 10.1212/WNL.0b013e3182872e80	
PROMIS pediatric peer relationships scale: Development of a peer relationships item bank as part of social health measurement DeWalt, D A; Thissen, D; Stucky, B D; Langer, M M; DeWitt, E M; Irwin, D E; Lai, J.-S.; Yeatts, Karin B; Gross, H E; Taylor, O; Varni, J W Health Psychology // 2013;32(10):1093-1103 2013 // DOI: 10.1037/a0032670	Does not utilize or assess tool
Concurrent validity of the PROMISA (R) pediatric global health measure Forrest, Christopher B; Tucker, Carole A; Ravens-Sieberer, Ulrike; Pratiwadi, Ramya; Moon, JeanHee; Teneralli, Rachel E; Becker, Brandon; Bevans, Katherine B QUALITY OF LIFE RESEARCH 03// 2016;25(3):739-751 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2016 03// DOI: 10.1007/s11136-015-1111-7	Duplicate
Quantifying 'problematic' DIF within an IRT framework: application to a cancer stigma index Edelen, M O; Stucky, B D; Chandra, A Quality of Life Research // 2015;24(1):95-103 2015 // DOI: 10.1007/s11136-013-0540-4	Does not utilize or assess tool
PedsQL eosinophilic esophagitis module: Feasibility, reliability, and validity Franciosi, J P; Hommel, K A; Bendo, C B; King, E C; Collins, M H; Eby, M D; Marsolo, K; Abonia, J P; Von Tiehl, K F; Putnam, P E; Greenler, A J; Greenberg, A B; Bryson, R A; Davis, C M; Olive, A P; Gupta, S K; Erwin, E A; Klinnert, M D; Spergel, J M; Denham, J M; Furuta, G T; Rothenberg, M E; Varni, J W Journal of Pediatric Gastroenterology and Nutrition // 2013;57(1):57-66 2013 // DOI: 10.1097/MPG.0b013e31828f1fd2	Does not utilize or assess tool
Symptoms and quality of life indicators among children with chronic medical conditions Kim, J; Chung, H; Amtmann, D; Salem, R; Park, R; Askew, R L Disability and Health Journal // 2014;7(1):96-104 2014 // DOI: 10.1016/j.dhjo.2013.08.007	Does not utilize or assess tool
Quality assessment of ophthalmic questionnaires: Review and recommendations Khadka, J; McAlinden, C; Pesudovs, K	Does not utilize or assess tool

Optometry and Vision Science // 2013;90(8):720-744 2013 // DOI: 10.1097/OPX.0000000000000001	
Development of a mHealth Real-Time Pain Self-Management App for Adolescents With Cancer: An Iterative Usability Testing Study Jibb, L A; Cafazzo, J A; Nathan, P C; Seto, E; Stevens, B J; Nguyen, C; Stinson, J N Journal of Pediatric Oncology Nursing // 2017;34(4):283-294 2017 // DOI: 10.1177/1043454217697022	Does not utilize or assess tool
A scoping review of pain in children after traumatic brain injury: Is there more than headache? Kwan, V; Vo, M; Noel, M; Yeates, K Journal of Neurotrauma // 2018;35(7):877-888 2018 // DOI: 10.1089/neu.2017.5281	Not an original study
Validation of the Sickle Cell Disease Pain Burden Interview-Youth Zempsky, William T; O'hara, Emily A; Santanelli, James P; Palermo, Tonya M; New, Tamara; Smith-Whitley, Kim; Casella, James F // 2013;(): 2013 // DOI: 10.1016/j.jpain.2013.03.007	Does not include at least one of: Tool Development or Psychometric Evaluation
Factorial invariance of pediatric patient self-reported fatigue across age and gender: A multigroup confirmatory factor analysis approach utilizing the PedsQLTM Multidimensional Fatigue Scale Varni, J W; Beaujean, A A; Limbers, C A Quality of Life Research // 2013;22(9):2581-2594 2013 // DOI: 10.1007/s11136-013-0370-4	Does not utilize or assess tool
Development of the pediatric quality of life inventory neurofibromatosis type 1 module items for children, adolescents and young adults: qualitative methods Nutakki, K; Varni, J W; Steinbrenner, S; Draucker, C B; Swigonski, N L Journal of Neuro-Oncology // 2017;132(1):135-143 2017 // DOI: 10.1007/s11060-016-2351-2	Does not utilize or assess tool
PedsQL gastrointestinal symptoms module: Feasibility, reliability, and validity	Does not utilize or assess tool

Varni, J W; Bendo, C B; Denham, J; Shulman, R J; Self, M M; Neigut, D A; Nurko, S; Patel, A S; Franciosi, J P; Saps, M; Verga, B; Smith, A; Yeckes, A; Heinz, N; Langseder, A; Saeed, S; Zacur, G M; Pohl, J F Journal of Pediatric Gastroenterology and Nutrition // 2014;59(3):347-355 2014 // DOI: 10.1097/MPG.0000000000000414	
A qualitative study of the impact of cancer on romantic relationships, sexual relationships, and fertility: Perspectives of Canadian adolescents and parents during and after treatment Stinson, J N; Jibb, L A; Greenberg, M; Barrera, M; Luca, S; White, M E; Gupta, A Journal of Adolescent and Young Adult Oncology // 2015;4(2):84-90 2015 // DOI: 10.1089/jayao.2014.0036	Does not utilize or assess tool
An observational study of patient versus parental perceptions of health-related quality of life in children and adolescents with a chronic pain condition: who should the clinician believe? Vetter, T R; Bridgewater, C L; McGwin Jr, G Health and Quality of Life Outcomes // 2012;10(): 2012 // DOI: 10.1186/1477-7525-10-85	Does not utilize or assess tool
Somatosensory test responses and physical and psychological functioning of children and adolescents with chronic non-neuropathic pain: An exploratory study Lim, S W; Gunaratne, Y; Jaaniste, T; McCormick, M; Champion, D Clinical Journal of Pain // 2017;33(2):116-125 2017 // DOI: 10.1097/AJP.0000000000000385	Does not include at least one of: Tool Development or Psychometric Evaluation
Application of item response theory to tests of substance-related associative memory Shono, Y; Grenard, J L; Ames, S L; Stacy, A W Psychology of Addictive Behaviors // 2014;28(3):852-862 2014 // DOI: 10.1037/a0035877	Does not utilize or assess tool
Applying the patient-reported outcomes measurement information system to assess upper extremity function among children with congenital hand differences Waljee, J F; Carlozzi, N; Franzblau, L E; Zhong, L; Chung, K C Plastic and Reconstructive Surgery // 2015;136(2):200e-207e 2015 //	Does not utilize or assess tool

DOI: 10.1097/PRS.0000000000001444	
Accelerating the drug delivery pipeline for acute and chronic pancreatitis-knowledge gaps and research opportunities: Overview summary of a National Institute of Diabetes and Digestive and Kidney Diseases workshop Uc, A; Andersen, D K; Borowitz, D; Glesby, M J; Mayerle, J; Sutton, R; Pandol, S J Pancreas // 2018;47(10):1180-1184 2018 // DOI: 10.1097/MPA.0000000000001176	Does not utilize or assess tool
Developing Item Response Theory–Based Short Forms to Measure the Social Impact of Burn Injuries Marino, M E; Dore, E C; Ni, P; Ryan, C M; Schneider, J C; Acton, A; Jette, A M; Kazis, L E Archives of Physical Medicine and Rehabilitation // 2018;99(3):521-528 2018 // DOI: 10.1016/j.apmr.2017.06.037	Do not utilize or assess tool
Stigma and Pain in Adolescents Hospitalized for Sickle Cell Vasoocclusive Pain Episodes Martin, S R; Cohen, L L; Mougianis, I; Griffin, A; Sil, S; Dampier, C Clinical Journal of Pain // 2018;34(5):438-444 2018 // DOI: 10.1097/AJP.0000000000000553	Does not include at least one of: Tool Development or Psychometric Evaluation
Comparing the predictive value of task performance and task-specific sensitivity during physical function testing among people with knee osteoarthritis Wideman, T H; Edwards, R R; Finan, P H; Haythornthwaite, J A; Smith, M T Journal of Orthopaedic and Sports Physical Therapy // 2016;46(5):346-356 2016 // DOI: 10.2519/jospt.2016.6311	Does not utilize or assess tool
A high preoperative pain and symptom profile predicts worse pain outcomes for children after spine fusion surgery Voepel-Lewis, T; Caird, M S; Tait, A R; Malviya, S; Farley, F A; Li, Y; Abbott, M D; Van Veen, T; Hassett, A L; Clauw, D J Anesthesia and Analgesia // 2017;124(5):1594-1602 2017 // DOI: 10.1213/ANE.0000000000001963	Does not include at least one of: Tool Development or Psychometric Evaluation
Development of the PedsQL (TM) sickle cell disease module items: qualitative methods Panepinto, Julie A; Torres, Sylvia; Varni, James W	Does not utilize or assess tool

QUALITY OF LIFE RESEARCH 03// 2012;21(2):341-357 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2012 03// DOI: 10.1007/s11136-011-9941-4	
Evaluating PROMISA (R) instruments and methods for patient-centered outcomes research: Patient and provider voices in a substance use treatment setting Johnston, Kelly L; Lawrence, Suzanne M; Dodds, Nathan E; Yu, Lan; Daley, Dennis C; Pilkonis, Paul A QUALITY OF LIFE RESEARCH 03// 2016;25(3):615-624 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2016 03// DOI: 10.1007/s11136-015-1131-3	Duplicate
A method to create a standardized generic and condition-specific patient-reported outcome measure for patient care and healthcare improvement Schifferdecker, K E; Yount, S E; Kaiser, K; Adachi-Mejia, A; Cella, D; Carluzzo, K L; Eisenstein, A; Kallen, M A; Greene, G J; Eton, D T; Fisher, E S Quality of Life Research // 2018;27(2):367-378 2018 // DOI: 10.1007/s11136-017-1675-5	Not chronic pain population
Longitudinal associations among asthma control, sleep problems, and health-related quality of life in children with asthma: A report from the PROMIS® Pediatric Asthma Study Li, Z; Thompson, L A; Gross, H E; Shenkman, E A; Reeve, B B; DeWalt, D A; Huang, I.-C. Sleep Medicine // 2016;20():41-50 2016 // DOI: 10.1016/j.sleep.2015.12.003	Not chronic pain population
Promising insights into the health related quality of life for children with severe obesity Selewski, D T; Collier, D N; MacHardy, J; Gross, H E; Pickens, E M; Cooper, A W; Bullock, S; Earls, M F; Pratt, K J; Scanlon, K; McNeill, J D; Messer, K L; Lu, Y; Thissen, D; DeWalt, D A; Gipson, D S Health and Quality of Life Outcomes // 2013;11(1): 2013 // DOI: 10.1186/1477-7525-11-29	Not chronic pain population
Acute and Chronic Pain in Children and Adolescents With Cerebral Palsy: Prevalence, Interference, and Management Ostojic, K; Paget, S; Kyriagis, M; Morrow, A Archives of Physical Medicine and Rehabilitation // 2020;101(2):213-219 2020 //	Does not include at least one of: Tool Development or Psychometric Evaluation

DOI: 10.1016/j.apmr.2019.08.475	
Screening and assessment of chronic pain among children with cerebral palsy: a process evaluation of a pain toolbox Orava, T; Provvidenza, C; Townley, A; Kingsnorth, S Disability and Rehabilitation // 2019;41(22):2695-2703 2019 // DOI: 10.1080/09638288.2018.1471524	Not an original study
Development of a Smartphone Application to Monitor Pediatric Patient-Reported Outcomes Wang, J; Yao, N A; Liu, Y; Geng, Z; Wang, Y; Shen, N; Zhang, X; Shen, M; Yuan, C CIN - Computers Informatics Nursing // 2017;35(11):590-598 2017 // DOI: 10.1097/CIN.0000000000000357	Not chronic pain population
HABIT efficacy and sustainability trial, a multi-center randomized controlled trial to improve hydroxyurea adherence in youth with sickle cell disease: A study protocol Smaldone, A; Manwani, D; Aygun, B; Smith-Whitley, K; Jia, H; Bruzzese, J.-M.; Findley, S; Massei, J; Green, N S BMC Pediatrics // 2019;19(1): 2019 // DOI: 10.1186/s12887-019-1746-6	Not an original study
Psychological Interventions for Headache in Children and Adolescents Sieberg, Christine B; Huguet, Anna; von Baeyer, Carl L; Seshia, Shashi S CANADIAN JOURNAL OF NEUROLOGICAL SCIENCES 01// 2012;39(1):26-34 32 AVENUE OF THE AMERICAS, NEW YORK, NY 10013-2473 USA CAMBRIDGE UNIV PRESS 2012 01// DOI: 10.1017/S0317167100012646	Not an original study
Establishing clinical meaning and defining important differences for Patient-Reported Outcomes Measurement Information System (PROMISA (R)) measures in juvenile idiopathic arthritis using standard setting with patients, parents, and providers Morgan, Esi M; Mara, Constance A; Huang, Bin; Barnett, Kimberly; Carle, Adam C; Farrell, Jennifer E; Cook, Karon F QUALITY OF LIFE RESEARCH 03// 2017;26(3):565-586 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2017 03// DOI: 10.1007/s11136-016-1468-2	Duplicate
Subjective well-being measures for children were developed within the PROMIS project: Presentation of first results Ravens-Sieberer, U; Devine, J; Bevans, K; Riley, A W; Moon, J; Salsman, J M; Forrest, C B	Does not utilize or assess tool

Journal of Clinical Epidemiology // 2014;67(2):207-218 2014 // DOI: 10.1016/j.jclinepi.2013.08.018	
The impact of disease duration on quality of life in children with nephrotic syndrome: a Midwest Pediatric Nephrology Consortium study Selewski, D T; Troost, J P; Massengill, S F; Gbadegesin, R A; Greenbaum, L A; Shatat, I F; Cai, Y; Kapur, G; Hebert, D; Somers, M J; Trachtman, H; Pais, P; Seifert, M E; Goebel, J; Sethna, C B; Mahan, J D; Gross, H E; Herreshoff, E; Liu, Y; Song, P X; Reeve, B B; DeWalt, D A; Gipson, D S Pediatric Nephrology // 2015;30(9):1467-1476 2015 // DOI: 10.1007/s00467-015-3074-x	Not chronic pain population
Responsiveness of the PROMIS® measures to changes in disease status among pediatric nephrotic syndrome patients: A Midwest pediatric nephrology consortium study Selewski, D T; Troost, J P; Cummings, D; Massengill, S F; Gbadegesin, R A; Greenbaum, L A; Shatat, I F; Cai, Y; Kapur, G; Hebert, D; Somers, M J; Trachtman, H; Pais, P; Seifert, M E; Goebel, J; Sethna, C B; Mahan, J D; Gross, H E; Herreshoff, E; Liu, Y; Carlozzi, N E; Reeve, B B; DeWalt, D A; Gipson, D S Health and Quality of Life Outcomes // 2017;15(1): 2017 // DOI: 10.1186/s12955-017-0737-2	Not chronic pain population
Developing a standardized approach to the assessment of pain in children and youth presenting to pediatric rheumatology providers: A Delphi survey and consensus conference process followed by feasibility testing Stinson, J N; Connelly, M; Jibb, L A; Schanberg, L E; Walco, G; Spiegel, L R; Tse, S M L; Chalom, E C; Chira, P; Rapoff, M Pediatric Rheumatology // 2012;10(): 2012 // DOI: 10.1186/1546-0096-10-7	Does not utilize or assess tool
Using the PedsQLTM 3.0 asthma module to obtain scores comparable with those of the PROMIS pediatric asthma impact scale (PAIS) Thissen, D; Varni, J W; Stucky, B D; Liu, Y; Irwin, D E; DeWalt, D A Quality of Life Research // 2011;20(9):1497-1505 2011 // DOI: 10.1007/s11136-011-9874-y	Does not utilize or assess tool
Using Logistic Approximations of Marginal Trace Lines to Develop Short Assessments Stucky, B D; Thissen, D; Orlando Edelen, M	Not an original study

Applied Psychological Measurement // 2013;37(1):41-57 2013 // DOI: 10.1177/0146621612462759	
Using PROMIS® to create clinically meaningful profiles of nephrotic syndrome patients Troost, J P; Gipson, D S; Carlozzi, N E; Reeve, B B; Nachman, P H; Gbadegesin, R; Wang, J; Modersitzki, F; Massengill, S; Mahan, J D; Liu, Y; Trachtman, H; Herreshoff, E G; Dewalt, D A; Selewski, D T Health Psychology // 2019;38(5):410-421 2019 // DOI: 10.1037/hea0000679	Not chronic pain population
TBI-QOL: Development and calibration of item banks to measure patient reported outcomes following traumatic brain injury Tulsky, D S; Kisala, P A; Victorson, D; Carlozzi, N; Bushnik, T; Sherer, M; Choi, S W; Heinemann, A W; Chiaravalloti, N; Sander, A M; Englander, J; Hanks, R; Kolakowsky-Hayner, S; Roth, E; Gershon, R; Rosenthal, M; Cella, D Journal of Head Trauma Rehabilitation // 2016;31(1):40-51 2016 // DOI: 10.1097/HTR.0000000000000131	Does not utilize or assess tool
Feasibility of a randomized controlled trial of paediatric interdisciplinary pain management using home-based telehealth Hilyard, Anna; Kingsley, Julia; Sommerfield, David; Taylor, Susan; Bear, Natasha; Gibson, Noula Journal of Pain Research 2020;13():897-908 Dove Medical Press Ltd. 2020 DOI: 10.2147/JPR.S217022	Does not utilize or assess tool
The Epidemiology of Back Pain in American Children and Adolescents Fabricant, Peter D.; Heath, Madison R.; Schachne, Jonathan M.; Doyle, Shevaun M.; Green, Daniel W.; Widmann, Roger F. Spine 2020;45(16):1135-1142 Lippincott Williams and Wilkins 2020 DOI: 10.1097/BRS.0000000000003461	Not chronic pain population
Dutch–Flemish translation of nine pediatric item banks from the Patient-Reported Outcomes Measurement Information System (PROMIS)® Haverman, L; Grootenhuis, M A; Raat, H; van Rossum, M A J; van Dulmen-den Broeder, E; Hoppenbrouwers, K; Correia, H; Cella, D; Roorda, L D; Terwee, C B Quality of Life Research // 2016;25(3):761-765 2016 // DOI: 10.1007/s11136-015-0966-y	Is a translation article

Disclosure and self-report of emotional, social, and physical health in children and adolescents with chronic pain - A qualitative study of PROMIS pediatric measures Jacobson, C J; Farrell, J E; Kashikar-Zuck, S; Seid, M; Verkamp, E; Dewitt, E M Journal of Pediatric Psychology // 2013;38(1):82-93 2013 // DOI: 10.1093/jpepsy/jss099	Qualitative study
PROMIS pediatric measures in pediatric oncology: Valid and clinically feasible indicators of patient-reported outcomes Hinds, P S; Nuss, S L; Ruccione, K S; Withycombe, J S; Jacobs, S; Deluca, H; Faulkner, C; Liu, Y; Cheng, Y I; Gross, H E; Wang, J; Dewalt, D A Pediatric Blood and Cancer // 2013;60(3):402-408 2013 // DOI: 10.1002/pbc.24233	Not chronic pain population
Chinese Version of Pediatric Patient-Reported Outcomes Measurement Information System Short Form Measures Reliability, Validity, and Factorial Structure Assessment in Children With Cancer in China Liu, Yanyan; Yuan, Changrong; Wang, Jichuan; Shen, Nanping; Shen, Min; Hinds, Pamela S CANCER NURSING // 2019;42(6):430-438 TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA LIPPINCOTT WILLIAMS & WILKINS 2019 // DOI: 10.1097/NCC.0000000000000633	Not chronic pain population
Psychometric evaluation of the pediatric and parent-proxy Patient-Reported Outcomes Measurement Information System and the Neurology and Traumatic Brain Injury Quality of Life measurement item banks in pediatric traumatic brain injury Bertisch, H; Rivara, F P; Kisala, P A; Wang, J; Yeates, K O; Durbin, D; Zonfrillo, M R; Bell, M J; Temkin, N; Tulsky, D S Quality of Life Research // 2017;26(7):1887-1899 2017 // DOI: 10.1007/s11136-017-1524-6	Not chronic pain population
Feasibility and acceptability of the patient-reported outcomes measurement information system measures in children and adolescents in active cancer treatment and survivorship Menard, J C; Hinds, P S; Jacobs, S S; Cranston, K; Wang, J; DeWalt, D A; Gross, H E Cancer Nursing // 2014;37(1):66-74 2014 // DOI: 10.1097/NCC.0b013e3182a0e23d	Not chronic pain population

The Validity of Patient-reported Outcome Measurement Information System (PROMIS) Parent Proxy Instruments to Assess Function in Children with Talipes Equinovarus Masrouha, K Z; Moses, M J; Sala, D A; Litrenta, J; Lehman, W B; Chu, A Journal of Pediatric Orthopaedics // 2019;39(10):E787-E790 2019 // DOI: 10.1097/BPO.0000000000001368	Not chronic pain population
Comparative Effectiveness Research and Children with Cerebral Palsy: Identifying a Conceptual Framework and Specifying Measures Gannotti, M E; Law, M; Bailes, A F; O'Neil, M E; Williams, U; Direzze, B Pediatric Physical Therapy // 2016;28(1):58-69 2016 // DOI: 10.1097/PEP.0000000000000203	Not chronic pain population
Comparability of the Patient-Reported Outcomes Measurement Information System Pediatric short form symptom measures across culture: examination between Chinese and American children with cancer Liu, Y; Yuan, C; Wang, J; Brown, J G; Zhou, F; Zhao, X; Shen, M; Hinds, P S Quality of Life Research // 2016;25(10):2523-2533 2016 // DOI: 10.1007/s11136-016-1312-8	Not chronic pain population
Gaining the Patient Reported Outcomes Measurement Information System (PROMIS) perspective in chronic kidney disease: a Midwest Pediatric Nephrology Consortium study Selewski, D T; Massengill, S F; Troost, J P; Wickman, L; Messer, K L; Herreshoff, E; Bowers, C; Ferris, M E; Mahan, J D; Greenbaum, L A; MacHardy, J; Kapur, G; Chand, D H; Goebel, J; Barletta, G M; Geary, D; Kershaw, D B; Pan, C G; Gbadegesin, R; Hidalgo, G; Lane, J C; Leiser, J D; Song, P X; Thissen, D; Liu, Y; Gross, H E; DeWalt, D A; Gipson, D S Pediatric Nephrology // 2014;29(12):2347-2356 2014 // DOI: 10.1007/s00467-014-2858-8	Not chronic pain population
Clinical meaning of PROMIS pain domains for children with sickle cell disease Singh, A; Panepinto, J A Blood Advances // 2019;3(15):2244-2249 2019 // DOI: 10.1182/bloodadvances.2019000381	Not exclusive chronic pain population
Translation and cross-cultural adaptation of eight pediatric PROMIS® item banks into Spanish and German Devine, J; Klasen, F; Moon, J; Herdman, M; Hurtado, M P; Castillo, G; Haller, A C; Correia, H; Forrest, C B; Ravens-Sieberer, U	Is a translation article

Quality of Life Research // 2018;27(9):2415-2430 2018 // DOI: 10.1007/s11136-018-1874-8	
Patient-Reported Outcomes Measurement Information System Tools for Collecting Patient-Reported Outcomes in Children With Juvenile Arthritis Brandon, T G; Becker, B D; Bevans, K B; Weiss, P F Arthritis Care and Research // 2017;69(3):393-402 2017 // DOI: 10.1002/acr.22937	Not exclusive chronic pain population
PROMIS® pediatric self-report scales distinguish subgroups of children within and across six common pediatric chronic health conditions DeWalt, D A; Gross, H E; Gipson, D S; Selewski, D T; DeWitt, E M; Dampier, C D; Hinds, P S; Huang, I.-C.; Thissen, D; Varni, J W Quality of Life Research // 2015;24(9):2195-2208 2015 // DOI: 10.1007/s11136-015-0953-3	Not exclusive chronic pain population
Patterns of symptoms and functional impairments in children with cancer Buckner, T W; Wang, J; Dewalt, D A; Jacobs, S; Reeve, B B; Hinds, P S Pediatric Blood and Cancer // 2014;61(7):1282-1288 2014 // DOI: 10.1002/pbc.25029	Not exclusive chronic pain population
Pain location and widespread pain in youth with orthopaedic conditions: Exploration of the reliability and validity of a body map Foxen-Craft, E; Scott, E L; Kullgren, K A; Philliben, R; Hyman, C; Dorta, M; Murphy, A; Voepel-Lewis, T European Journal of Pain (United Kingdom) // 2019;23(1):57-65 2019 // DOI: 10.1002/ejp.1282	Not exclusive chronic pain population
Development and Evaluation of the PROMIS® Pediatric Positive Affect Item Bank, Child-Report and Parent-Proxy Editions Forrest, C B; Ravens-Sieberer, U; Devine, J; Becker, B D; Teneralli, R E; Moon, J H; Carle, A C; Tucker, C A; Bevans, K B Journal of Happiness Studies // 2018;19(3):699-718 2018 // DOI: 10.1007/s10902-016-9843-9	Not exclusive chronic pain population

Validation of Patient-Reported Outcomes Measurement Information System Short Forms for Use in Childhood-Onset Systemic Lupus Erythematosus Jones, J T; Carle, A C; Wootton, J; Liberio, B; Lee, J; Schanberg, L E; Ying, J; Morgan DeWitt, E; Brunner, H I Arthritis Care and Research // 2017;69(1):133-142 2017 // DOI: 10.1002/acr.22927	Not exclusive chronic pain population
``Asking Too Much?{"}: Randomized N-of-1 Trial Exploring Patient Preferences and Measurement Reactivity to Frequent Use of Remote Multidimensional Pain Assessments in Children and Young People With Juvenile Idiopathic Arthritis Lee, Rebecca Rachael; Shoop-Worrall, Stephanie; Rashid, Amir; Thomson, Wendy; Cordingley, Lis JOURNAL OF MEDICAL INTERNET RESEARCH 01// 2020;22(1): 130 QUEENS QUAY E, STE 1102, TORONTO, ON M5A 0P6, CANADA JMIR PUBLICATIONS, INC 2020 01// DOI: 10.2196/14503	Not exclusive chronic pain population
Translation and linguistic validation of the pediatric patient-reported outcomes measurement information system measures into simplified chinese using cognitive interviewing methodology Liu, Y; Hinds, P S; Wang, J; Correia, H; Du, S; Ding, J; Gao, W J; Yuan, C Cancer Nursing // 2013;36(5):368-376 2013 // DOI: 10.1097/NCC.0b013e3182962701	Is a translation article
Assessing responsiveness over time of the PROMIS® pediatric symptom and function measures in cancer, nephrotic syndrome, and sickle cell disease Reeve, B B; Edwards, L J; Jaeger, B C; Hinds, P S; Dampier, C; Gipson, D S; Selewski, D T; Troost, J P; Thissen, D; Barry, V; Gross, H E; DeWalt, D A Quality of Life Research // 2018;27(1):249-257 2018 // DOI: 10.1007/s11136-017-1697-z	Not exclusive chronic pain population
Integration of Electronic Patient-Reported Outcomes (ePROs) into pediatric clinic settings across hematology/oncology/bone marrow transplant Myrvik, M P; Beverung, L M; Panepinto, J A; Igler, E C; Englebert, N; Bingen, K M Clinical Practice in Pediatric Psychology // 2014;2(1):39-49 2014 // DOI: 10.1037/cpp0000052	Not exclusive chronic pain population

Establishing clinical meaning and defining important differences for Patient-Reported Outcomes Measurement Information System (PROMIS®) measures in juvenile idiopathic arthritis using standard setting with patients, parents, and providers Morgan, E M; Mara, C A; Huang, B; Barnett, K; Carle, A C; Farrell, J E; Cook, K F Quality of Life Research // 2017;26(3):565-586 2017 // DOI: 10.1007/s11136-016-1468-2	Not exclusive chronic pain population
Qualitative Evaluation of Pediatric Pain Behavior, Quality, and Intensity Item Candidates and the PROMIS Pain Domain Framework in Children with Chronic Pain Jacobson Jr., C J; Kashikar-Zuck, S; Farrell, J; Barnett, K; Goldschneider, K; Dampier, C; Cunningham, N; Crosby, L; Dewitt, E M Journal of Pain // 2015;16(12):1243-1255 Department of Anthropology, University of Cincinnati, College of Arts and Sciences, Cincinnati, OH, United States Churchill Livingstone Inc. 2015 // DOI: 10.1016/j.jpain.2015.08.007	Qualitative study
Initial Evaluation of the Pediatric PROMIS® Health Domains in Children and Adolescents With Sickle Cell Disease Dampier, C; Barry, V; Gross, H E; Lui, Y; Thornburg, C D; Dewalt, D A; Reeve, B B Pediatric Blood and Cancer // 2016;63(6):1031-1037 2016 // DOI: 10.1002/pbc.25944	Not exclusive chronic pain population
Differential item functioning in the Patient Reported Outcomes Measurement Information System Pediatric Short Forms in a sample of children and adolescents with cerebral palsy Coster, W J; Ni, P; Slavin, M D; Kisala, P A; Nandakumar, R; Mulcahey, M J; Tulsky, D S; Jette, A M Developmental Medicine and Child Neurology // 2016;58(11):1132-1138 2016 // DOI: 10.1111/dmcn.13138	Not exclusive chronic pain population
Development of six PROMIS pediatrics proxy-report item banks Irwin, D E; Gross, H E; Stucky, B D; Thissen, D; DeWitt, E M; Lai, J S; Amtmann, D; Khastou, L; Varni, J W; DeWalt, D A Health and Quality of Life Outcomes // 2012;10(): 2012 // DOI: 10.1186/1477-7525-10-22	Not exclusive chronic pain population
Estimating minimally important difference (MID) in PROMIS pediatric measures using the scale-judgment method	Not exclusive chronic pain population

Thissen, D; Liu, Y; Magnus, B; Quinn, H; Gipson, D S; Dampier, C; Huang, I.-C.; Hinds, P S; Selewski, D T; Reeve, B B; Gross, H E; DeWalt, D A Quality of Life Research // 2016;25(1):13-23 2016 // DOI: 10.1007/s11136-015-1058-8	
The use of PROMIS and assessment center to deliver Patient-Reported Outcome Measures in clinical research Gershon, R C; Rothrock, N; Hanrahan, R; Bass, M; Cella, D Journal of Applied Measurement // 2010;11(3):304-314 2010 //	Not exclusive chronic pain population
Parental Proxy PROMIS Pain Interference Scores are only Modestly Concordant with Their Child's Scores: An Effect of Child Catastrophizing Scott, E L; Foxen-Craft, E; Caird, M; Philliben, R; Desebour, T; Currier, E; Voepel-Lewis, T Clinical Journal of Pain // 2020;36(1):1-7 2020 // DOI: 10.1097/AJP.0000000000000772	Not exclusive chronic pain population
Psychometric properties of the PROMIS® pediatric scales: Precision, stability, and comparison of different scoring and administration options Varni, J W; Magnus, B; Stucky, B D; Liu, Y; Quinn, H; Thissen, D; Gross, H E; Huang, I.-C.; Dewalt, D A Quality of Life Research // 2014;23(4):1233-1243 2014 // DOI: 10.1007/s11136-013-0544-0	Not exclusive chronic pain population
The role of trait mindfulness in the pain experience of adolescents Petter, M; Chambers, C T; McGrath, P J; Dick, B D Journal of Pain // 2013;14(12):1709-1718 2013 // DOI: 10.1016/j.jpain.2013.08.015	Not exclusive chronic pain population
Item-level informant discrepancies between children and their parents on the PROMIS® pediatric scales Varni, J W; Thissen, D; Stucky, B D; Liu, Y; Magnus, B; He, J; DeWitt, E M; Irwin, D E; Lai, J.-S.; Amtmann, D; DeWalt, D A Quality of Life Research // 2015;24(8):1921-1937 2015 // DOI: 10.1007/s11136-014-0914-2	Not exclusive chronic pain population

PROMIS Pediatric Pain Interference Scale: An Item Response Theory Analysis of the Pediatric Pain Item Bank Varni, James W; Stucky, Brian D; Thissen, David; Dewitt, Esi Morgan; Irwin, Debra E; Lai, Jin-Shei; Yeatts, Karin; Dewalt, Darren A Journal of Pain // 2010;11(11):1109-1119 2010 // DOI: 10.1016/j.jpain.2010.02.005	Not exclusive chronic pain population
Item-level informant discrepancies between children and their parents on the PROMISA (R) pediatric scales Varni, James W; Thissen, David; Stucky, Brian D; Liu, Yang; Magnus, Brooke; He, Jason; DeWitt, Esi Morgan; Irwin, Debra E; Lai, Jin-Shei; Amtmann, Dagmar; DeWalt, Darren A QUALITY OF LIFE RESEARCH 08// 2015;24(8):1921-1937 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2015 08// DOI: 10.1007/s11136-014-0914-2	Does not utilize or assess tool
Using item response theory to enrich and expand the PROMIS® pediatric self report banks Quinn, H; Thissen, D; Liu, Y; Magnus, B; Lai, J.-S.; Amtmann, D; Varni, J W; Gross, H E; DeWalt, D A Health and Quality of Life Outcomes // 2014;12(1): 2014 // DOI: 10.1186/s12955-014-0160-x	Not exclusive chronic pain population
PROMIS® parent proxy report scales for children ages 5-7 years: An item response theory analysis of differential item functioning across age groups Varni, J W; Thissen, D; Stucky, B D; Liu, Y; Magnus, B; Quinn, H; Irwin, D E; Dewitt, E M; Lai, J.-S.; Amtmann, D; Gross, H E; Dewalt, D A Quality of Life Research // 2014;23(1):349-361 2014 // DOI: 10.1007/s11136-013-0439-0	Not exclusive chronic pain population
PROMIS® parent proxy report scales: An item response theory analysis of the parent proxy report item banks Varni, J W; Thissen, D; Stucky, B D; Liu, Y; Gorder, H; Irwin, D E; DeWitt, E M; Lai, J.-S.; Amtmann, D; DeWalt, D A Quality of Life Research // 2012;21(7):1223-1240 2012 // DOI: 10.1007/s11136-011-0025-2	Not exclusive chronic pain population

Psychometric properties of the PROMISA (R) pediatric scales: precision, stability, and comparison of different scoring and administration options Varni, James W; Magnus, Brooke; Stucky, Brian D; Liu, Yang; Quinn, Hally; Thissen, David; Gross, Heather E; Huang, I-Chan; DeWalt, Darren A QUALITY OF LIFE RESEARCH 05// 2014;23(4):1233-1243 VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS SPRINGER 2014 05// DOI: 10.1007/s11136-013-0544-0	Not exclusive chronic pain population
The Adolescent Knee Pain (AK-Pain) prognostic tool: protocol for a prospective cohort study Andreucci, Alessandro; Holden, Sinead; Bach Jensen, Martin; Skovdal Rathleff, Michael F1000Research 2019;8():2148-2148 F1000 Research Ltd 2019 DOI: 10.12688/f1000research.21740.1	Does not utilize or assess tool
Using nationally representative percentiles to interpret PROMIS pediatric measures Carle, Adam C.; Bevans, Katherine B.; Tucker, Carole A.; Forrest, Christopher B. Quality of Life Research 2021;30(4):997-1004 Springer Science and Business Media Deutschland GmbH 2021 DOI: 10.1007/s11136-020-02700-5	Not exclusive chronic pain population
Parent cognitive, behavioural, and affective factors and their relation to child pain and functioning in pediatric chronic pain: A systematic review and meta-analysis Donnelly, Theresa J.; Palermo, Tonya M.; Newton-John, Toby R.O. Pain 2020;161(7):1401-1419 Lippincott Williams and Wilkins 2020 DOI: 10.1097/j.pain.0000000000001833	Not an original study
Towards an Effective Patient Health Engagement System Using Cloud-Based Text Messaging Technology Cheng, Chih Wen; Brown, Clark R.; Venugopalan, Janani; Wang, May D. IEEE Journal of Translational Engineering in Health and Medicine 2020;8(): Institute of Electrical and Electronics Engineers Inc. 2020 DOI: 10.1109/JTEHM.2018.2868358	Not exclusive chronic pain population
Randomized clinical trial of Fibromyalgia Integrative Training (FIT teens) for adolescents with juvenile fibromyalgia – Study design and protocol	Not exclusive chronic pain population

Kashikar-Zuck, Susmita; Briggs, Matthew S.; Bout-Tabaku, Sharon; Connelly, Mark; Daffin, Morgan; Guite, Jessica; Ittenbach, Richard; Logan, Deirdre E.; Lynch-Jordan, Anne M.; Myer, Gregory D.; Ounpuu, Sylvia; Peugh, James; Schikler, Kenneth; Sugimoto, Dai; Stinson, Jennifer N.; Ting, Tracy V.; Thomas, Staci; Williams, Sara E.; Zempsky, William Contemporary Clinical Trials 2021;103(): Elsevier Inc. 2021 DOI: 10.1016/j.cct.2021.106321	
Risk models for predicting the health-related quality of life of caregivers of youth with gastrointestinal concerns Lynch, Mary K.; Thompson, Kathryn A.; Dimmitt, Reed A.; Barnes, Margaux J.; Goodin, Burel R. Quality of Life Research 2020;29(12):3343-3351 Springer Science and Business Media Deutschland GmbH 2020 DOI: 10.1007/s11136-020-02601-7	Not exclusive chronic pain population
Pain and internalizing symptoms in youth with gastrointestinal conditions including recurrent abdominal pain, eosinophilic esophagitis, and gastroesophageal reflux disease Lynch, Mary K.; Thompson, Kathryn A.; Dimmitt, Reed A.; Barnes, Margaux J.; Goodin, Burel R. Children's Health Care 2021;50(1):28-43 Routledge 2021 DOI: 10.1080/02739615.2020.1810575	Not exclusive chronic pain population
Natural Language Processing and Machine Learning Methods to Characterize Unstructured Patient-Reported Outcomes: Validation Study Lu, Zhaohua; Sim, Jin-ah; Wang, Jade X; Forrest, Christopher B; Krull, Kevin R; Srivastava, Deokumar; Hudson, Melissa M; Robison, Leslie L; Baker, Justin N; Huang, I-Chan Journal of Medical Internet Research 2021;23(11):e26777-e26777 JMIR Publications Inc. 2021 DOI: 10.2196/26777	Not exclusive chronic pain population
Development and Psychometric Evaluation of the PROMIS Pediatric Pain Intensity Measure in Children and Adolescents with Chronic Pain Mara, Constance A.; Kashikar-Zuck, Susmita; Cunningham, Natoshia; Goldschneider, Kenneth R.; Huang, Bin; Dampier, Carlton; Sherry, David D.; Crosby, Lori; Farrell Miller, Jennifer; Barnett, Kimberly; Morgan, Esi M. Journal of Pain 2021;22(1):48-56 Churchill Livingstone Inc. 2021 DOI: 10.1016/j.jpain.2020.04.001	Not exclusive chronic pain population
Utility of the PROMIS pediatric pain interference scale in juvenile fibromyalgia Fussner, L M; Black, W R; Lynch-Jordan, A; Morgan, E M; Ting, T V; Kashikar-Zuck, S	Not exclusive chronic pain population

Journal of Pediatric Psychology // 2019;44(4):436-441 2019 // DOI: 10.1093/jpepsy/jsy110	
Development and validation of the self-reported PROMIS pediatric pain behavior item bank and short form scale Cunningham, Natoshia R.; Kashikar-Zuck, Susmita; Mara, Constance; Goldschneider, Kenneth R.; Revicki, Dennis A.; Dampier, Carlton; Sherry, David D.; Crosby, Lori; Carle, Adam; Cook, Karon F.; Morgan, Esi M. PAIN 07// 2017;158(7):1323-1331 2017 07// DOI: 10.1097/j.pain.0000000000000914	Not exclusive chronic pain population
Pediatric chronic postsurgical pain and functional disability: A prospective study of risk factors up to one year after major surgery Rosenbloom, B N; Pagé, M G; Isaac, L; Campbell, F; Stinson, J N; Wright, J G; Katz, J Journal of Pain Research // 2019;12():3079-3098 2019 // DOI: 10.2147/JPR.S210594	Not pediatric population

Tool 3 Child Activity Limitations Questionnaire (n=23 citations excluded)

Chronic non-cancer pain in children: We have a problem, but also solutions Vega, E; Beaulieu, Y; Gauvin, R; Ferland, C; Stabile, S; Pitt, R; Gonzalez Cardenas, V H; Ingelmo, P M Minerva Anestesiologica // 2018;84(9):1081-1092 Chronic Pain Service, Department of Anesthesia, Montreal Children's Hospital, McGill University Health Center, 1001 Boulevard Decarie, Montreal, QC H4A 3J1, Canada Edizioni Minerva Medica 2018 // DOI: 10.23736/S0375-9393.18.12367-4	Does not utilize or assess tool
Chronic pain assessment tools for cerebral palsy: A systematic review Kingsnorth, S; Orava, T; Provvidenza, C; Adler, E; Ami, N; Gresley-Jones, T; Mankad, D; Slonim, N; Fay, L; Joachimides, N; Hoffman, A; Hung, R; Fehlings, D Pediatrics // 2015;136(4):e947-e960 Evidence to Care, Holland Bloorview Kids Rehabilitation Hospital, 150 Kilgour Rd, Toronto, ON M4G 1R8, Canada American Academy of Pediatrics 2015 // DOI: 10.1542/peds.2015-0273	Not an original study
Chronic Pain Assessments in Children and Adolescents: A Systematic Literature Review of the Selection, Administration, Interpretation, and Reporting of Unidimensional Pain Intensity Scales Lee, R R; Rashid, A; Ghio, D; Thomson, W; Cordingley, L	Does not utilize or assess tool

Pain Research and Management // 2017;2017(): NIHR Manchester Biomedical Research Centre, Central Manchester University Hospitals NHS Foundation Trust, Manchester Academic Health Science Centre, University of Manchester, Manchester, M139PT, United Kingdom Hindawi Limited 2017 // DOI: 10.1155/2017/7603758	
Predicting parent health-related quality of life: evaluating conceptual models Defenderfer, E K; Rybak, T M; Davies, W H; Berlin, K S Quality of Life Research // 2017;26(6):1405-1415 Psychology Department, University of Wisconsin-Milwaukee, 2441 E Hartford Ave., 413, Milwaukee, WI 53201, United States Springer International Publishing 2017 // DOI: 10.1007/s11136-016-1491-3	Not exclusive chronic pain population
School functioning and chronic pain: A review of Method s and measures Gorodzinsky, A Y; Hainsworth, K R; Weisman, S J Journal of Pediatric Psychology // 2011;36(9):991-1002 Department of Psychology, University of Wisconsin-Milwaukee, Milwaukee, WI 53211, United States 2011 // DOI: 10.1093/jpepsy/jsr038	Does not utilize or assess tool
Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology Palermo, T M; Long, A C; Lewandowski, A S; Drotar, D; Quittner, A L; Walker, L S Journal of Pediatric Psychology // 2008;33(9):983-996 Oregon Health and Science University 2008 // DOI: 10.1093/jpepsy/jsn038	Not an original study
Patient versus parental perceptions about pain and disability in children and adolescents with a variety of chronic pain conditions Vetter, T R; Bridgewater, C L; Ascherman, L I; Madan-Swain, A; McGwin Jr., G L Pain Research and Management // 2014;19(1):7-14 Department of Anesthesiology, University of Alabama, School of Medicine, 619 19th Street South, Birmingham, AL 35249-6810, United States Hindawi Limited 2014 // DOI: 10.1155/2014/736053	Does not utilize or assess tool
Pain perception of adolescents with chronic functional pain. Adaptation and psychometric validation of the pain perception scale (SES) by geissner Wager, J; Tietze, A.-L.; Denecke, H; Schroeder, S; Vocks, S; Kosfelder, J; Zernikow, B; Hechler, T Schmerz // 2010;24(3):236-250 Vodafone Stiftungsinstitut und Lehrst. fur Kinderschmerztherapie und Padiatrische Pallia-Tivmedizin, Vestische Kinder- und Jugendklinik Datteln, Universität Witten/Herdecke, Dr.-Friedrich-Steiner Str. 5, 45711 Datteln, Germany 2010 //	Not English or French

DOI: 10.1007/s00482-010-0920-4	
Measuring adolescents' HRQoL via self reports and parent proxy reports: An evaluation of the psychometric properties of both versions of the KINDL-R instrument Erhart, M; Ellert, U; Kurth, B.-M.; Ravens-Sieberer, U Health and Quality of Life Outcomes // 2009;7():77-77 Child Public Health, Department of Psychosomatics in Children and Adolescents, University Medical Center Hamburg-Eppendorf, Martinistr 52, D-20246 Hamburg, Germany 2009 // DOI: 10.1186/1477-7525-7-77	Does not utilize or assess tool
Utility of the PROMIS pediatric pain interference scale in juvenile fibromyalgia Fussner, L M; Black, W R; Lynch-Jordan, A; Morgan, E M; Ting, T V; Kashikar-Zuck, S Journal of Pediatric Psychology // 2019;44(4):436-441 2019 // DOI: 10.1093/jpepsy/jsy110	Does not utilize or assess tool
Pain-related disability in adolescents suffering from chronic pain: Preliminary examination of the Pediatric Pain Disability Index (P-PDI) Hübner, B; Hechler, T; Dobe, M; Damschen, U; Kosfelder, J; Denecke, H; Schroeder, S; Zernikow, B Schmerz // 2009;23(1):20-32 Vodafone Stiftungsinstitut für Kinderschmerztherapie und Pädiatrische Palliativmedizin, Vestische Kinder- und Jugendklinik Datteln, Universität Witten/Herdecke, Datteln 2009 // DOI: 10.1007/s00482-008-0730-0	Not English or French
The prevalence, impact and cost of chronic non-cancer pain in Irish primary schoolchildren (PRIME-C): Protocol for a longitudinal school-based survey O'Higgins, S; Doherty, E; NicGabhainn, S; Murphy, A; Hogan, M; O'Neill, C; McGuire, B E BMJ Open // 2015;5(5): Centre for Pain Research, School of Psychology, National University of Ireland, Galway, Ireland BMJ Publishing Group 2015 // DOI: 10.1136/bmjopen-2014-007426	Does not utilize or assess tool
Bidirectional associations between pain and physical activity in adolescents Rabbitts, J A; Holley, A L; Karlson, C W; Palermo, T M Clinical Journal of Pain // 2014;30(3):251-258 Department of Anesthesiology and Pain Medicine, Seattle Children's Hospital and University of Washington School of Medicine, 4800 Sand Point Way NE, Seattle, WA 98105, United States 2014 // DOI: 10.1097/AJP.0b013e31829550c6	Does not utilize or assess tool
Pain assessment-can it be done with a computerised system? A systematic review and meta-analysis	Not an original study

Pombo, N; Garcia, N; Bousson, K; Spinsante, S; Chorbev, I International Journal of Environmental Research and Public Health // 2016;13(4): Instituto de Telecomunicações (Telecommunications Institute), University of Beira Interior, Covilhã, 6200-001, Portugal MDPI AG 2016 // DOI: 10.3390/ijerph13040415	
PROMIS Pediatric Pain Interference Scale: An Item Response Theory Analysis of the Pediatric Pain Item Bank Varni, James W; Stucky, Brian D; Thissen, David; Dewitt, Esi Morgan; Irwin, Debra E; Lai, Jin-Shei; Yeatts, Karin; Dewalt, Darren A Journal of Pain // 2010;11(11):1109-1119 2010 // DOI: 10.1016/j.jpain.2010.02.005	Does not utilize or assess tool
The Effect of Pain Catastrophizing on Outcomes: A Developmental Perspective Across Children, Adolescents, and Young Adults With Chronic Pain Feinstein, A B; Sturgeon, J A; Darnall, B D; Dunn, A L; Rico, T; Kao, M C; Bhandari, R P Journal of Pain // 2017;18(2):144-154 2017 // DOI: 10.1016/j.jpain.2016.10.009	Does not utilize or assess tool
Co-occurring chronic pain and obesity in children and adolescents: The impact on health-related quality of life Hainsworth, K R; Davies, W H; Khan, K A; Weisman, S J Clinical Journal of Pain // 2009;25(8):715-721 Medical College of Wisconsin, United States Lippincott Williams and Wilkins 2009 // DOI: 10.1097/AJP.0b013e3181a3b689	Does not utilize or assess tool
The Contribution of Parent and Family Variables to the Well-Being of Youth With Arthritis Knafl, K; Leeman, J; Havill, N L; Crandell, J L; Sandelowski, M Journal of Family Nursing // 2015;21(4):579-616 University of North Carolina, Chapel Hill, United States SAGE Publications Inc. 2015 // DOI: 10.1177/1074840715601475	Not an original study
The CALI-9: A brief measure for assessing activity limitations in children and adolescents with chronic pain Holley, A L; Zhou, C; Wilson, A C; Hainsworth, K; Palermo, T M Pain // 2018;159(1):48-56 2018 //	Does not utilize or assess tool

DOI: 10.1097/j.pain.0000000000001063	
Validation of a self-report questionnaire version of the Child Activity Limitations Interview (CALI): The CALI-21 Palermo, T M; Lewandowski, A S; Long, A C; Burant, C J Pain // 2008;139(3):644-652 Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239-3098, United States 2008 // DOI: 10.1016/j.pain.2008.06.022	Does not utilize or assess tool
Parent Pain Responses as Predictors of Daily Activities and Mood in Children with Juvenile Idiopathic Arthritis: The Utility of Electronic Diaries Connelly, M; Anthony, K K; Sarniak, R; Bromberg, M H; Gil, K M; Schanberg, L E Journal of Pain and Symptom Management // 2010;39(3):579-590 Children's Mercy Hospitals and Clinics, Kansas City, MO, United States 2010 // DOI: 10.1016/j.jpainsymman.2009.07.013	Not exclusive chronic pain population
Use of smartphones to prospectively evaluate predictors and outcomes of caregiver responses to pain in youth with chronic disease Connelly, M; Bromberg, M H; Anthony, K K; Gil, K M; Schanberg, L E Pain // 2017;158(4):629-636 Division of Developmental and Behavioral Sciences, Children's Mercy Hospital, 2401 Gillham Rd, Kansas City, MO 64108, United States Lippincott Williams and Wilkins 2017 // DOI: 10.1097/j.pain.0000000000000804	Not exclusive chronic pain population
Quantitative sensory testing in adolescents with co-occurring chronic pain and obesity: A pilot study Hainsworth, Keri R.; Simpson, Pippa M.; Ali, Omar; Varadarajan, Jaya; Rusy, Lynn; Weisman, Steven J. Children 2020;7(6): MDPI 2020 DOI: 10.3390/children7060055	Does not utilize or assess tool

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Cortical correlates of an attentional bias to painful and innocuous somatic stimuli in children with recurrent abdominal pain Hermann, C; Zohsel, K; Hohmeister, J; Flor, H Pain // 2008;136(3):397-406	Does not utilize or assess tool

Department of Clinical and Cognitive Neuroscience, University of Heidelberg, Central Institute of Mental Health, Square J5, D-68159 Mannheim, Germany 2008 // DOI: 10.1016/j.pain.2008.01.007	
Social risk and resilience factors in adolescent chronic pain: Examining the role of parents and Peers Ross, A C; Simons, L E; Feinstein, A B; Yoon, I A; Bhandari, R P Journal of Pediatric Psychology // 2018;43(3):303-313 2018 // DOI: 10.1093/jpepsy/jsx118	Does not utilize or assess tool
Toward a taxonomy of adolescents with chronic pain: Exploratory cluster and discriminant analyses of the bath adolescent pain questionnaire Vowles, K E; Jordan, A; Eccleston, C European Journal of Pain // 2010;14(2):214-221 Centre for Pain Research, School for Health, University of Bath, Norwood House, Claverton Down, Bath BA2 7AY, United Kingdom 2010 // DOI: 10.1016/j.ejpain.2009.05.004	Does not utilize or assess tool
Assessment of chronic pain in children: Current status and emerging topics Palermo, T M Pain Research and Management // 2009;14(1):21-26 Department of Anesthesiology and Peri-Operative Medicine, Oregon Health and Science University, 3181 SW Sam Jackson Park Road, Portland, OR 97239, United States Hindawi Limited 2009 // DOI: 10.1155/2009/236426	Not an original study
Measuring musculoskeletal pain in infants, children, and adolescents Michaleff, Z A; Kamper, S J; Stinson, J N; Hestbaek, L; Williams, C M; Campbell, P; Dunn, K M Journal of Orthopaedic and Sports Physical Therapy // 2017;47(10):712-730 2017 // DOI: 10.2519/jospt.2017.7469	Not an original study
Medication usage, emotional disturbance, and pain behavior in chronic low back pain patients McCreary, C; Colman, A Journal of Clinical Psychology // 1984;40(1):15-19 U. C. L. A. School of Medicine, United States 1984 // DOI: 10.1002/1097-4679(198401)40:1<15::AID-JCLP2270400103>3.0.CO;2-J	Does not utilize or assess tool
Racial and ethnic disparities in cancer pain management. Stephenson, N; Dalton, J A; Carlson, J; Youngblood, R; Bailey, D	Does not utilize or assess tool

Journal of National Black Nurses' Association : JNBNA // 2009;20(1):11-18 East Carolina University College of Nursing, Greenville, NC, USA. 2009 //	
Assessment of pain anxiety, pain catastrophizing, and fear of pain in children and adolescents with chronic pain: A systematic review and meta-analysis Fisher, E; Heathcote, L C; Eccleston, C; Simons, L E; Palermo, T M Journal of Pediatric Psychology // 2018;43(3):314-325 Center for Child Health, Behavior, and Development, Seattle Children's Research Institute, Seattle, WA, United States Oxford University Press 2018 // DOI: 10.1093/jpepsy/jsx103	Does not utilize or assess tool
The roles of ethnicity, sex, and parental pain modeling in rating of experienced and imagined pain events Boissoneault, J; Bunch, J R; Robinson, M Journal of Behavioral Medicine // 2015;38(5):809-816 Pain Research and Intervention Center of Excellence, University of Florida, Gainesville, FL, United States Springer New York LLC 2015 // DOI: 10.1007/s10865-015-9650-5	Not exclusive chronic pain population
Development and preliminary validation of the child pain anxiety symptoms scale in a community sample Pagé, M G; Fuss, S; Martin, A L; Escobar, E M R; Katz, J Journal of Pediatric Psychology // 2010;35(10):1071-1082 Department of Psychology, BSB 232, York University, 4700 Keele Street, Toronto, ON M3J 1P3, Canada 2010 // DOI: 10.1093/jpepsy/jsq034	Does not utilize or assess tool
Disentangling the complex relations among caregiver and adolescent responses to adolescent chronic pain Vowles, K E; Cohen, L L; McCracken, L M; Eccleston, C Pain // 2010;151(3):680-686 Interdisciplinary Musculoskeletal Pain Assessment and Community Treatment Service, Haywood Hospital, Keele University, Stoke-on-Trent, United Kingdom 2010 // DOI: 10.1016/j.pain.2010.08.031	Does not utilize or assess tool
What do pain scales measure in patients with rheumatoid arthritis? Curio, I; Scholz, O B Der Schmerz // 1990;4(4):207-213 Psychologisches Institut Lehrstuhl für Klinische, und Angewandte Psychologie der Universität, Römerstraße 164, Bonn 1, W-5300, Germany Springer-Verlag 1990 // DOI: 10.1007/BF02527905	Not English or French

Paediatric chronic pain Rolfe, P M Anaesthesia and Intensive Care Medicine // 2019;20(10):539-542 NHS Foundation Trust, United Kingdom Elsevier Ltd 2019 // DOI: 10.1016/j.mpaic.2019.07.010	Not an original study
Somatic pain sensitivity in children with recurrent abdominal pain Zohsel, K; Hohmeister, J; Flor, H; Hermann, C American Journal of Gastroenterology // 2008;103(6):1517-1523 Department of Clinical and Cognitive Neuroscience, University of Heidelberg, Central Institute of Mental Health, Mannheim, Germany 2008 // DOI: 10.1111/j.1572-0241.2008.01911.x	Does not include at least one of: Tool Development and/ or Psychometric Evaluation
The impact of parental gender, catastrophizing and situational threat upon parental behaviour to child pain: A vignette study Goubert, L; Vervoort, T; De Ruddere, L; Crombez, G European Journal of Pain (United Kingdom) // 2012;16(8):1176-1184 Department of Experimental-Clinical and Health Psychology, Ghent University, Belgium 2012 // DOI: 10.1002/j.1532-2149.2012.00116.x	Does not utilize or assess tool
Dyadic analysis of child and parent trait and state pain catastrophizing in the process of children's pain communication Birnie, K A; Chambers, C T; Chorney, J; Fernandez, C V; McGrath, P J Pain // 2016;157(4):938-948 Department of Psychology and Neuroscience, Dalhousie University, Halifax, NS, Canada Lippincott Williams and Wilkins 2016 // DOI: 10.1097/j.pain.0000000000000461	Does not utilize or assess tool
Chronic postsurgical pain in children: Prevalence and risk factors. A prospective observational study Batoz, H; Semjen, F; Bordes-Demolis, M; Bnard, A; Nouette-Gaulain, K British Journal of Anaesthesia // 2016;117(4):489-496 CHU de Bordeaux, Service d'Anesthsie Ṕdiatrique, Hôpital Pellegrin, Place Aḿlie Raba Ĺon, Bordeaux, F-33076, France Oxford University Press 2016 // DOI: 10.1093/bja/aew260	Does not utilize or assess tool
Pain and its Impact on the Functional Ability in Children Treated at the Children's Cancer Center of Lebanon Madi, D; Clinton, M Journal of Pediatric Nursing // 2018;39():e11-e20	Does not utilize or assess tool

Hariri School of Nursing, American University of Beirut, Hamra-Bliss Street, Beirut, Lebanon W.B. Saunders 2018 // DOI: 10.1016/j.pedn.2017.12.004	
Rasch Analysis of the Arabic Language Version of the Functional Disability Inventory Madi, Dina; Clinton, Michael Journal of Pediatric Oncology Nursing // 2015;32(4):230-239 Los Angeles, CA 2015 // DOI: 10.1177/1043454214554010	Does not utilize or assess tool
Anxiety, coping, and disability: A test of mediation in a pediatric chronic pain sample Kaczynski, K J; Simons, L E; Claar, R L Journal of Pediatric Psychology // 2011;36(8):932-941 Pain Treatment Service, Children's Hospital, Boston, 300 Longwood Ave, Boston, MA 02115, United States 2011 // DOI: 10.1093/jpepsy/jsr024	Does not utilize or assess tool
Evaluation of Psychometric and Linguistic Properties of the Italian Adolescent Pain Assessment Scales: A Systematic Review Marti, Flavio; Paladini, Antonella; Varrassi, Giustino; Latina, Roberto PAIN AND THERAPY 06// 2018;7(1):77-104 GEWERBESTRASSE 11, CHAM, CH-6330, SWITZERLAND SPRINGER INTERNATIONAL PUBLISHING AG 2018 06// DOI: 10.1007/s40122-018-0093-x	Not an original study
Age-related differences among adults coping with pain: Evaluation of a developmental life-context model Lachapelle, D L; Hadjistavropoulos, T Canadian Journal of Behavioural Science // 2005;37(2):123-137 University of New Brunswick, Canada American Psychological Association Inc. 2005 // DOI: 10.1037/h0087250	Does not utilize or assess tool
Influence of culture on cancer pain management in hispanic patients Juarez, G; Ferrell, B; Borneman, T Cancer Practice // 1998;6(5):262-269 City of Hope National Medical Center, Duarte, CA, United States 1998 // DOI: 10.1046/j.1523-5394.1998.00020.x	Does not utilize or assess tool
The relationship between pain experience with mindfulness and psychological hardiness in chronic patients Shaykh, Ameneh; Anvari, Najla MEDICAL SCIENCE // 2018;22(93):468-472	Does not utilize or assess tool

KANYAKUMARI DISTRICT, TAMILNADU, 00000, INDIA DISCOVERY PUBLICATION 2018 //	
Sex Differences in Prior Pain Experience Stutts, L A; McCulloch, R C; Chung, K; Robinson, M E Journal of Pain // 2009;10(12):1226-1230 Center for Pain Research and Behavioral Health, Department of Clinical and Health Psychology, University of Florida, PO Box 100165, Gainesville, FL 32610-0165, United States 2009 // DOI: 10.1016/j.jpain.2009.04.016	Does not utilize or assess tool
Parent cognitive, behavioural, and affective factors and their relation to child pain and functioning in pediatric chronic pain: A systematic review and meta-analysis Donnelly, Theresa J.; Palermo, Tonya M.; Newton-John, Toby R.O. Pain 2020;161(7):1401-1419 Lippincott Williams and Wilkins 2020 DOI: 10.1097/j.pain.0000000000001833	Not an original study

Tool 5 Pain Interference Index (n=217 citations excluded)

Patient-reported outcomes of pain and physical functioning in neurofibromatosis clinical trials Wolters, P L; Martin, S; Merker, V L; Tonsgard, J H; Solomon, S E; Baldwin, A; Bergner, A L; Walsh, K; Thompson, H L; Gardner, K L; Hingtgen, C M; Schorry, E; Dudley, W N; Franklin, B Neurology // 2016;87(7):S4-S12 Pediatric Oncology Branch, National Cancer Institute, National Institutes of Health, Bethesda, MD, United States Lippincott Williams and Wilkins 2016 // DOI: 10.1212/WNL.0000000000002927	Not an original study
Anxiety, coping, and disability: A test of mediation in a pediatric chronic pain sample Kaczynski, K J; Simons, L E; Claar, R L Journal of Pediatric Psychology // 2011;36(8):932-941 Pain Treatment Service, Children's Hospital, Boston, 300 Longwood Ave, Boston, MA 02115, United States 2011 // DOI: 10.1093/jpepsy/jsr024	Does not utilize or assess tool
Latent Class Analysis of the Short and Long Forms of the Chronic Pain Acceptance Questionnaire: Further Examination of Patient Subgroups Rovner, G; Vowles, K E; Gerdle, B; Gillanders, D Journal of Pain // 2015;16(11):1095-1105 Division of Rehabilitation Medicine, Section for Highly Specialized Pain Rehabilitation, Department of Clinical Sciences, Danderyd Hospital, Karolinska Institutet, Stockholm, Sweden Churchill Livingstone Inc. 2015 // DOI: 10.1016/j.jpain.2015.07.007	Does not utilize or assess tool

The effectiveness of acceptance and commitment therapy (ACT) on the anxiety, depression and psychological well-being of patients with hypothyroidism Fakharian, N; Samari Safa, J; Ghezelsefloo, M Iranian Journal of Endocrinology and Metabolism // 2019;21(2):65-72 Department of Guidance & Counseling, Faculty of Humanities, Islamic Azad University Khomeinishahr Branch, Isfahan, Iran Endocrine Research Center 2019 //	Not English or French
Systematic review and meta-analysis of psychological therapies for children with chronic pain Fisher, E; Heathcote, L; Palermo, T M; De C. Williams, A C; Lau, J; Eccleston, C Journal of Pediatric Psychology // 2014;39(8):763-782 Centre for Pain Research, University of Bath, Bath, BA2 7AY, United Kingdom Oxford University Press 2014 // DOI: 10.1093/jpepsy/jsu008	Does not utilize or assess tool
Pain Acceptance in Adolescents: Development of a Short Form of the CPAQ-A Gauntlett-Gilbert, J; Alamire, B; Duggan, G B Journal of Pediatric Psychology // 2019;44(4):453-462 2019 // DOI: 10.1093/jpepsy/jsy090	Does not utilize or assess tool
Internet-Delivered Acceptance and Values-Based Exposure Treatment for Fibromyalgia: A Pilot Study Ljótsson, B; Atterlöf, E; Lagerlöf, M; Andersson, E; Jernelöv, S; Hedman, E; Kemani, M; Wicksell, R K Cognitive Behaviour Therapy // 2014;43(2):93-104 Department of Clinical Neuroscience, Division of Psychology, Karolinska Institutet, Stockholm, Sweden Taylor and Francis A.S. 2014 // DOI: 10.1080/16506073.2013.846401	Does not utilize or assess tool
Acceptance of pain in adolescents with chronic pain: Validation of an adapted assessment instrument and preliminary correlation analyses McCracken, L M; Gauntlett-Gilbert, J; Eccleston, C European Journal of Pain // 2010;14(3):316-320 Bath Centre for Pain Services, Royal National Hospital for Rheumatic Diseases, Centre for Pain Research, Bath, BA1 1RL, United Kingdom 2010 // DOI: 10.1016/j.ejpain.2009.05.002	Does not utilize or assess tool
The psychological flexibility model: A basis for integration and progress in psychological approaches to chronic pain management McCracken, L M; Morley, S Journal of Pain // 2014;15(3):221-234 2014 //	Does not utilize or assess tool

DOI: 10.1016/j.jpain.2013.10.014	
Processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on Acceptance and Commitment Therapy McCracken, L M; Gutiérrez-Martínez, O Behaviour Research and Therapy // 2011;49(4):267-274 2011 // DOI: 10.1016/j.brat.2011.02.004	Does not utilize or assess tool
Somatoform and related disorders Elena Garralda, M; Rask, C U Rutter's Child and Adolescent Psychiatry: Sixth Edition // 2015;():1035-1054 Academic Unit of Child and Adolescent Psychiatry, Imperial College London, London, United Kingdom John Wiley and Sons Ltd 2015 // DOI: 10.1002/9781118381953.ch72	Does not utilize or assess tool
The use of functional neuroimaging to evaluate psychological and other non-pharmacological treatments for clinical pain Jensen, K B; Berna, C; Loggia, M L; Wasan, A D; Edwards, R R; Gollub, R L Neuroscience Letters // 2012;520(2):156-164 Department of Psychiatry, Massachusetts General Hospital (MGH), Harvard Medical School (HMS), Boston, MA, United States 2012 // DOI: 10.1016/j.neulet.2012.03.010	Does not utilize or assess tool
One-day behavioral intervention in depressed migraine patients: Effects on headache Dindo, L; Recober, A; Marchman, J; O'Hara, M W; Turvey, C Headache // 2014;54(3):528-538 Department of Psychiatry, University of Iowa College of Medicine, Psychiat. Res. MEB 2-203, Iowa City, IA 52242-1000, United States Blackwell Publishing Inc. 2014 // DOI: 10.1111/head.12258	Does not utilize or assess tool
Acceptance and commitment therapy (ACT) to foster resilience in pediatric chronic illness Ernst, M M; Mellon, M W Child and Adolescent Resilience Within Medical Contexts: Integrating Research and Practice // 2016;():193-207 Department of Pediatrics, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, United States Springer International Publishing 2016 // DOI: 10.1007/978-3-319-32223-0_11	Does not utilize or assess tool

Pain Intensity, Psychological Inflexibility, and Acceptance of Pain as Predictors of Functioning in Adolescents with Juvenile Idiopathic Arthritis: A Preliminary Investigation Feinstein, Amanda B; Forman, Evan M; Masuda, Akihiko; Cohen, Lindsey L; Herbert, James D; Moorthy, L Nandini; Goldsmith, Donald P JOURNAL OF CLINICAL PSYCHOLOGY IN MEDICAL SETTINGS 09// 2011;18(3):291-298 233 SPRING ST, NEW YORK, NY 10013 USA SPRINGER/PLENUM PUBLISHERS 2011 09// DOI: 10.1007/s10880-011-9243-6	Does not utilize or assess tool
The Co-occurrence of Pediatric Chronic Pain and Anxiety: A Theoretical Review of a Developmentally Informed Shared Vulnerability Model Jastrowski Mano, K E; O'bryan, E M; Gibler, R C; Beckmann, E Clinical Journal of Pain // 2019;35(12):989-1002 Department of Psychology, University of Cincinnati, 5130D Edwards One, ML 0376, Cincinnati, OH 45221-0376, United States Lippincott Williams and Wilkins 2019 // DOI: 10.1097/AJP.0000000000000763	Does not utilize or assess tool
Acceptation and Commitment Therapy (ACT) and Mindfulness, a model of psychological flexibility for chronic pain Masselin-Dubois, A Douleurs // 2016;17(5):233-251 2016 // DOI: 10.1016/j.douler.2016.08.003	Cannot locate full text
A Case Study: Acceptance and Commitment Therapy for Pediatric Sickle Cell Disease Masuda, Akihiko; Cohen, Lindsey L; Wicksell, Rikard K; Kemani, Mike K; Johnson, Alcuin JOURNAL OF PEDIATRIC PSYCHOLOGY 05// 2011;36(4):398-408 JOURNALS DEPT, 2001 EVANS RD, CARY, NC 27513 USA OXFORD UNIV PRESS INC 2011 05// DOI: 10.1093/jpepsy/jsq118	Does not utilize or assess tool
Comparing the effectiveness of mindfulness-based stress reduction and multidisciplinary intervention programs for chronic pain: A randomized comparative trial Wong, S.Y.-S.; Chan, F.W.-K.; Wong, R.L.-P.; Chu, M.-C.; Kitty Lam, Y.-Y.; Mercer, S W; Ma, S H Clinical Journal of Pain // 2011;27(8):724-734 School of Public Health and Primary Care, Centre for Population and Health Sciences, University of Glasgow, United Kingdom Lippincott Williams and Wilkins 2011 // DOI: 10.1097/AJP.0b013e3182183c6e	Does not utilize or assess tool
Evolving the future: Toward a science of intentional change	Does not utilize or assess tool

Wilson, D S; Hayes, S C; Biglan, A; Embry, D D Behavioral and Brain Sciences // 2014;89(3):1-99 SUNY, Departments of Biology and Anthropology, Binghamton University, Binghamton, NY 13903, United States Cambridge University Press 2014 // DOI: 10.1017/S0140525X13001593	
Acceptance and Commitment Therapy (ACT): The foundation of the therapeutic model and an overview of its contribution to the treatment of patients with chronic physical diseases Prevedini, A B; Presti, G; Rabitti, E; Miselli, G; Moderato, P Giornale Italiano di Medicina del Lavoro ed Ergonomia // 2011;33(1 SUPPL. A):A53-A63 IULM University-Milan-Italy, IESCUM, ACT-Italia, Italy 2011 //	Does not utilize or assess tool
Physician Complicity in the Transformation of Pain Medicine from a "Profession" to a "Business": Strategies for Reversing a Growing Trend Schatman, M E Pain Medicine (United States) // 2012;13(9):1149-1151 Foundation for Ethics in Pain Care, Bellevue, WA, United States Blackwell Publishing Inc. 2012 // DOI: 10.1111/j.1526-4637.2012.01464.x	Does not utilize or assess tool
The efficacy of group-based acceptance and commitment therapy on psychological capital and school engagement: A pilot study among Chinese adolescents Fang, S; Ding, D Journal of Contextual Behavioral Science // 2020;16():134-143 Department of Psychology, Anhui Normal University, Wuhu, China Elsevier Inc. 2020 // DOI: 10.1016/j.jcbs.2020.04.005	Does not utilize or assess tool
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Comparison of motivational interviewing with acceptance and commitment therapy: A conceptual and clinical review Bricker, J; Tollison, S Behavioural and Cognitive Psychotherapy // 2011;39(5):541-559 University of Washington, Fred Hutchinson Cancer Research Center, 1100 Fairview Avenue North, M3-B232, Seattle, WA 98195, United States 2011 // DOI: 10.1017/S1352465810000901	Does not utilize/ assess tool

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Acceptance and Commitment Therapy (ACT) for Adolescents: Outcomes of a Large-Sample, School-Based, Cluster-Randomized Controlled Trial Van der Gucht, K; Griffith, J W; Hellemans, R; Bockstaele, M; Pascal-Claes, F; Raes, F Mindfulness // 2017;8(2):408-416 Faculty of Psychology and Educational Sciences, University of Leuven, Tiensestraat 102, Leuven, 3000, Belgium Springer New York LLC 2017 // DOI: 10.1007/s12671-016-0612-y	Does not utilize/ assess tool
The research journey of acceptance and commitment therapy (ACT) Hooper, N; Larsson, A The Research Journey of Acceptance and Commitment Therapy (ACT) // 2015;():1-212 2015 // DOI: 10.1057/9781137440174	Cannot locate full text
Clinical utility and validity of the Functional Disability Inventory among a multicenter sample of youth with chronic pain Kashikar-Zuck, S; Flowers, S R; Claar, R L; Guite, J W; Logan, D E; Lynch-Jordan, A M; Palermo, T M; Wilson, A C Pain // 2011;152(7):1600-1607 Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, United States 2011 // DOI: 10.1016/j.pain.2011.02.050	Does not utilize/ assess tool
Psychological therapy of migraine: Systematic review Fritsche, G; Kröner-Herwig, B; Kropp, P; Niederberger, U; Haag, G Schmerz // 2013;27(3):263-274 Neurologische Klinik, Universität Essen, Hufelandstr. 55, 45122 Essen, Germany 2013 //	Does not utilize/ assess tool

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Cognitive Behavioral Therapy increases pain-evoked activation of the prefrontal cortex in patients with fibromyalgeia Jensen, K B; Kosek, E; Wicksell, R; Kemani, M; Olsson, G; Merle, J V; Kadetoff, D; Ingvar, M Pain // 2012;153(7):1495-1503 Department of Psychiatry, Massachusetts General Hospital, Harvard Medical School, Boston, MA, United States 2012 // DOI: 10.1016/j.pain.2012.04.010	Does not utilize/ assess tool
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Age moderates response to acceptance and commitment therapy vs. cognitive behavioral therapy for chronic pain Wetherell, J L; Petkus, A J; Alonso-Fernandez, M; Bower, E S; Steiner, A R W; Afari, N International Journal of Geriatric Psychiatry // 2016;31(3):302-308 VA San Diego Healthcare System, San Diego, CA, United States John Wiley and Sons Ltd 2016 // DOI: 10.1002/gps.4330	Does not utilize/ assess tool
Acceptance and Commitment Therapy for the Treatment of Posttraumatic Stress Among Adolescents Woidneck, M R; Morrison, K L; Twohig, M P Behavior Modification // 2014;38(4):451-476 Utah State University, Logan, United States SAGE Publications Inc. 2014 // DOI: 10.1177/0145445513510527	Does not utilize/ assess tool
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Psychological Interventions for Children with Functional Somatic Symptoms: A Systematic Review and Meta-Analysis Bonvanie, I J; Kallesøe, K H; Janssens, K A M; Schröder, A; Rosmalen, J G M; Rask, C U	Does not utilize/ assess tool

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Acceptance of premonitory urges and tics Gev, E; Pilowsky-Peleg, T; Fennig, S; Benaroya-Milshtein, N; Woods, D W; Piacentini, J; Apter, A; Steinberg, T Journal of Obsessive-Compulsive and Related Disorders // 2016;10():78-83 Matta and Harry Freund Neuropsychiatry Tourette Syndrome and Tic Disorders Clinic, Schneider Children's Medical Center of Israel, Petach Tikva, 49202, Israel Elsevier B.V. 2016 // DOI: 10.1016/j.jocrd.2016.06.001	Does not utilize/ assess tool
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Acceptance and Commitment Therapy (ACT): Advances and Applications with Children, Adolescents, and Families Coyne, L W; McHugh, L; Martinez, E R Child and Adolescent Psychiatric Clinics of North America // 2011;20(2):379-399 Psychology Department, Early Childhood Research Clinic, Suffolk University, 41 Temple Street, Boston, MA 02114, United States 2011 // DOI: 10.1016/j.chc.2011.01.010	Does not utilize/ assess tool
Risk severity moderated effectiveness of pain treatment in adolescents Vuorimaa, H; Leppänen, L; Kautiainen, H; Mikkelsson, M; Hietanen, M; Vilen, H; Pohjankoski, H Scandinavian Journal of Pain // 2019;19(2):287-298 Department of Pediatrics, Päijät-Häme Central Hospital, Keskussairaalankatu 7, Lahti, 15850, Finland De Gruyter 2019 // DOI: 10.1515/sjpain-2018-0312	Does not utilize/ assess tool
Anxiety, coping, and disability: A test of mediation in a pediatric chronic pain sample Kaczynski, K J; Simons, L E; Claar, R L Journal of Pediatric Psychology // 2011;36(8):932-941 Pain Treatment Service, Children's Hospital, Boston, 300 Longwood Ave, Boston, MA 02115, United States 2011 // DOI: 10.1093/jpepsy/jsr024	Does not utilize/ assess tool

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The efficacy of group-based acceptance and commitment therapy on psychological capital and school engagement: A pilot study among Chinese adolescents Fang, S; Ding, D Journal of Contextual Behavioral Science // 2020;16():134-143 Department of Psychology, Anhui Normal University, Wuhu, China Elsevier Inc. 2020 // DOI: 10.1016/j.jcbs.2020.04.005	Does not utilize/ assess tool
Lessons learned from a mindfulness-based intervention with chronically ill youth Lagor, A F; Williams, D J; Lerner, J B; McClure, K S Clinical Practice in Pediatric Psychology // 2013;1(2):146-158 Department of Psychology, La Salle University, 1900 West Olney Avenue, Box 275, Philadelphia, PA 19141, United States American Psychological Association Inc. 2013 // DOI: 10.1037/cpp0000015	Does not utilize/ assess tool
Pharmacodynamic Study of Miransertib in Individuals with Proteus Syndrome Keppler-Noreuil, K M; Sapp, J C; Lindhurst, M J; Darling, T N; Burton-Akright, J; Bagheri, M; Dombi, E; Gruber, A; Jarosinski, P F; Martin, S; Nathan, N; Paul, S M; Savage, R E; Wolters, P L; Schwartz, B; Widemann, B C; Biesecker, L G American Journal of Human Genetics // 2019;104(3):484-491 Medical Genomics and Metabolic Genetics Branch, National Human Genome Research Institute, NIH, Bethesda, MD 20892, United States Cell Press 2019 // DOI: 10.1016/j.ajhg.2019.01.015	Not pediatric population
Acceptance and Commitment Therapy for children and adolescents with physical health concerns Wicksell, R K; Kanstrup, M; Kemani, M K; Holmström, L; Olsson, G L Current Opinion in Psychology // 2015;2():1-5 Behavior Medicine Pain Treatment Service, Karolinska University Hospital, Sweden Elsevier 2015 // DOI: 10.1016/j.copsyc.2014.12.029	Does not utilize/ assess tool
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Department of Social Work, University of Michigan Health System, Ann Arbor, MI, United States Academic Press Inc. 2014 // DOI: 10.1016/j.yebeh.2014.07.024	
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Physical therapy and functional rehabilitation Jaremko, K; Hsu, B Complex Regional Pain Syndrome: Past, Present and Future // 2015;():145-193 Jefferson Medical College, Philadelphia, PA, United States Nova Science Publishers, Inc. 2015 //	Cannot locate full text
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Insomnia in paediatric chronic pain and its impact on depression and functional disability Kanstrup, M; Holmström, L; Ringström, R; Wicksell, R K European Journal of Pain (United Kingdom) // 2014;18(8):1094-1102 Behavior Medicine Pain Treatment Services, Karolinska University Hospital, Solna, Sweden Blackwell Publishing Ltd 2014 // DOI: 10.1002/j.1532-2149.2013.00450.x	Does not utilize/ assess tool
The role of parent psychological flexibility in relation to adolescent chronic pain: Further instrument development Wallace, D P; McCracken, L M; Weiss, K E; Harbeck-Weber, C Journal of Pain // 2015;16(3):235-246 Pain Management, Children's Mercy Kansas City, 2401 Gillham Road, Kansas City, MO 64108, United States Churchill Livingstone Inc. 2015 // DOI: 10.1016/j.jpain.2014.11.013	Does not utilize/ assess tool
Fear of pain in children and adolescents with neuropathic pain and complex regional pain syndrome Simons, L E Pain // 2016;157():S90-S97 Division of Pain Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, Boston Children's Hospital, 21 Autumn St, Boston, MA 02215, United States Lippincott Williams and Wilkins 2016 // DOI: 10.1097/j.pain.0000000000000377	Does not utilize/ assess tool

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Nonpharmacologic Treatment of Pain Agoston, A M; Sieberg, C B Seminars in Pediatric Neurology // 2016;23(3):220-223 Department of Psychiatry, Boston Children's Hospital, Boston, MA, United States W.B. Saunders 2016 // DOI: 10.1016/j.spen.2016.10.005	Does not utilize/ assess tool
Psychological treatments for pediatric headache Krner-Herwig, B Expert Review of Neurotherapeutics // 2011;11(3):403-410 Department of Clinical Psychology and Psychotherapy, Georg-Elias-Müller Institute of Psychology, Georg-August-University of Gttingen, Gosslerstr., 1437073 Gttingen, Germany 2011 // DOI: 10.1586/ern.11.10	Does not utilize/ assess tool
Systematic review: Issues in measuring clinically meaningful change in self-reported chronic pediatric pain intensity Lavigne, J V Journal of Pediatric Psychology // 2016;41(7):715-734 Department of Child and Adolescent Psychiatry, Ann and Robert H. Lurie Children's Hospital of Chicago, 225 East Chicago Avenue, Chicago, IL 60611, United States Oxford University Press 2016 //	Does not utilize/ assess tool

DOI: 10.1093/jpepsy/jsv161	
Collaborating on evolving the future Wilson, D S; Hayes, S C; Biglan, A; Embry, D D Behavioral and Brain Sciences // 2014;37(4):438-460 Departments of Biology and Anthropology, SUNY Binghamton, Binghamton, NY 13903, United States Cambridge University Press 2014 // DOI: 10.1017/S0140525X14000016	Does not utilize/ assess tool
Implementing an acceptance and commitment therapy group protocol with veterans using VA's stepped care model of pain management Cosio, D; Schafer, T Journal of Behavioral Medicine // 2015;38(6):984-997 Anesthesiology/Pain Clinic #124, Jesse Brown VA Medical Center, Chicago, IL 60612, United States Springer New York LLC 2015 // DOI: 10.1007/s10865-015-9647-0	Does not utilize/ assess tool
Coaching of patients with an isolated minimally displaced fracture of the radial head immediately increases range of motion Teunis, T; Thornton, E R; Guitton, T G; Vranceanu, A.-M.; Ring, D Journal of Hand Therapy // 2016;29(3):314-319 Orthopaedic Hand and Upper Extremity Service, Massachusetts General Hospital, Harvard Medical School, Boston, MA, United States Hanley and Belfus Inc. 2016 // DOI: 10.1016/j.jht.2016.02.003	Does not utilize/ assess tool
Psychological treatments and psychotherapies in the neurorehabilitation of pain: Evidences and recommendations from the italian consensus conference on pain in neurorehabilitation Castelnuovo, G; Giusti, E M; Manzoni, G M; Saviola, D; Gatti, A; Gabrielli, S; Lacerenza, M; Pietrabissa, G; Cattivelli, R; Spatola, C A M; Corti, S; Novelli, M; Villa, V; Cottini, A; Lai, C; Pagnini, F; Castelli, L; Tavola, M; Torta, R; Arreghini, M; Zanini, L; Brunani, A; Capodaglio, P; D'Aniello, G E; Scarpina, F; Brioschi, A; Priano, L; Mauro, A; Riva, G; Repetto, C; Regalia, C; Molinari, E; Notaro, P; Paolucci, S; Sandrini, G; Simpson, S G; Wiederhold, B; Tamburin, S; Agostini, M; Alfonsi, E; Aloisi, A M; Alvisi, E; Aprile, I; Armando, M; Avenali, M; Azicnuda, E; Barale, F; Bartolo, M; Bergamaschi, R; Berlangieri, M; Berlincioni, V; Berliocchi, L; Berra, E; Berto, G; Bonadiman, S; Bonazza, S; Bressi, F; Brugnera, A; Brunelli, S; Buzzi, M G; Cacciatori, C; Calvo, A; Cantarella, C; Caraceni, A; Carone, R; Carraro, E; Casale, R; Castellazzi, P; Castino, A; Cerbo, R; Chiò, A; Ciotti, C; Cisari, C; Coraci, D; Toffola, E D; Defazio, G; De Icco, R; Del Carro, U; Dell'Isola, A; De Tanti, A; D'Ippolito, M; Fazzi, E; Ferrari, A; Ferrari, S; Ferraro, F; Formaglio, F; Formisano, R; Franzoni, S; Gajofatto, F; Gandolfi, M; Gardella, B; Geppetti, P; Giammò, A; Gimigliano, R; Greco, E; Ieraci, V; Invernizzi, M; Jacopetti, M; La Cesa, S; Lobba, D; Magrinelli, F; Mandrini, S; Manera, U; Marchettini, P; Marchioni, E; Mariotto, S; Martinuzzi, A; Masciullo, M; Mezzarobba, S; Miotti, D; Modenese, A; Molinari, M; Monaco, S; Morone, G; Nappi, R; Negrini, S; Pace, A; Padua, L; Pagliano, E; Palmerini, V; Pazzaglia, C; Pecchioli, C; Picelli, A; Porro, C A; Porru, D; Romano, M; Roncari, L;	Does not utilize/ assess tool

Rosa, R; Saccavini, M; Sacerdote, P; Schenone, A; Schweiger, V; Scivoletto, G; Smania, N; Solaro, C; Spallone, V; Springhetti, I; Tassorelli, C; Tinazzi, M; Togni, R; Torre, M; Traballesi, M; Tramontano, M; Truini, A; Tugnoli, V; Turolla, A; Vallies, G; Verzini, E; Vottero, M; Zerbinati, P; Neurorehabilitation, Italian Consensus Conference on Pain in Frontiers in Psychology // 2016;7(FEB): Psychology Research Laboratory, Istituto Auxologico Italiano IRCCS, San Giuseppe Hospital, Verbania, Italy Frontiers Media S.A. 2016 // DOI: 10.3389/fpsyg.2016.00115	

Tool 6 Pain Related Problems List for Adolescents

Evaluation of Psychometric and Linguistic Properties of the Italian Adolescent Pain Assessment Scales: A Systematic Review Marti, Flavio; Paladini, Antonella; Varrassi, Giustino; Latina, Roberto PAIN AND THERAPY 06// 2018;7(1):77-104 GEWERBESTRASSE 11, CHAM, CH-6330, SWITZERLAND SPRINGER INTERNATIONAL PUBLISHING AG 2018 06// DOI: 10.1007/s40122-018-0093-x	Not an original study
Chronic pain in adolescents: Psychosocial consequences, predictors and intervention Hunfeld, J A M; Merlijn, V.P.B.M. Tijdschrift voor Kindergeneeskunde // 2008;76(4):172-179 Afdeling Medische Psychologie en Psychotherapie, Erasmus MC, Rotterdam, Netherlands Bohn Stafleu van Loghum 2008 // DOI: 10.1007/BF03078200	Cannot locate full text
Early signaling, referral, and treatment of adolescent chronic pain: A study protocol Voerman, J S; Remerie, S; de Graaf, L E; van de Looij-Jansen, P; Westendorp, T; van Elderen, I; de Waart, F; Passchier, J; van Berkel, A D; de Klerk, C BMC Pediatrics // 2012;12(): Department of Medical Psychology and Psychotherapy, Erasmus MC University Medical Hospital, PO Box 2040, Rotterdam, CA, 3000, Netherlands 2012 // DOI: 10.1186/1471-2431-12-66	Does not utilize/ assess tool
Effects of a Guided Internet-Delivered Self-Help Intervention for Adolescents with Chronic Pain Voerman, J S; Remerie, S; Westendorp, T; Timman, R; Busschbach, J J V; Passchier, J; De Klerk, C Journal of Pain // 2015;16(11):1115-1126 Department of Psychiatry, Section Medical Psychology and Psychotherapy, Erasmus MC, University Medical Centre, P.O. Box 2040, Rotterdam, 3000 CA, Netherlands Churchill Livingstone Inc. 2015 // DOI: 10.1016/j.jpain.2015.07.011	Does not utilize/ assess tool
Measuring Pain in Adolescents	Not an original study

Ameringer, S Journal of Pediatric Health Care // 2009;23(3):201-204 2009 // DOI: 10.1016/j.pedhc.2009.01.006	

Qualitative Study Supplementary File 2: Semi-Structured Interview Guide

Introduction: Thank you very much for taking the time to participate in this study. As you have read in the letter of information, the objective of this study is to explore and describe how nurses make decisions and what factors influence their decisions when triaging patients to interdisciplinary pediatric chronic pain programs. This study is part of a larger study aimed to develop a Clinical Decision Support tool to guide triage decisions within interdisciplinary pediatric chronic pain programs. We will first go through some demographic questions, and discuss your clinical experience working with the pediatric chronic pain population. We will then move onto questions about how you make triage decisions and will then discuss the factors that influence your decisions. We will then discuss whether or not you are currently using a tool to guide your triage decisions, and your interest in using a tool to guide future triage decisions. The interview will conclude with any additional comments, questions or feedback you may have. The interview takes approximately 60 minutes to complete. The interview will be audio-recorded and will be transcribed verbatim in order to best analyze the data at a later date. I want to assure you again that all of your responses will be kept confidential, and that your name will not be linked to your interview. If you do not feel comfortable answering a question, we can skip to the next. If you wish to withdraw at any point, please do not hesitate to let me know. In that case, any data you provide will be destroyed and will not be used in the analysis. Thank you for sending your signed consent form ahead of time. Do you have any questions, concerns or comments before we begin?

SECTION 1: DEMOGRAPHICS & GENERAL			
Research Objectives	**Definition/ Description**	**Question**	**Probes**
Demographics	Includes: nursing role, clinical experience, formation of interdisciplinary/ multidisciplinary team, geographical location of work	1. In what province, city do you work? 2. Are you a licensed nurse? 3. What is your nursing role? 4. What is your highest level of education? 5. Do you work on an interprofessional (e.g multidisciplinary, interdisciplinary) pediatric chronic pain team? 6. How many years have you worked with your team? With the pediatric chronic pain population?	Are you an RN? NP? APN? CNS? Other? What other disciplines/ professions make up your team?

		7. How long have you been triaging referrals within your team? 8. Approximately how many referrals do you triage per week/ month?	
SECTION 2: TRIAGE DECISION MAKING & PROCESSES			
Research Objectives	**Definition/ Description**	**Question**	**Probes**
Objective #1	Explore the types of decisions involved in triage within interdisciplinary pediatric chronic pain programs	What information did you collect? What types of decisions needed to be made? What influenced your decision from a patient perspective? A family perspective? An organizational perspective? A referring provider perspective? A team perspecrtive?	Too difficult to answer case example.
Objective #2	Explore triage processes within interdisciplinary pediatric chronic pain programs (Includes referral processes and triage processes)	10. Tell me about triage processes within your program.	Do you require referring physicians to complete a referral form? If so, in what format (i.e., paper vs electronic)? If so, what types of data do you request? If so, are most of the referral forms complete? Incomplete? Do you have contact with patients before triaging them? Do you require patients to complete any measures prior to referral to your program?

			Approximately how long does it take from when you receive a referral to when you make a triage decision? Approximately how long does it take from when you triage a referral to when the patient is seen by someone on your team/ your whole team? What is the approximate percentage of referrals you accept/ deny?
Objective #3	Explore the determinants (i.e., barriers, facilitators and contextual factors) that influence triage decision making in interdisciplinary pediatric chronic pain programs	11. Explain how you prioritize patients.	What patient reported outcomes would you consider important in understanding the biopsychosocial urgency of a patient referred to you? (e.g., sleep, pain rating, etc.) What types of patient information make it easiest for you to make a triage decision? What do you consider the most important factor(s) in making a triage decision (e.g., pain severity? Functional impairment? Referral date? Type of pain? What are some barriers in making triage decisions?
SECTION 3: CLINICAL DECISION SUPPORT TRIAGE TOOL			
Research Objectives	**Domain/Definition/ Description**	**Question**	**Example Answer/ Scenario**
Objective #4	Explore current use of a Clinical Decision Support (CDS) triage tools in	12. What are your thoughts about using a tool to help guide your triage decisions?	Do you currently use a CDS tool of any kind to help guide your triage decisions

	making triage decisions within interdisciplinary pediatric chronic pain programs		(i.e., algorithm, decision tree, triage scale, clinical practice guidelines etc.)? On a scale of 1-10, how interested are you in using a CDS tool to help guide future triage decisions? (10 being the most interested) Please list the elements you would consider important to include in such a CDS triage tool.
Objective #5	Explore interest in using a Clinical Decision Support (CDS) triage tool in making future triage decisions		

Before we close, do you have any questions, comments or feedback you would like to share with me? Thank you again for taking the time to participate in this study. You will receive a $10 Amazon gift card as a token of appreciation for your participation in this study. Can I confirm that your email address is x? In order to ensure validity of the data for this study, we are planning to conduct a 'member check' strategy, by which we will all participants following data analysis to allow your opinion regarding our interpretation of study findings. Are you interested in participating in our member check? If so, please email (PI) to set up a date and time to review the data. There will be an additional study coming up that will involve end users (i.e., pediatric chronic pain nurses, referring providers and other interdisciplinary members) in developing a CDS triage tool for use in interdisciplinary pediatric chronic pain programs. If you are interested in participating in this study, please email (PI) and the study's letter of information will be sent to you.

References:

Cane, J., O'Connor, D. & Michie, S. (2012). Validation of the theoretical domains framework for use in behavior change and implementation research. Implementation Science 7(37), 1-17.

Standing, M. (2008). Clinical judgement and decision-making in nursing – nine modes of practice in a revised cognitive continuum. *Journal of Advanced Nursing* 62(1), 124-134.

Qualitative Study Supplementary File 3: Summary of Coding Analysis

General Node	Sub-node	Definition	Mapping to Theoretical Framework/ Model		Minor Node	Number of Participants	Number of References	Theme
			CCT	TDF				
Nursing Role Within Triaging	Triage Development & Adaptation	This would include the nurses' role in developing triage systems	N/A	Beliefs about Consequences Beliefs about Capabilities Social & Professional Role Identify	N/A	7	14	Nurse-Led Triage Determinants
	Nursing Led Triage	This would include any nurse led triage processes	N/A	Beliefs about Consequences Beliefs about Capabilities Social & Professional Role Identify	N/A	7	10	Nurse-Led Triage Determinants
	Ensuring a smooth and thorough process	This would include any actions or tasks the nurse does to ensure the triage process is smooth and thorough	N/A	Beliefs about Capabilities Social & Professional Role Identify	N/A	6	9	Nurse-Led Triage Determinants
Additional Comments & Feedback	This included any additional information participants					6	13	Nurse-Led Triage Determinants
Interest in Using a CDS Triage Tool	N/A	This would include interest and/ or thoughts and/ or advice/ recommendations on components that would	N/A	Optimism	N/A	12	30	Nurse-Lead Triage Determinants

		be important to add in a CDS triage tool						
Triage Complexity	N/A	This would include how nurse explains how the nature of triage within interdisciplinary pediatric chronic pain programs is complex	Intuitive Judgement Optimism	Beliefs about Consequences Beliefs about Capabilities Social & Professional Role Identify	N/A	9	32	Nurse-Lead Triage Determinants
Triage Process	Triage Logistics	Steps and/ or actions taken after receiving and processing a patient referral	N/A	Environmental Context & Resources	Linking Patients with Resources	6	15	Process of Triage Decision-Making
					Communicating with Referring Providers	7	18	Process of Triage Decision-Making
					Mandatory Components Before Patient Accepted	11	33	Process of Triage Decision-Making
	Biological or Medical Data Collected	Data collected on pain diagnosis, pain description, co-morbidities, etc.	N/A	Knowledge	N/A	12	26	Process of Triage Decision-Making
	Psychological or Psychiatric Data	Any information on mental health history, symptoms, or diagnoses. This also includes data on sleep functioning and developmental considerations.	N/A	Knowledge	N/A	12	19	Process of Triage Decision-Making
	Social Data	Any information on social functioning, school functioning, psychosocial stressors, etc.	N/A	Knowledge	N/A	9	11	Process of Triage Decision-Making
	Services Involved	Any information on current specialty services (e.g., orthopedics) or community services (e.g., physio, OT, psychologist, etc.) involved.	N/A	Knowledge	N/A	8	14	Process of Triage Decision-Making

	Physical Data Collected	Data collected on physical abilities, dysfunction, mobility, etc.	N/A	Knowledge	N/A	6	10	Process of Triage Decision-Making
	Pharmacotherapy Data	Data collected on current or previously tried medications for pain.	N/A	Knowledge	N/A	5	6	Process of Triage Decision-Making
	Family Dynamics Data	Any information on family dynamics, functioning, family history, etc.	N/A	Knowledge	N/A	3	4	Process of Triage Decision-Making
	Patient/ Family Goals	Any information on what the patient/ family hope to achieve within the chronic pain program	N/A	Motivation & Goals	N/A	2	2	Process of Triage Decision-Making
	Interventional Data/ Treatments Tried	Any information on interventions tried (e.g., peripheral nerve block, infusions, etc.).	N/A	Knowledge	N/A	1	1	Process of Triage Decision-Making
Triage Decisions	Eligibility Criteria	Any information on inclusion or exclusion criteria, and/ or what data would consider a patient inappropriate for the program.	System-Aided Judgement	Environmental Context and Resources Skills	Diagnostic Investigations Complete	10	20	Process of Triage Decision-Making
					When Pain is Not the Primary Concern	10	15	Process of Triage Decision-Making
					Patient Readiness and Engagement	5	9	Process of Triage Decision-Making
					Chronicity of Pain	4	7	Process of Triage Decision-Making
					Patient Must Have a Primary Care Provider	3	4	Process of Triage Decision-Making
					Developmental and Intellectual Disabilities	2	2	Process of Triage Decision-Making
					Foundational Pain Management Strategies Have Been Tried	1	1	Process of Triage Decision-Making
	Anticipating Patient Needs	Any information on how anticipated patient needs (e.g., only needs	N/A	Beliefs about Consequences Skills	N/A	8	27	Process of Triage Decision-Making

		medications) influences the triage decision.						
	Diagnostic Clarification	Any information on how a diagnosis (or lack thereof) influences the triage decision.	N/A	Beliefs about Consequences Skills	N/A	10	36	Process of Triage Decision-Making
	Prioritization	How urgency of the patient is classified (e.g., urgent vs non-urgent). Some participants do not classify urgency and it is simply first come first serve.	System-aided Judgement	Memory, Attention and Decision Processes Skills	Prioritization Based on Diagnosis	11	25	Process of Triage Decision-Making
					Prioritization Based on Functional Interference	9	17	Process of Triage Decision-Making
					Prioritization Based on Age	6	7	Process of Triage Decision-Making
					Prioritization Based on Mental Health Symptoms	6	9	Process of Triage Decision-Making
					Prioritization Based on Healthcare Utilization	6	7	Process of Triage Decision-Making
					Prioritization Based on Physical Symptoms	3	5	Process of Triage Decision-Making
					Prioritization Based on Referring Provider Impression/ Opinion	3	6	Process of Triage Decision-Making
	Facilitators	Factors that make the triage decision easier to make.	N/A	Motivation & Goals	Diagnostic Clarification	11	34	Process of Triage Decision-Making
					Completeness of Referrals	9	14	Process of Triage Decision-Making
					Having Clarity for Reason of Referral	4	4	Process of Triage Decision-Making
					Use of Patient Reported Outcome Measures and Intake Forms	3	4	Process of Triage Decision-Making
					Having Positive Interprofessional Collaborative Relationships	2	3	Process of Triage Decision-Making
					Use of a Standardized Referral Form	2	3	Process of Triage Decision-Making
					Having Access to Clinical Documentation	2	2	Process of Triage Decision-Making

					Having Family Buy In	2	2	Process of Triage Decision-Making
					Having Clear Eligibility Criteria	1	1	Process of Triage Decision-Making
					Having Protected Time for Triage	1	1	Process of Triage Decision-Making
	Barriers	Factors that make the triage decision more challenging to make.	N/A	Motivation & Goals	Incomplete Referrals	10	22	Process of Triage Decision-Making
					Patient Complexity	7	9	Process of Triage Decision-Making Nurse-Lead Triage
					Lack of Resources	6	8	Process of Triage Decision-Making
					Lack of Time	3	3	Process of Triage Decision-Making
					Lack of Clinic Availability	2	3	Process of Triage Decision-Making
					Lack of Patient Resources/ Insurance	2	3	Process of Triage Decision-Making
					Lack of Standardized Triage Pathways	1	3	Process of Triage Decision-Making
	Clinical Instinct	This would include how some triage decisions are based on a gut feeling.	Intuitive Judgement	Memory, Attention and Decision Processes	N/A	5	8	Nurse-Led Triage Determinants
	Personal Bias & Influence	How personal values and morals of the triage nurse impacts the triage decision	Intuitive Judgement	Believes about Consequences	N/A	5	7	Nurse-Led Triage Determinants
Triage Influences	Patient or Family Influences	This would include how the family may influence the triage decision.	Patient and Peer Aided Judgement	Social Influences Emotions	N/A	12	43	External Influences on Triage Decision-Making
	Referring Provider Influences	This would include how the referring provider influences the triage decision. For	Patient and Peer Aided	Social Influences Emotions	N/A	9	40	External Influences on Triage Decision-Making

		example, providing misinformation about the patient in hopes that they might be seen sooner.	Judgement					
	Interdisciplinary Team Influences	This would include how various team members may influence the triage decision.	Patient and Peer Aided Judgement	Social Influences Beliefs about Capabilities	N/A	8	29	External Influences on Triage Decision-Making
	Organizational Influences	This would include how the organizational culture may influence the triage decision. For example, if a donor requested a certain patient be expedited the decision is accommodated to keep the donor happy.	Patient and Peer Aided Judgement	Environmental Context and Resources Emotions	N/A	8	19	External Influences on Triage Decision-Making

Delphi Survey: Attaining Expert Consensus on Significant Clinical Indicators and Diagnostic Approaches that are Required on Patients Prior to Acceptance into Interdisciplinary Pediatric Chronic Pain Programs

You are invited to participate as an expert in the field of pediatric chronic pain in the following Delphi survey conducted by the Principle Investigator. The purpose of using a Delphi technique is to assess group consensus about a topic in their respective field of work. This study is part of a larger mixed methods study intended to create a Clinical Decision Support (CDS) tool for nurses triaging patients to interdisciplinary pediatric chronic pain programs.

Purpose of the Study: The purpose of this study is to attain expert consensus on all necessary medical diagnostic approaches and indicators that are required on patients prior to acceptance into interdisciplinary pediatric chronic pain programs for common primary chronic pain diagnoses in the pediatric population. For the purpose of this study, diagnoses will be limited to 1) Chronic headaches, 2) Chronic abdominal pain, 3) Chronic pelvic pain, 4) Chronic musculoskeletal and joint pain, 5) Chronic back pain and 6) Complex Regional Pain Syndrome (CRPS) Type 1.

Specific study objectives are to attain expert consensus on the following for the common pediatric chronic primary pain diagnoses listed above:

1. Confirm list of significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) for each diagnosis

2. Identify best course of action if referred patient has significant clinical indicators for each diagnosis

3. Identify most appropriate lab work if patient has no significant clinical indicators for each diagnosis

4. Identify most appropriate diagnostic imaging if patient has no significant clinical indicators for each diagnosis

5. Identify most appropriate diagnostic procedures if patient has no significant clinical indicators for each diagnosis

6. Identify suggested diagnostic algorithms and/ or guidelines and/ or criteria to identify necessary diagnostic investigations and indicators for each diagnosis respectively

Please complete the survey below.

Thank you!

Do you work with the pediatric chronic pain population?	◯ Yes ◯ No
What is your medical or nursing designation?	◯ Anesthesiologist ◯ General Practitioner ◯ Paediatrician ◯ Registered Nurse ◯ Nurse Practitioner ◯ Clinical Nurse Specialist ◯ Advanced Practice Nurse ◯ Other
If your medical or nursing designation is not listed above, please provide it here.	_____
What is your highest level of education?	◯ Bachelor's Degree ◯ Master's Degree ◯ Doctorate Degree ◯ Doctor of Medicine Degree

Please list any other diplomas/ degrees/ certifications you have achieved that are not listed in the question above.	_____
Do you work in an interdisciplinary pediatric chronic pain program/ clinic/ team? (*To note - we define 'interdisciplinary' as a combination of two or more clinical disciplines that work together within one team to serve the pediatric chronic pain population. Disciplines may include, but are not limited to: physicians, nurses, physiotherapists, psychologists, psychiatrists, occupational therapists, pharmacists, recreational therapists, etc.)	◯ Yes ◯ No
Please state the clinical role you have within your team/ clinic/ program	_____
How many years of experience do you have working with the pediatric chronic pain population?	◯ 0-5 years ◯ 5-10 years ◯ 10-20 years ◯ 20-30 years ◯ 30+ years
In what geographical location do you work?	◯ Canada ◯ United States of America ◯ Europe ◯ Australia ◯ New Zealand ◯ South America ◯ Asia ◯ Africa
Please indicate the province/ state within which you work.	_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic headaches.

	Not at all important	Somewhat important	Important	Very important	Extremely important
Child is between 3 and 5 years of age	◯	◯	◯	◯	◯
New or different severe headache	◯	◯	◯	◯	◯
Change in headache frequency	◯	◯	◯	◯	◯
Described by patient as 'worst headache of life'	◯	◯	◯	◯	◯
Headache wakes from sleep	◯	◯	◯	◯	◯
Headache of sudden onset	◯	◯	◯	◯	◯

Headache that worsens with Valsalva (i.e., coughing, sneezing, straining)	◯	◯	◯	◯	◯
Neurological abnormalities (i.e., history of seizures, weakness, altered level of consciousness, papilledema, etc.)	◯	◯	◯	◯	◯
Systemic signs and symptoms (i.e., fever, weight loss, rash, joint pain, history of immunosuppression, etc.)	◯	◯	◯	◯	◯

If you can think of other significant clinical indicators (i.e., clinical red flags/ signs of organic pathology) to consider in the diagnostic work up for chronic headaches, please list them here

_____

What would be your course of action if a patient referred to you with chronic headache HAS significant clinical indicators (i.e., clinical red flags/ signs of organic pathology)? (*please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section)

◯ Deny patient with no suggestions to referring provider
◯ Deny patient with suggestions to referring provider
◯ Re-direct referral to Emergency Department
◯ Re-direct referral to Neurology and/ or Pediatrics and/ or other relevant specialist (as outpatient)
◯ Accept patient and request that referring provider complete additional workup
◯ Accept patient and assess yourself
◯ Other (will explain below)

If none of the options listed are apart of your practice, please explain/ describe your course of action here

_____

Please rate the importance of completing the following laboratory investigations for patients with chronic headaches WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your chronic pain program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Serum Complete Blood Count (i.e., Hemoglobin, Hematocrit, Red Blood Cell Count, White Blood Cell Count, Platelet Count, etc.)	◯	◯	◯	◯	◯
Serum Thyroid Function (i.e., TSH, T4, etc.)	◯	◯	◯	◯	◯
Serum Electrolytes (i.e., Sodium, Potassium, Chloride, etc.)	◯	◯	◯	◯	◯

Serum Glucose	◯	◯	◯	◯	◯
Serum Calcium	◯	◯	◯	◯	◯
Serum Albumin	◯	◯	◯	◯	◯
Serum Creatinine	◯	◯	◯	◯	◯
Serum Blood Urea Nitrogen	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional laboratory investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic headaches WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic headache, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Computed Tomography (CT) of the head	◯	◯	◯	◯	◯
Magnetic Resonance Imaging (MRI) of the head	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic imaging investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic headaches WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic procedures for patients with chronic headache, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Sleep Study	◯	◯	◯	◯	◯
Lumbar Puncture	◯	◯	◯	◯	◯
Temporomandibular Joint (TMJ) Assessment	◯	◯	◯	◯	◯
Visual Acuity Examination	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic procedures you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic headaches WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)	_____
Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing chronic headaches (e.g., International Headache Society (HIS) international classification of headache disorders)?	◯ Yes ◯ No
If yes, please list.	_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with Chronic Abdominal Pain.

	Not at all important	Somewhat important	Important	Very important	Extremely important
Persistent right upper quadrant pain and/ or persistent right lower quadrant pain	◯	◯	◯	◯	◯
Persistent vomiting	◯	◯	◯	◯	◯
Persistent diarrhea	◯	◯	◯	◯	◯
Bloody stools	◯	◯	◯	◯	◯
Bloody emesis	◯	◯	◯	◯	◯
Unexplained weight loss	◯	◯	◯	◯	◯
Systemic signs and symptoms (i.e., fever, rash, oral lesions, etc.)	◯	◯	◯	◯	◯
History of prior surgeries	◯	◯	◯	◯	◯
Concern or diagnosis of an eating disorder	◯	◯	◯	◯	◯

If you can think of other significant clinical indicators (i.e., clinical red flags/ signs of organic pathology) to consider in the diagnostic work up for chronic abdominal pain, please list them here.	_____

What would be your course of action if a patient referred to you HAS significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology)? (*please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section)	◯ Deny patient with no suggestions to referring provider ◯ Deny patient with suggestions to referring provider ◯ Re-direct referral to Emergency Department ◯ Re-direct referral to Gastroenterology and/ or Pediatrics and/ or other relevant specialist (as outpatient) ◯ Accept patient and request referring provider complete required work-up ◯ Accept patient and assess yourself ◯ Other (will explain below)
If none of the options listed are apart of your practice, please explain/ describe your course of action here	_____

Please rate the importance of completing the following laboratory investigations for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Serum Complete Blood Count (i.e., Hemoglobin, Hematocrit, Red Blood Cell Count, White Blood Cell Count, Platelets, etc.)	◯	◯	◯	◯	◯
Serum Glucose	◯	◯	◯	◯	◯
Serum Calcium	◯	◯	◯	◯	◯
Serum Albumin	◯	◯	◯	◯	◯
Serum Creatinine	◯	◯	◯	◯	◯
Serum Blood Urea Nitrogen	◯	◯	◯	◯	◯
Serum Thyroid Function (i.e., TSH, T4, etc.)	◯	◯	◯	◯	◯
Serum Electrolytes (i.e., Sodium, Potassium, Chloride, etc.)	◯	◯	◯	◯	◯
Serum Liver Function (i.e., Alkaline Phosphatase, Alanine Amino Transferase, Aspartate Amino Transferase, Bilirubin, etc.)	◯	◯	◯	◯	◯
Serum Lipase and/ or Amylase	◯	◯	◯	◯	◯
Serum C-Reactive Protien	◯	◯	◯	◯	◯
Serum Tissue Transglutaminase (TTG)	◯	◯	◯	◯	◯
Fecal Occult Blood Test (FOBT)	◯	◯	◯	◯	◯
Fecal Culture and Sensitivity	◯	◯	◯	◯	◯
Fecal Ova and Parasite	◯	◯	◯	◯	◯

Urine Culture and Sensitivity	◯	◯	◯	◯	◯
Urinalysis	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional laboratory investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic abdominal pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Abdominal X-Ray	◯	◯	◯	◯	◯
Abdominal Ultrasound	◯	◯	◯	◯	◯
Abdominal Computed Tomography (CT)	◯	◯	◯	◯	◯
Abdominal Magnetic Resonance Imaging (MRI)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic images you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic abdominal pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic procedures for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Hydrogen Breath Test (for fructose/ lactose sensitivities)	◯	◯	◯	◯	◯
Endoscopy with biopsies	◯	◯	◯	◯	◯
Endoscopy without biopsies	◯	◯	◯	◯	◯

Local anesthetic injection to rule in or out Abdominal Cutaneous Nerve Entrapment Syndrome (ACNES)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic procedure investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic abdominal pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)

_____

Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing chronic abdominal pain? (e.g., American Academy of Pediatrics Recommendations on Chronic Abdominal Pain in Children)

◯ Yes
◯ No

If yes, please list.

_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with Chronic Pelvic Pain.

	Not at all important	Somewhat important	Important	Very important	Extremely important
Rectal bleeding	◯	◯	◯	◯	◯
Post-coital bleeding	◯	◯	◯	◯	◯
Excessive or unexplained weight loss	◯	◯	◯	◯	◯
Pelvic mass	◯	◯	◯	◯	◯
Dysmenorrhea	◯	◯	◯	◯	◯
Menorrhagia	◯	◯	◯	◯	◯
Vaginal discharge	◯	◯	◯	◯	◯
Tenesmus (i.e., rectal spasm)	◯	◯	◯	◯	◯
Testicular mass	◯	◯	◯	◯	◯
History of physical trauma	◯	◯	◯	◯	◯
History of sexual trauma	◯	◯	◯	◯	◯
History of congenital anomalies	◯	◯	◯	◯	◯

If you can think of other significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) to consider in the diagnostic work up for chronic pelvic pain, please list them here.

_____

What would be your course of action if a patient referred to you has significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology). Please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section.

- ◯ Deny patient with no suggestions to referring provider
- ◯ Deny patient with suggestions to referring provider
- ◯ Re-direct referral to the Emergency Department
- ◯ Re-direct referral to Gynecology and/ or Urology and/ or Pediatrics and/ or other relevant specialist (as outpatient)
- ◯ Accept patient and request referring provider complete required work-up
- ◯ Accept patient and assess yourself
- ◯ Other (will explain below)

If none of the options listed are apart of your practice, please explain/ describe your course of action here

_____

Please rate the importance of completing the following laboratory investigations for patients with Chronic Pelvic Pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Urinalysis	◯	◯	◯	◯	◯
Urine Culture and Sensitivity	◯	◯	◯	◯	◯
Swab for Sexually Transmitted Infections	◯	◯	◯	◯	◯
Serum or urine beta hCG	◯	◯	◯	◯	◯
Serum CBC (i.e., Hemoglobin, Hematocrit, Red Blood Cell count, White Blood Cell count, Platelets, etc.)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional laboratory investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic pelvic pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology).

_____

Please rate the importance of completing the following diagnostic imaging investigations for patients with Chronic Pelvic Pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important

Transvaginal Ultrasound (for females)	◯	◯	◯	◯	◯
Testicular Ultrasound (for males)	◯	◯	◯	◯	◯
Abdominal & Pelvis Ultrasound	◯	◯	◯	◯	◯
Computed Tomography (CT) of pelvis	◯	◯	◯	◯	◯
Magnetic Resonance Imaging (MRI) of pelvis	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic imaging investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic pelvic pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)

_____

Please rate the importance of completing the following diagnostic procedures for patients with Chronic Pelvic Pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Diagnostic laparoscopy	◯	◯	◯	◯	◯
Colonoscopy	◯	◯	◯	◯	◯
Barium enema	◯	◯	◯	◯	◯
Cystoscopy	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list any additional diagnostic procedure investigations you would consider either important, very important or extremely important to consider in the diagnostic work-up of referred patients with chronic pelvic pain WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)

_____

Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing chronic pelvic pain? (e.g., Canadian Association of Radiologists/ Society of Obstetricians and Gynaecologists statement on performing ultrasound examinations of female pelvis)

◯ Yes
◯ No

If yes, please list.

_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic musculoskeletal and/ or joint pain.

	Not at all important	Somewhat important	Important	Very important	Extremely important
Arthralgia with redness and edema	◯	◯	◯	◯	◯
Pain and stiffness in the morning	◯	◯	◯	◯	◯
Pain at night	◯	◯	◯	◯	◯
Bony tenderness	◯	◯	◯	◯	◯
Unexplained weight loss	◯	◯	◯	◯	◯
Systemic signs and symptoms (i.e., rash, diarrhea, etc.)	◯	◯	◯	◯	◯
History of congenital anomalies	◯	◯	◯	◯	◯
History of prior surgery	◯	◯	◯	◯	◯
History of significant physical trauma	◯	◯	◯	◯	◯
Radiculopathy	◯	◯	◯	◯	◯

If you can think of other significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) to consider in the diagnostic work up for chronic musculoskeletal and/ or joint pain, please list them here.

_____

What would be your course of action if a patient referred to you HAS significant clinical indicators (i.e, clinical red flags/ clinical signs of organic pathology). Please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section.

- ◯ Deny patient with no suggestions to referring provider
- ◯ Deny patient with suggestions to referring provider
- ◯ Re-direct referral to Emergency Department
- ◯ Re-direct referral to Rheumatology and/ or Orthopedics and/ or Pediatrics and/ or other relevant specialist (as outpatient)
- ◯ Accept patient and request referring provider complete required work-up
- ◯ Accept patient and assess yourself
- ◯ Other (will explain below)

If none of the options listed are apart of your practice, please explain/ describe your course of action here

_____

Please rate the importance of completing the following laboratory investigations for patients with chronic musculoskeletal and/ or joint pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important

Serum Complete Blood Count (i.e., Hemoglobin, Hematocrit, Red Blood Cell Count, White Blood Cell Count, Platelets, etc.)	◯	◯	◯	◯	◯
Serum Glucose	◯	◯	◯	◯	◯
Serum Calcium	◯	◯	◯	◯	◯
Serum Albumin	◯	◯	◯	◯	◯
Serum Creatinine	◯	◯	◯	◯	◯
Serum Blood Urea Nitrogen	◯	◯	◯	◯	◯
Serum Creatinine Kinase (CK)	◯	◯	◯	◯	◯
Serum Erythrocyte Sedimentation Rate (ESR)	◯	◯	◯	◯	◯
Serum C-Reactive Protein (CRP)	◯	◯	◯	◯	◯
Serum Antinuclear Antibodies (ANA)	◯	◯	◯	◯	◯
Serum Rheumatoid Factor (RF)	◯	◯	◯	◯	◯
Serum Thyroid Function (i.e., TSH, T4, etc.)	◯	◯	◯	◯	◯
Serum Tissue Transglutaminase (TTG)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional laboratory investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic musculoskeletal and/ or joint pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
X-Ray of affected area(s)	◯	◯	◯	◯	◯
Ultrasound of affected area(s)	◯	◯	◯	◯	◯
Computed Tomography (CT) of affected area(s)	◯	◯	◯	◯	◯
Magnetic Resonance Imaging of affected area(s)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional diagnostic imaging investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)

_____

Please rate the importance of completing the following diagnostic procedure investigations for patients with chronic musculoskeletal and/ or joint pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Muscle biopsy	◯	◯	◯	◯	◯
Nerve Conduction Studies (NCS)	◯	◯	◯	◯	◯
Electromyography (EMG)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional diagnostic procedure investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)

_____

Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing chronic musculoskeletal and/ or joint pain in children and adolescents?

◯ Yes
◯ No

If yes, please list.

_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic back pain.

	Not at all important	Somewhat important	Important	Very important	Extremely important
Pain unrelated to activity	◯	◯	◯	◯	◯
Unrelenting night pain	◯	◯	◯	◯	◯
Widespread neurological symptoms	◯	◯	◯	◯	◯
Bilateral sciatica	◯	◯	◯	◯	◯
Radiculopathy	◯	◯	◯	◯	◯

Incontinence (bladder and/ or bowel)	◯	◯	◯	◯	◯
Unexplained weight loss	◯	◯	◯	◯	◯
Fever or chills	◯	◯	◯	◯	◯
History of infection or trauma	◯	◯	◯	◯	◯
History of immunocompromised condition	◯	◯	◯	◯	◯
History of cancer	◯	◯	◯	◯	◯

If you can think of other significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) to consider in the diagnostic work up for chronic back pain, please list them here.

_____

What would be your course of action if a patient referred to you HAS significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology)? Please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section.

- ◯ Deny patient with no suggestions to referring provider
- ◯ Deny patient with suggestions to referring provider
- ◯ Re-direct referral to Emergency Department
- ◯ Re-direct referral to Orthopedics and/ or Neurology and/ or Pediatrics and/ or other relevant specialist
- ◯ Accept patient and request referring provider complete required work-up
- ◯ Accept patient and assess yourself
- ◯ Other (will explain below)

If none of the options listed are apart of your practice, please explain/ describe your course of action here

_____

Please rate the importance of completing the following laboratory investigations for patients with chronic back pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Serum Complete Blood Count (i.e., Hemoglobin, Hematocrit, Red Blood Cell Count, White Blood Cell Count, Platelets, etc.)	◯	◯	◯	◯	◯
Serum Creatinine Kinase (CK)	◯	◯	◯	◯	◯
Serum C-Reactive Protein (CRP)	◯	◯	◯	◯	◯
Serum Erythrocyte Sedimentation Rate (ESR)	◯	◯	◯	◯	◯
Serum Calcium	◯	◯	◯	◯	◯
Serum Alkaline Phosphate	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional laboratory investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)	_____

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic back pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
X-Ray of affected area(s)	◯	◯	◯	◯	◯
Ultrasound of affected area(s)	◯	◯	◯	◯	◯
Computed Tomography (CT) of affected area(s)	◯	◯	◯	◯	◯
Magnetic Resonance Imaging (MRI) of affected area(s)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional diagnostic imaging investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology)	_____
Would you require any diagnostic procedures to be completed before seeing the patient if the patient DOES NOT have any significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology)?	◯ Yes ◯ No
If yes, please list	_____
Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing chronic back pain in children and adolescents?	◯ Yes ◯ No
If yes, please list	_____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with suspected CRPS Type 1

	Not at all important	Somewhat important	Important	Very important	Extremely important
Suspicion of neuropathies	◯	◯	◯	◯	◯
Fever and/ or chills	◯	◯	◯	◯	◯
Suspicion of active bone and/ or soft tissue damage (e.g., stress fracture, ligament injury, etc.)	◯	◯	◯	◯	◯

Other (*please list additional significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology, you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients with suspected CRPS Type 1) _____

What would be your course of action if a patient referred to you HAS significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology)? Please select only one option. If none of the options listed are a part of your practice, please explain/ describe your course of action in the 'other' section.

◯ Deny patient with no suggestions to referring provider
◯ Deny patient with suggestions to referring provider
◯ Re-direct referral to Emergency Department
◯ Re-direct referral to Orthopedics and/ or Neurology and/ or Pediatrics and/ or other relevant specialist (as outpatient)
◯ Accept patient and request referring provider complete required work-up
◯ Accept patient and assess yourself
◯ Other (will explain below)

If none of the options listed are apart of your practice, please explain/ describe your course of action here _____

Please rate the importance of completing the following laboratory investigations for patients with suspected CRPS Type 1, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Complete Blood Count (i.e., Hemoglobin, Hematocrit, Red Cell Count, White Cell Count, Platelets, etc.)	◯	◯	◯	◯	◯
Serum Creatinine Kinase (CK)	◯	◯	◯	◯	◯
Serum C-Reactive Protein (CRP)	◯	◯	◯	◯	◯
Serum Erythrocyte Sedimentation Rate (ESR)	◯	◯	◯	◯	◯

None	◯	◯	◯	◯	◯

Other (*please list additional laboratory investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic imaging investigations for patients with suspected CRPS Type 1, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Duplex Ultrasonography of affected area(s)	◯	◯	◯	◯	◯
Bone scan of affected area(s)	◯	◯	◯	◯	◯
X-Ray of affected area(s)	◯	◯	◯	◯	◯
Magnetic Resonance Imaging (MRI) of affected area(s)	◯	◯	◯	◯	◯
Computed Tomography (CT) of affected area(s)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional diagnostic imaging investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Please rate the importance of completing the following diagnostic procedures for patients with suspected CRPS Type 1, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

	Not at all important	Somewhat important	Important	Very important	Extremely important
Nerve Conduction Studies (NCS)	◯	◯	◯	◯	◯
Local anesthetic injection trial of affected area(s)	◯	◯	◯	◯	◯
None	◯	◯	◯	◯	◯

Other (*please list additional diagnostic procedure investigations you would consider either extremely important, very important or important to consider in the diagnostic work-up of referred patients WITHOUT significant clinical indicators, i.e., clinical red flags/ clinical signs of organic pathology) _____

Do you have/ know of/ use any clinical decision support tools or diagnostic algorithms for diagnosing CRPS in children and adolescents (e.g., Budapest criteria)?	◯ Yes ◯ No
If yes, please list	_____
Please list what patient reported outcomes you consider important to capture/ collect in patients referred to you with any of the primary chronic pain diagnoses listed above PRIOR to acceptance into your program (e.g., Numerical Rating Scale, Brief Pain Inventory, PROMIS Pain Interference Scale, Brief Pain Inventory, BATH Adolescent Pain Questionnaire, etc.).	_____
Do you have any additional comments or feedback regarding the diagnostic approach in pediatric patients with chronic pain?	_____

Delphi Survey Round 2: Attaining Expert Consensus on Significant Clinical Indicators and Diagnostic Approaches that are Required on Patients Prior to Acceptance into Pediatric Chronic Pain Programs

You have participated in the first round of this Delphi study as an expert in the field of pediatric chronic pain. We have since aggregated participant results and found that many survey items have met consensus. However, There are several items that we still require consensus on. We are therefore inviting you to participate in the second round of this Delphi study in attempt to attain further consenus on pending items.

As a friendly reminder, the purpose of this study is to attain expert consensus on all necessary medical diagnostic approaches and indicators that are required on patients prior to acceptance into interdisciplinary pediatric chronic pain programs for common primary chronic pain diagnoses in the pediatric population. For the purpose of this study, diagnoses will be limited to 1) Chronic headaches, 2) Chronic abdominal pain, 3) Chronic pelvic pain, 4) Chrnic musculoskeletal and/ or joint pain, 5) Chronic back pain and 6) Complex Regional Pain Syndrome (CRPS) Type 1.

1) Please provide your record ID which was provided in your invitation email.

_____

2) What is your medical or nursing designation?

◯ Anesthesiologist
◯ General Practitioner
◯ Pediatrician
◯ Registered Nurse
◯ Clinical Nurse Specialist
◯ Advanced Practice Nurse
◯ Other

3) If your medical or nursing designation is not listed above, please provide it here

_____

4) Do you work in an interdisciplinary pediatric chronic pain program/ clinic/ team? (*To note - we define 'interdisciplinary' as a combination of two or more clinical disciplines that work together within one team to serve the pediatric chronic pain population. Disciplines include, but are not limited to: physicians, nurses, physiotherapists, psychologists, psychiatrists, occupational therapists, pharmacists, recreational therapists, etc.)

◯ Yes
◯ No

5) Please state the clinical role you have within your team/ clinic/ program

_____

6) How many years of experience do you have working with the pediatric chronic pain population?

◯ 0-5 years
◯ 5-10 years
◯ 10-20 years
◯ 20-30 years
◯ 30+ years

7) In what geographical location do you work?

◯ Canada
◯ United States of America
◯ Europe
◯ Australia
◯ New Zealand
◯ South America
◯ Asia
◯ Africa

8) Please indicate the province/ state within which you work _____

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic headaches.
***Please note - Consensus has been met on 100% of items in this category from round 1 survey. Additional items listed below have been added as other important significant clinical indicators by participants during round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
9)	Vomiting	○	○	○	○	○
10)	History of family neurological disease	○	○	○	○	○
11)	History of cancer	○	○	○	○	○
12)	History of ventriculoperitoneal (VP) shunt	○	○	○	○	○
13)	History of tooth pain	○	○	○	○	○
14)	Postural headache	○	○	○	○	○
15)	Headache upon wakening	○	○	○	○	○
16)	Weight loss/ loss of appetite	○	○	○	○	○
17)	Loss of developmental milestones	○	○	○	○	○

Please rate the importance of completing the following laboratory investigations for patients with chronic headaches, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 87.5% of the items in this category from the round 1 survey. The items provided below represent laboratory investigations that participants have not yet met consensus on, as well as other laboratory investigations listed as important by participants in the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
18)	Serum Thyroid Function: 1) Not at all important, n=7(31.8%). 2) Somewhat important, n=5 (22.7%). 3) Important, n=9(40.9%). 4) Very important, n=1(4.5%)	○	○	○	○	○
19)	Serum Vitamin D level: Other suggestion	○	○	○	○	○
20)	Serum Ferritin level: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following diagnostic procedure investigations for patients with chronic headaches, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 75% of the items in this category from the round 1 survey. The items provided below represent diagnostic procedure investigations that participants have not yet met consensus on, as well as other laboratory investigations listed as important by participants in the round 1 survey.**

	Not at all important	Somewhat important	Important	Very important	Extremely important
21) Visual acuity examination: 1) Not at all important, n=7(31.8%). 2) Somewhat important, n=7(31.8%). 3) Important, n=4(18.2%). 4) Very important, n=3(13.6%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
22) Papilledema assessment: Other suggestion	○	○	○	○	○

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic abdominal pain.

***Please note - Consensus has been met on 100% of items in this category from round 1 survey. Additional items listed below have been added as other important significant clinical indicators by participants during round 1 survey.**

	Not at all important	Somewhat important	Important	Very important	Extremely important
23) Pain that wakes from sleep: Other suggestion	○	○	○	○	○
24) Family history of a GI cancer: Other suggestion	○	○	○	○	○
25) History of trauma: Other suggestion	○	○	○	○	○
26) Referred back pain: Other suggestion	○	○	○	○	○
27) Bilious emesis: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following laboratory investigations for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 13% of the items in this category from the round 1 survey. The items provided below represent laboratory investigations that participants have not yet met consensus on, as well as additional other laboratory investigations listed as important by participants in the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
28)	Serum Complete Blood Cell Count: 1) Not at all important, n=3(13.6%). 2) Somewhat important, n=10(45.5%). 3) Important, n=4(18.2%). 4) Very important, n=2 (9.1%). 5) Extremely important, n=3(13.6%)	○	○	○	○	○
29)	Serum Glucose: 1) Not at all important, n=8(36.4%). 2) Somewhat important, n=7(31.8%). 3) Important, n=6(27.3%). 4) Very Important, n=0. 5) Extremely Important, n=1(4.5%)	○	○	○	○	○
30)	Serum Albumin: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=6(27.3%). 3) Important, n=7(31.8%). 4) Very important, n=2(9.1%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
31)	Serum Creatinine: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=7(31.8%). 3) Important, n=7(31.8%). 4) Very important, n=1(4.5%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
32)	Serum Blood Urea Nitrogen: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=7(31.8%). 3) Important, n=7(31.8%). 4) Very important, n=1(4.5%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
33)						

	Serum Thyroid Function: 1) Not at all important, n=7(31.8). 2) Somewhat important, n=7(31.8). 3) Important, n=7(31.8). 4) Very important, n=0. 5) Extremely important, n=1(4.5%)	○	○	○	○	○
34)	Serum Electrolytes: 1) Not at all important, n=8(36.4). 2) Somewhat important, n=5(22.7). 3) Important, n=7(31.8). 4) Very important, n=2(9.1). 5) Extremely important, n=0	○	○	○	○	○
35)	Serum Liver Function: 1) Not at all important, n=2(9.1%). 2) Somewhat important, n=8(36.4%). 3) Important, n=6(27.3%). 4) Very important, n=4(18.2%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
36)	Serum Lipase/Amylase: 1) Not at all important, n=3(13.6%). 2) Somewhat important, n=7(31.8%). 3) Important, n=6(27.3%). 4) Very important, n=6(27.3%). 5) Extremely important, n=0	○	○	○	○	○
37)	Serum C-Reactive Protein: 1) Not at all important, n=5(22.7%). 2) Somewhat important, n=8(36.4%). 3) Important, n=5(22.7%). 4) Very important, n=3(13.6%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
38)	Serum Tissue Transglutaminase: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=5(22.7%). 3) Important, n=7(31.8%). 4) Very important, n=2(9.1%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
39)						

	Fecal Occult Blood Test: 1) Not at all important, n=7(31.8%). 2) Somewhat important, n=5(22.7%). 3) Important, n=5(22.7%). 4) Very important, n=4(18.2%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
40)	Fecal Culture & Sensitivity: 1) Not at all important, n=9(40.9%). 2) Somewhat important, n=6(27.3%). 3) Important, n=4(18.2%). 4) Very important, n=2(9.1%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
41)	Fecal Ova & Parasite:1) Not at all important, n=9(40.9%). 2) Somewhat important, n=6(27.3%). 3) Important, n=4(18.2%). 4) Very important, n=2(9.1%). 5) Extremely important, n=1(4.5%	○	○	○	○	○
42)	Urinalysis: 1) Not at all important, n=7(31.8%). 2) Somewhat important, n=8(36.4%). 3) Important, n=5(22.7%). 4) Very important, n=1(4.5%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
43)	H. Pylori screen: Other suggestion	○	○	○	○	○
44)	Fecal calprotectin: Other suggestion	○	○	○	○	○
45)	Serum Erythrocyte Sedimentation Rate: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 50% of the items in this category from the round 1 survey. The items provided below represent diagnostic imaging investigations that participants have not yet met consensus on. No other important diagnostic investigations were listed as important by participants in this category from round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
46)						

	Abdominal X-Ray: 1) Not at all important, n=11(50%). 2) Somewhat important, n=4(18.2%). 3) Important, n=3(13.6%). 4) Very important, n=3(13.6%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○
47)	Abdominal Ultrasound: 1) Not at all important, n=1(4.5%). 2) Somewhat important, n=14(63.6%). 3) Important, n=4(18.2%). 4) Very important, n=3(13.6%). 5) Extremely important, n=0	○	○	○	○	○

Please rate the importance of completing the following diagnostic procedure investigations for patients with chronic abdominal pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 100% of the items in this category from the round 1 survey. The items provided below represent other diagnostic imaging investigations that participants listed as important during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
48)	Gastric emptying study: Other suggestion	○	○	○	○	○

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic pelvic pain.

***Please note - Consensus has been met on 100% of items in this category from round 1 survey. Additional items listed below have been added as other important significant clinical indicators by participants during round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
49)	Dyspareunia (pain with intercourse): Other suggestion	○	○	○	○	○
50)	Hematuria: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following laboratory investigations for patients with chronic pelvic pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 0% of the items in this category from the round 1 survey. The items provided below represent laboratory investigations that participants have not yet met consensus on. No additional important laboratory investigations were listed by participants in this category during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
51)	Urinalysis: 1) Not at all important, n=5(22.7%). 2) Somewhat important, n=4(18.2%). 3) Important, n=6(27.3%). 4) Very important, n=1(4.5%). 5) Extremely important, n=6(27.3%)	○	○	○	○	○
52)	Urine Culture & Sensitivity: 1) Not at all important, n=4(18.2%). 2) Somewhat important, n=6(27.3%). 3) Important, n=6(27.3%). 4) Very important, n=2(9.1%). 5) Extremely important, n=4(18.2%)	○	○	○	○	○
53)	Swab for Sexually Transmitted Infections: 1) Not at all important, n=3(13.6%). 2) Somewhat important, n=8(36.4%). 3) Important, n=3(13.6%). 4) Very important, n=2(9.1%). 5) Extremely important, n=6(27.3%)	○	○	○	○	○
54)	Serum or Urine beta hCG: 1) Not at all important, n=4(18.2%). 2) Somewhat important, n=5(22.7%). 3) Important, n=4(18.2%). 4) Very important, n=3(13.6%). 5) Extremely important, n=6(27.3%)	○	○	○	○	○
55)	Serum Complete Blood Cell count: 1) Not at all important, n=4(18.2%). 2) Somewhat important, n=6(27.3%). 3) Important, n=8(36.4%). 4) Very important, n=0. 5. Extremely important, n=4(18.2%)	○	○	○	○	○

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic pelvic pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 40% of the items in this category from the round 1 survey. The items provided below represent diagnostic imaging investigations that participants have not yet met consensus on. No additional diagnostic imaging investigations were listed by participants in this category during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
56)	Testicular ultrasound: 1) Not at all important, n=9(40.9%). 2) Somewhat important, n=5(22.7%). 3) Important, n=4(18.2%). 4) Very important, n=2(9.1%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
57)	Abdominal & Pelvis ultrasound: 1) Not at all important, n=8(36.4%). 2) Somewhat important, n=6(27.3%). 3) Important, n=3(13.6%). 4) Very important, n=3(13.6%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic musculoskeletal and/or joint pain.

***Please note - Consensus has been met on 90% of items in this category from round 1 survey. The items provided below represent significant clinical indicators that participants have not yet met consensus on, as well as other laboratory investigations listed as important by participants in the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
58)	History of prior surgeries: 1) Not at all important, n=2(9.1%). 2) Somewhat important, n=6(27.3%). 3) Important, n=5(22.7%). 4) Very important, n=7(31.8%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
59)	History of cancer: Other suggestion	○	○	○	○	○
60)						

	Positive trigger points: Other suggestion	○	○	○	○	○
61)	Known Ehlers-Danlos Syndrome (EDS): Other suggestion	○	○	○	○	○

Please rate the importance of completing the following laboratory investigations for patients with chronic musculoskeletal and/ or joint pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 38% of the items in this category from the round 1 survey. The items provided below represent laboratory investigations that participants have not yet met consensus on, as well as additional items listed by participants that were considered important during the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
62)	Serum Complete Blood Cell Count: 1) Not at all important, n=5(22.7%). 2) Somewhat important, n=8(36.4%). 3) Important, n=4(18.2%). 4) Very important, n=3(13.6%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
63)	Serum Blood Urea Nitrogen: 1) Not at all important, n=11(50%). 2) Somewhat important, n=4(18.2%). 3) Important, n=6(27.3%). 4) Very important, n=1(4.5%). 5) Extremely important, n=0	○	○	○	○	○
64)	Serum Creatinine Kinase: 1) Not at all important, n=6 (27.3%). 2) Somewhat important, n=4(18.2%). 3) Important, n=7(31.8%). 4) Very important, n=3(13.6%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
65)	Serum C-Reactive Protein: 1) Not at all important, n=6 (27.3%). 2) Somewhat important, n=5(22.7%). 3) Important, n=5(22.7%). 4) Very important, n=4(18.2%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
66)						

	Serum Antinuclear Antibodies: 1) Not at all important, n=5 (22.7%). 2) Somewhat important, n=9 (40.9%). 3) Important, n=2 (9.1%). 4) Very important, n=5 (22.7%). 5) Extremely important, n=1 (4.5%)	○	○	○	○	○
67)	Serum Rheumatoid Factor:1) Not at all important, n=5 (22.7%). 2) Somewhat important, n=9 (40.9%). 3) Important, n=2 (9.1%). 4) Very important, n=5 (22.7%). 5) Extremely important, n=1 (4.5%)	○	○	○	○	○
68)	Serum Thyroid Function: 1) Not at all important, n=7 (31.8%). 2) Somewhat important, n=6 (27.3%). 3) Important, n=6 (27.3%). 4) Very important, n=2 (9.1%). 5) Extremely important, n=1 (4.5%)	○	○	○	○	○
69)	Serum HLA B27: Other suggestion	○	○	○	○	○
70)	Serum Vitamin D: Other suggestion	○	○	○	○	○
71)	Serum Vitamin B12: Other suggestion	○	○	○	○	○
72)	Serum Folate: Other suggestion	○	○	○	○	○
73)	Serum Complement Levels: Other suggestion	○	○	○	○	○
74)	Urinalysis: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic musculoskeletal and/ or joint pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic

***Please note: Consensus has been met on 25% of the items in this category from the round 1 survey. The items provided below represent diagnostic imaging investigations that participants have not yet met consensus on. No additional diagnostic imaging investigations were listed by participants in this category during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
75)						

	X-Ray of affected area(s): 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=3 (13.6%). 3) Important, n=5(22.7%). 4) Very important, n=5(22.7%). 5) Extremely important, n=3(13.6%)	○	○	○	○	○
76)	Ultrasound of affected area(s): 1) Not at all important, n=7(31.8%). 2) Somewhat important, n=7(31.8%). 3) Important, n=6(27.3%). 4) Very important, n=2(9.1%). 5) Extremely important, n=0	○	○	○	○	○
77)	Magnetic Resonance Imaging of affected area(s): 1) Not important, n=7(31.8%). 2) Somewhat important, n=6(27.3%). 3) Important, n=6(27.3%). 4) Very important, n=3(13.6%). 5) Extremely important, n=0.	○	○	○	○	○

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with chronic back pain.

***Please note - Consensus has been met on 90% of items in this category from round 1 survey. The items provided below represent significant clinical indicators that participants have not yet met consensus on, as well as other items listed as important by participants in the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
78)	Pain unrelated to activity: 1) Not at all important, n=2(9.1%). 2) Somewhat important, n=6(27.3%). 3) Important, n=8(36.4%). 4) Very important, n=4(18.2%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
79)	Constant pain: Other suggestion	○	○	○	○	○
80)	Redness and edema at painful site: Other suggestion	○	○	○	○	○
81)	History of scoliosis: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following laboratory investigations for patients with chronic back pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 50% of the items in this category from the round 1 survey. The items provided below represent laboratory investigations that participants have not yet met consensus on, as well as additional items listed by participants that were considered important during the round 1 survey.**

		Not at all important	Somewhat important	Important	Very important	Extremely important
82)	Serum Complete Blood Cell Count: 1) Not at all important, n=9(40.9%). 2) Somewhat important, n=6(27.3%). 3) Important, n=6(27.3%). 4) Very important, n=1(4.5%). 5) Extremely important, n=0	○	○	○	○	○
83)	Serum C-Reactive Protein: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=8(36.4%). 3) Important, n=5(22.7%). 4) Very important, n=2(9.1%). 5) Extremely important, n=0	○	○	○	○	○
84)	Serum Erythrocyte Sedimentation Rate: 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=9(40.9%). 3) Important, n=5(22.7%). 4) Very important, n=2(9.1%). 5) Extremely important, n=0	○	○	○	○	○
85)	Serum Antinuclear Antibody: Other suggestion	○	○	○	○	○

Please rate the importance of completing the following diagnostic imaging investigations for patients with chronic back pain, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 50% of the items in this category from the round 1 survey. The items provided below represent diagnostic imaging investigations that participants have not yet met consensus on. No additional diagnostic imaging investigations were listed by participants in this category during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
86)						

	X-Ray of affected area(s): 1) Not at all important, n=5(22.7%). 2) Somewhat important, n=5(22.7%). 3) Important, n=7(31.8%). 4) Very important, n=2(9.1%). 5) Extremely important, n=3(13.6%)	○	○	○	○	○
87)	Magnetic Resonance Imaging of affected area(s): 1) Not at all important, n=6(27.3%). 2) Somewhat important, n=5(22.7%). 3) Important, n=7(31.8%). 4) Very important, n=3(13.6%). 5) Extremely important, n=1(4.5%)	○	○	○	○	○

Please rate the importance of considering the following significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) in the diagnostic work-up of referred patients with Complex Regional Pain Syndrome (CRPS), Type 1.
***Please note - Consensus has been met on 100% of items in this category from round 1 survey. Additional items listed below have been added as other important significant clinical indicators by participants during round 1 survey.**

		Not at all important	Somewhat important	Very important	Extremely important
88)	Neurovascular changes: Other suggestion	○	○	○	○
89)	History of surgery: Other suggestion	○	○	○	○
90)	History of trauma: Other suggestion	○	○	○	○
91)	Concern of pulselessness: Other suggestion	○	○	○	○

Please rate the importance of completing the following diagnostic imaging investigations for patients with Complex Regional Pain Syndrome (CRPS), Type 1, WITHOUT significant clinical indicators (i.e., clinical red flags/ clinical signs of organic pathology) prior to referral/ acceptance to your program/ team/ clinic
***Please note: Consensus has been met on 60% of the items in this category from the round 1 survey. The items provided below represent diagnostic imaging investigations that participants have not yet met consensus on. No additional diagnostic imaging investigations were listed by participants in this category during round 1 survey**

		Not at all important	Somewhat important	Important	Very important	Extremely important
92)						

	X-Ray of affected area(s): 1) Not at all important, n=5(22.7%). 2) Somewhat important, n=7(31.8%). 3) Important, n=4(18.2%). 4) Very important, n=2(9.1%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○
93)	Magnetic Resonance Imaging of affected area(s): 1) Not at all important, n=9(40.9%). 2) Somewhat important, n=5(22.7%). 3) Important, n=4(18.2%). 4) Very important, n=2(9.1%). 5) Extremely important, n=2(9.1%)	○	○	○	○	○

94) Do you have any additional comments or feedback regarding the results from the round 1 Delphi survey? _____