The PARTNERSHIP Study: Exploring Recommendations and Practice Using EMRS To Help Kids In Pain

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Notes on the *Print Edition*

This is the *Print Edition* of the thesis, optimised for physical printing and binding. It includes blank pages where needed to ensure new chapters, appendices and major front and back matter sections start on odd-numbered pages.

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Abstract

Background

Studies from multiple countries report that most hospitalised children, especially the youngest and sickest, experience pain that is often severe yet inadequately treated. Undertreated pain is associated with harmful immediate and lifelong consequences impacting children, families, and communities. A growing evidence base demonstrates that electronic medical records (EMR) and inpatient portal systems (electronic personal health record applications linked to hospital EMRs) can improve care quality and safety, child and family engagement, and outcomes during hospitalisation.

Aim

The research reported in this thesis addressed the research question, 'How can we design and use EMRs and patient portal systems to optimize pain care and outcomes for hospitalised children with pain?' It examined recommendations, practices, and perspectives regarding EMR and patient portal use and designs to optimise pain care and outcomes for hospitalized children and their families.

Methods

Underpinned by a pragmatic research paradigm and the Quality Health Outcomes Model, this exploratory multiphase mixed methods project comprised three original discrete but interrelated studies. Each study addressed a distinct objective of either qualitative (Study One and Study Two) or quantitative (Study Three) orientation. The authors applied qualitative content analysis to examine qualitative data managed in NVivo 10© software (QRS International, 2014) and descriptive statistics and Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) for Windows (Version 22, 2013) for quantitative data analysis.

Results

In Study One, 14 nursing and medical experts from five countries (USA, Canada, UK, Australia, and Qatar) were interviewed online using Zoom for Healthcare. The authors constructed four broad categories through qualitative content analysis. These were (1) capturing the pain story, (2) working with user-friendly systems, (3) patient and

family engagement and shared decision-making, and (4) augmenting pain knowledge and awareness.

Study Two examined the perspectives of primary caregivers of hospitalised children and of hospitalised youth about using an inpatient portal to support their engagement in pain care while in hospital. Twenty participants (15 caregivers; 5 youth) with various painful conditions in one tertiary referral paediatric hospital participated in semi-structured interviews. The authors applied qualitative content analysis to the data and developed three broad categories: (1) Connecting and sharing knowledge about pain, (2) User-centred designs, and (3) Preserving roles.

Study Three was a 14-item online cross-sectional survey of clinicians working at one of the five Australian paediatric hospitals with a comprehensive EMR. One hundred and ninety-four clinicians responded. The majority (74%) were nurses: most used EPIC (49%) or Cerner (38%) systems. Most (74%) agreed the EMR supported them in initiating pharmacological pain interventions. Fewer agreed that the EMR supported the initiation of physical (43%) or psychological interventions (37%). Forty-four percent reported their EMR had prompts reminding them about pain care and 78% of these perceived prompts as useful. Most agreed the EMR supported pain care provision (85%) and documentation (89%). Only 39% agreed the EMR improved their treatment of pain compared to before using EMR, and 31% agreed EMR improved how they involve children and families in pain care compared to when they did not use an EMR.

Conclusion

The research associated with this uniquely contributes to the literature on EMR and patient portal systems in pain care for hospitalised children. Three key recommendations to guide future clinical practice, research, and policy are provided to ensure continued progress towards improving outcomes for hospitalised children and their families. These recommendations are to leverage EMR and patient portal technologies to; (1) increase the visibility of the multidimensionality of pain, (2) empower children and families and support self-management, (3) increase clinician pain knowledge and awareness, and quality care.

Declaration

This is to certify that:

1. This thesis comprises only my original work toward the Doctor of Philosophy except where indicated in the preface.
2. The research reported in this thesis was conducted in accordance with the principles for the ethical treatment of human participants.
3. Due acknowledgment has been made in the text to all other material used.
4. This work has not been submitted previously, in whole or in part, to qualify for any other higher academic degree.
5. The thesis is less than 100,000 words long, excluding tables, bibliographies, and appendices.

Nicole Marie Pope

January 2024

Preface

This thesis is a compilation of original material written specifically for the thesis and publications arising from the research conducted as part of this project. The Advisory Committee has approved the inclusion of these publications in this thesis.

Publications Arising from This Thesis

This thesis contains two published manuscripts and a manuscript under review in an international journal. There is no requisite for written permissions from the journal publishers per the publisher guidelines. This right extends to posting the thesis to the University of Melbourne's repository as long as the manuscript is within the thesis and unable to be independently downloaded. To ensure consistency, page numbers, tables, figures, and spelling have been adjusted to conform to thesis formatting. All references are integrated into the final thesis reference list. Manuscript supplementary materials are included as appendices.

Publications included in this thesis.

Publication 1 (Chapter 5)

Pope, N., Candido, L.K., Crelin, D., Palmer, G., South, M. Harrison, D. (2023). A call to focus on digital health technologies in hospitalised children's pain care: clinician experts' qualitative insights on optimizing electronic medical records to improve care. *PAIN*.167(7):1608-1615. http://dx.doi.org/http://dx.doi.org/10.1097/j.pain.0000000000002863.

Publication 2 (Chapter 7)

Pope N, Jones S, Crellin D, Palmer G, South M, Harrison D. (2023). Seeing the light in the shade of it: Primary caregiver and youth perspectives on using an inpatient portal for pain care during hospitalization. *PAIN.* Epub ahead of print. http://dx.doi.org/10.1097/j.pain.0000000000003039.

Publication 3 (Chapter 9)

Pope N, Keyser J, Crellin D, Palmer G, South M, Harrison D. (Under-review). Using electronic medical records to care for hospitalised children in pain: Australian national survey of clinicians. *Journal of Child Health Care.* [Under Review].

Other Publications, Presentations and Awards Arising from This Thesis

Other Publications During My Candidature

Bueno, M., Pope, N., & Harrison, D., Pain in Infants and Children (Book Chapter). In: Christo, P., Katzman, J., Williams, K., & Gallagher, R. Pain in Vulnerable Populations. Oxford University Press: NY [In Press].

Harrison D, Pope N, Jones S, Larocque C, Jodi Wilding J, Campbell-Yeo M, Gilmore L, Harrold J, Hu J, Lavin Venegas C, Modanloo S, Nicholls S, O'Flaherty P, Premji SS, Reszel J, Semenic S, Squires J, Stevens B, Taljaard M, Trepanier MJ, O'Grady Venter K, Dunn S. Multisite cross-sectional study of nursing leaders' and clinical nurses' perceptions of implementation of a parent-targeted educational video and recommended pain management, for improving newborn pain treatment. *Journal of Neonatal Nursing* [Under-review].

Conference Presentations During My Candidature

Pope N, Crellin DJ, Palmer G, South M, Harrison D. Applying the Quality Health Outcomes Model in a Multiphase Mixed Methods Study. The University of Melbourne Research Colloquium, Melbourne, Australia. 2021

Pope N, Crellin DJ, Palmer G, South M, Harrison D. Using Information Power to Guide Sample Size in a Qualitative Study. Pain in Child Health (PICH) PICH2GO, Canada (online). 2021

Pope N, Korki de Candido L, Crellin DJ, Palmer G, South M, Harrison D. A Focus on Digital Health Technologies in Hospitalised Children's Pain Care; Qualitative Recommendations of Expert Clinicians. International Association for the Study of Pain (IASP) World Congress on Pain. Toronto, Canada. 2022

Pope N, Korki de Candido L, Crellin DJ, Palmer G, South M, Harrison D. Recommendations and Practice Using EMRs to Help Kids in Pain. PICH x IASP Paediatric SIG Pain Symposium, 2022, Toronto, Canada. 2022

Pope N, Korki de Candido L, Crellin DJ, Palmer G, South M, Harrison D. Expert Recommendations using Electronic Medical Records to Care for Children in Pain. RCH Research Symposium, Melbourne, Australia. 2022

Pope N, Crellin DJ, Palmer G, South M, Harrison D. The PARTNERSHIP Project: Exploring Recommendations and Practice to Help Kids in Pain. Australian Pain Society PainSTAR. Adelaide, South Australia. 2022

Pope N, Jones S, Crellin DJ, Palmer G, South M, Harrison D. Inpatient Portals for Paediatric Pain Care: Perspectives of Primary Caregivers and Youth. Australian Pain Society, Annual Scientific Meeting, Canberra, Australia. 2023

Pope N, Fechner R, Wallwork S, Harrison D, Stinson J. PICH Down Under: Pain in Child Health Australian Trainee Workshop. Australian Pain Society (APS), Annual Scientific Meeting (ASM), Canberra, Australia. 2023

Pope N, Jones S, Crellin DJ, Palmer G, South M, Harrison D. Let's Put the Puzzle Together to Get the End Result: Primary Caregiver and Youth Insights into Using an Inpatient Portal for Pain. RCH Research Symposium, Melbourne, Australia. 2023

Pope N, Jones S, Crellin DJ, Palmer G, South M, Harrison D. 'Putting the Jigsaw Puzzle Together': Perspectives of Primary Caregivers and Youth About Using Inpatient Portals for Pain Care. Pain In Child Health Webinar Series. Toronto, Canada (online). 2023

Pope N, Jones S, Crellin DJ, Palmer G, South M, Harrison D. Seeing the light in the shade of it. Primary Caregiver and Youth Perspectives on Using a Hospital Portal for Pain Care. International Symposium on Paediatric Pain, Halifax, Canada. 2023

Pope N, Mohabir V, Stinson J, Zempsky W. Harnessing the Power of Digital Health Technologies for Paediatric Acute and Chronic Pain. Panel Discussion. International Symposium on Paediatric Pain, Halifax, Canada. 2023

Pope N, Jones S, Crellin DJ, Palmer G, South M, Harrison D. Youth and Parent Perspectives about Using a Patient Portal for Pain Care During Hospitalization. Murdoch Children's Research Institute Symposium. Melbourne, Australia. 2023

Pope N, Keyser J, Crellin DJ, Palmer G, South M, Harrison D. Recommendations and practices using hospital-based technologies to optimise pain care for children and their families. The Royal Children's Hospital, Tuesdays@2pm. The Royal Children's Hospital, Melbourne, Australia. 2023

Pope N, Keyser J, Crellin DJ, Palmer G, South M, Harrison D. Current Practices Using EMRs for hospitalised Children's Pain: An Australian National Clinician Survey. The University of Melbourne Research Colloquium, Melbourne, Australia. 2023

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2021-2024	The Be Sweet to Babies Studentship, The University of Melbourne. $4500 AUD annual stipend-top up (Appendix B)
2021	The Vera Scantlebury Brown Memorial, The University of Melbourne. $8000 AUD (Appendix C)
2022	Pain in Child Health (PICH) Travel Award. $1500 CAD (Appendix E)

2022	Melbourne Abroad Travel Scholarship, The University of Melbourne. $1000 AUD (Appendix E)
2023	The Prince Henrys' Affiliates Scholarship, The Australian Nurses Memorial Centre, Melbourne. $5000 AUD (Appendix F)
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2023	Be Sweet to Babies Travel Scholarship. $5000 AUD (Appendix H)
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2023	Pain in Child Health (PICH) Postdoctoral Fellowship Award supported by the Louise and Alan Edwards Foundation. $50 000 CAD (Appendix L)
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Contributions by Others

As supervisors, Professor Denise Harrison, Dr. Dianne Crellin, Associate Professor Greta Palmer, and Professor Mike South contributed to the thesis's conceptualisation, writing, and editing. Contributions to the research design, data interpretation, and manuscript editing are outlined in the respective chapters containing submitted manuscripts.

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I kept my eye on the ball and played the full shot.

I dedicate this work to sick, hospitalised babies, children, and their families.

My aim for this work was to create positive changes for you. Wishing you comfort during hospitalisation.

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List of Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ATPH	Australian Tertiary Paediatric Hospital
CBT	Cognitive Behavioural Therapy
CDS	Clinical Decision Support
CLABSI	Central Line-Associated Bloodborne Infections
CPOE	Computerised Provider/Physician Order Entry
COVID-19	Coronavirus 2019
ED	Emergency Department
EHR	Electronic Health Record
EMR	Electronic Medical Record
eMAR	Electronic Medication Administration Record
FLACC	Faces, Legs, Activity, Cry, Consolability
FPS-R	Faces Pain Scale-Revised
GP	General Practice
HCP	Healthcare Professional
HoD	Heads of Department
HREC	Human Research Ethics Committee
ICU	Intensive Care Unit
IV	Intravenous
IM	Intramuscular
KT	Knowledge Translation
MBPS	Modified Behavioural Pain Scale
MCRI	Murdoch Children's Research Institute
NHS	National Health Service
NICU	Neonatal Intensive Care Unit
NRS	Numerical Rating Scale
NSAID	Non-Steroidal Anti-Inflammatory Drug
NSW	New South Wales
N2O	Nitrous Oxide
QCA	Qualitative Content Analysis
QHOM	Quality Health Outcomes Model

QLD	Queensland
QoL	Quality of Life
PCG	Primary Caregiver
PDSA	Plan Do Study Act
PI	Principal Investigator
PICU	Paediatric Intensive Care Unit
PPML	The Paediatric Pain Mailing List
RCH	The Royal Children's Hospital, Melbourne
RCT	Randomised Control Trial
REDCap®	Research Electronic Data Capture
SKIP	Solutions For Kids in Pain
SPSS	Statistical Package for Social Sciences
UK	United Kingdom
US/A	United States/United States of America
VAS	Visual Analogue Scales
VIC	Victoria
WBFPS	Wong-Baker Faces Pain Scale
WHO	World Health Organization

Nomenclature

Electronic medical record (EMR) systems and electronic health records (EHRs) are frequently used interchangeably in the literature. In this thesis, the term *electronic medical record (EMR)* is used and describes a complex hospital-based digital software system comprising patient medical information, such as vital signs, prescribed medications, test results, and clinical notes, that clinicians use to support patient care. These EMR systems possess mature software and clinical decision support tools to guide best practices at the point of care. They replace paper-based processes in hospitals. Patient portal systems are patient-facing tools that can be used via a web interface or mobile phone application, and offer patients access to aspects of their health information contained within an EMR. They also allow patients to view and book appointments, request, and review prescriptions, and facilitate patient-clinician communication via secure synchronous (real-time with both participants active simultaneously) or asynchronous (where participants respond to each other but not immediately) messaging.

Multiple terms exist in the literature to describe a parent, including primary caregiver, guardian, or carer. In this thesis, *primary caregiver* (PCG) refers to mothers, fathers, guardians, or any person with primary caregiver responsibilities for a child. A *child* is defined in this thesis as a person aged from birth to 18 years old. A *youth* and *adolescent* are any person aged between 12 years to 18 years old.

In this thesis, interventions for pain are categorised as pharmacological, physical, or psychological. Pharmacological interventions are medicines delivered by any route and dose and include topical agents and sucrose. Physical interventions include those that involve bodily movements, such as physiotherapy, muscle strengthening, sports, and conditioning, and passive physical interventions, such as comfort positioning, heat/cold, skin-to-skin care, and breastfeeding. Psychological interventions are cognitive or behavioural strategies, including cognitive behavioural therapy (CBT), behaviour therapy, hypnosis and distraction, and mindfulness.

Chapter One

1

Introduction

If I were to ask you to draw pain, to make a visual representation of the impact and meaning of pain to you, what would it look like?

Take a minute to think about it.

Setting the Scene

The research associated with this thesis follows on from my previous Master of Philosophy (MPhil) (Human Research Ethics Committee (HREC) approved) research exploring hospitalised children's pain care. Young, hospitalised children aged four to eight years old who suffered pain while in the hospital shared their experiences. Their voices, insights, knowledge, and expertise in their own pain experience were shared through their drawings and were tools for making the sometimes invisible or unseen suffering they face visible.

In conducting my MPhil research and in my clinical practice as a registered nurse, I was exposed to the harmful short and long-term effects of pain on children, physiologically, behaviourally, and psychologically, and on their families. I was also made aware of the literature describing that despite robust evidence of effective strategies to treat pain in hospitalised children, hospitalised children continue to suffer from inadequate and poorly managed pain.

Through this exposure, I learned that (1) the assessment of children's pain requires a broad approach that seeks to capture the impact of pain on physical, emotional, and social role function as well as pain intensity, (2) effective pain treatment calls for multimodal approaches beyond pharmacological treatments integrating psychological and physical modalities, (3) children in pain need to feel secure. Primary caregivers and clinicians play an essential role in fostering a sense of security for hospitalised children with pain, and (4) models of pain care are rapidly evolving with the modern use of digital technology.

Just as we have seen advancements in our knowledge and understanding of pain science, healthcare systems worldwide have witnessed an unprecedented evolution and investment in digital technologies to advance healthcare processes, synchronise multidisciplinary care team efforts, facilitate information exchange, and improve outcomes. Hospital EMRs possess mature software and clinical decision support tools that can guide best practices at the point of care to streamline clinical interactions and eliminate variability and errors. The ubiquitous use of mobile devices has also generated a cultural and technological shift. Devices such as smartphones and iPads are considered familiar interfaces, and society and healthcare have become accustomed to using these devices in their daily lives and as knowledge repositories.

It is essential that in light of technological and cultural trends, we study the relationship between pain care practices and the imminent widespread implementation of hospital-based

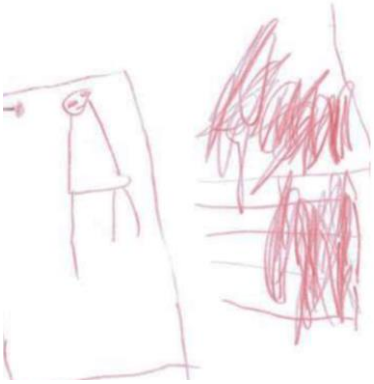
patient and clinician-facing digital technologies. The research undertaken as part of this Doctor of Philosophy (Ph.D.) thesis aspired to answer this need. It is the first to examine the role of electronic medical records and patient portal systems in hospitalised children's pain care. This work is also innovative because it marked the first step in establishing a program of research designed to study the use of digital technology in children's pain. I am the grateful recipient of a post-doctoral fellowship to pursue this work.

'I felt very sad because my arm was hurting'.
8-year-old girl

'It hurt a lot and I felt a bit sad'.
7 year old girl

'I felt sad'.
5 year old boy

'My mum feeled a bit sad, and I was being ok'.
7 year old boy



'It was about the, the lots of blood flooding the steps'.
5 year old boy

Child and Adolescent Health Service HREC Approval: 2014082EP

Preface

Over the past two decades, there has been a growing commitment among stakeholders from multiple disciplines to effectively assess, prevent, minimise, and treat hospitalised children's pain. However, major gaps in our clinical practice persist. This research

program focuses on the use of hospital-based digital health technology, specifically EMR and patient portal systems, in hospitalised children's pain care. In this chapter, the thesis context, background to paediatric pain, and its significance are outlined. The aim and three associated, interrelated objectives are presented. The chapter concludes with a summary of the thesis structure and the research components contained within each chapter.

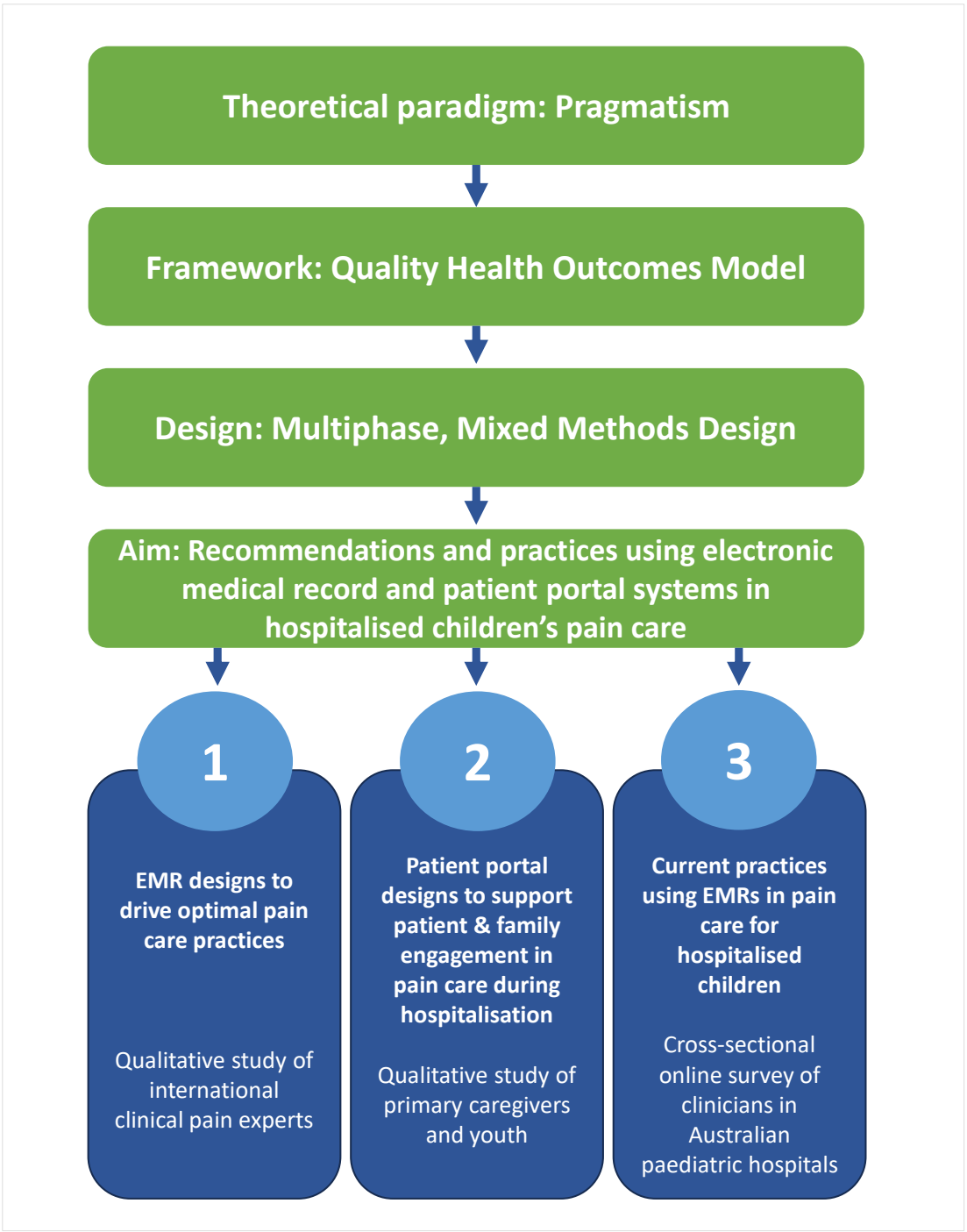
1.1 Thesis Context

Hospitalised children's pain is complex and challenging; EMR and patient portal designs offer promising means to drive optimal pain care practices and improve outcomes for children and families. The research reported in this thesis addressed the research question, 'How can we design and use EMRs and patient portal systems to optimize pain care and outcomes for hospitalised children with pain?' It examined recommendations, practices, and perspectives regarding EMR and patient portal use and designs to optimise pain care and outcomes for hospitalized children and their families. The aim was achieved by conducting three studies that addressed three interconnected objectives:

1. To explore the perspectives of international paediatric clinical pain experts about EMR designs that drive optimal child and family-centred pain care practices in hospitalised settings.
2. To examine the perspectives of primary caregivers of hospitalised children (0-18 years) and of hospitalised youth (12-18 years) about their potential use of an inpatient portal to support their engagement in their/their child's pain care.
3. To examine how paediatric clinicians use EMRs in hospitalised children's pain care in Australian tertiary paediatric hospitals.

Although there are many different elements to using EMR and patient portal systems in hospitalised children's pain care, three components are investigated in this thesis. These components underpinned by the thesis aim are presented in Figure 1.1.

Figure 1.1
Thesis aim and associated components



In understanding how these components contribute to the aim of this thesis, it is necessary to outline the current situation in paediatric pain and its implications, the opportunities that EMR and patient portal systems present, and provide a rationale for this work.

1.2 Background

Data from hospitals worldwide show that a high proportion of hospitalised children suffer from undertreated and preventable pain (Senger et al., 2021; Vejzovic et al., 2020). This is despite the widespread availability of evidence-based guidelines developed to address pain in hospitalised children of all ages. Pain may result from injury or illness, medical or surgical conditions, or painful diagnostic procedures and therapeutic interventions. A large European study, including 574 hospitalised children across four countries, demonstrated that most (87%; n= 504/574) paediatric patients underwent a painful procedure every 24 hours during admission (Vejzovic et al., 2020). Many described their pain as moderate to severe (Vejzovic et al., 2020). Similarly, a Canadian study that included 84 hospitalised children from birth to 16 years of age showed that pain was reported by most children (n=69/84; 82%), most often moderate to severe pain, and mostly from needle procedures (Senger et al., 2021). Critically unwell neonates are particularly vulnerable to undertreated pain. Prevalence studies demonstrate that neonates in a neonatal intensive care unit (NICU) can undergo up to 17 painful procedures each day (Cruz et al., 2016), many performed without any or adequate pain relief (Cruz et al., 2016). Hospitalised children with severe and chronic medical conditions also suffer inadequately treated disease-related pain and pain from invasive procedures (Fortier et al., 2020; Plummer et al., 2021).

1.2.1 The Importance of Early Life Pain

Pain is distressing for children and their families, and undertreated or poorly managed pain can lead to adverse short and longer-term biopsychosocial outcomes impacting children (Grunau et al., 2021; McMurtry et al., 2016; Walker, 2019a). The immature and developing neonatal nervous system is particularly susceptible to injury-induced changes to brain structure and function that can alter development and future pain responses (Williams & Lascelles, 2020). A systematic review of empirical studies (n=13) showed a strong positive association between acute pain exposure during neonatal intensive care and long-term changes in structure and subsequent adverse cognitive, motor, and developmental outcomes later in life (Valeri et al., 2015). Exposure to painful procedures during neonatal development also influences future sensitivity to noxious stimuli. For example, Valeri and colleagues found that a greater number of painful neonatal procedures were associated with higher self-reported pain intensity during venepuncture at 7.5 years among children born very preterm (Valeri et al., 2016). Repeated tissue injury, such as

heel lance, is known to induce sensitisation (Fitzgerald & McKelvey, 2016; Walker, 2019b); the persistence of sensitisation is a key characteristic of many types of chronic pain (DiLorenzo et al., 2016).

Alongside early neurodevelopmental effects, undertreated pain in children is associated with other negative short and long-term physiological, psychological, and social health consequences negatively impacting children, their families, health services, and communities. Poorly managed pain in hospitalised children is linked to delayed recovery from illness, surgery, and burns (Williams et al., 2015), prolonged hospital admissions, and increased risk of complications, such as infections (Rosenbloom et al., 2021). Higher levels of psychological consequences, such as catastrophic thoughts of pain, needle fears and phobias, and subsequent vaccine hesitancy and avoidance of medical care, have also been reported (McMurtry et al., 2015; McMurtry et al., 2016; Taddio et al., 2015). Acute nociceptive pain in children can progress to chronic pain and other chronic conditions, including depressive and anxiety disorders (Page, Stinson, et al., 2012; Pielech et al., 2014; Stone & Wilson, 2016).

1.2.2 Pain Management

Effective pain management combines multimodal approaches to thoroughly address biopsychosocial contributors to paediatric pain. It includes age and developmentally appropriate pharmacological (i.e., analgesics, anaesthetics), physical (i.e., comfort positioning, massage), and psychological interventions (distraction, CBT). These strategies are recommended for immunisations (Friedrichsdorf et al., 2018; World Health Organization, 2015), procedural pain (Birnie et al., 2018; Harrison et al., 2016), disease or illness-related pain, and chronic and persistent pain in infants and children (Birnie et al., 2018; Fortier et al., 2016) and are included in hospital clinical practice guidelines (CPG) around the world (Friedrichsdorf & Goubert, 2020; Health Standards Organization, 2023; The World Health Organization, 2021). Additional efforts include hospital certifications (ChildKind International: www.childkindinternational.org; (Schechter et al., 2009), standards of care (American Society of Anesthesiologists Task Force on Acute Pain Management, 2012; Friedrichsdorf & Goubert, 2020; Health Standards Organization, 2023) and social media initiatives targeting clinicians (BeSweet2Babies (Harrison, Larocque, Reszel, et al., 2017) and parents (#itdoesnthavetohurt; www.itdoesnthavetohurt.ca; (Chambers et al., 2020; Harrison, Larocque, Reszel, et al., 2017).

1.2.2.1 Policies and Priorities

In 2021 The Lancet Child & Adolescent Health Commission laid out four transformative goals to improve the lives of children and young people with pain and their families:

1. Make pain matter.
2. Make pain understood.
3. Make pain visible.
4. Make pain better (Eccleston et al., 2021).

Healthcare priorities for children and young people in Australia focus on preventing risk factors for chronic conditions and improving factors that promote and protect good health and well-being for children (Department of Health, 2021a). Principles of multi-sector collaboration and empowered families and communities underpin this vision. The recent National Strategic Action Plan for Pain Management (Department of Health, 2021b) establishes improved acute pain management as one of its eight action areas to minimise chronic pain trajectories, advocating for specific initiatives tailored to the needs of children and young people (Department of Health, 2021b). Policy acknowledges the multifaceted challenges of ensuring adequate pain care for hospitalised children (Health Standards Organization, 2023). Some hospital-based barriers to pain management include clinician lack of knowledge and misconceptions regarding biopsychosocial constructs of pain experience and treatment (Vagnoli et al., 2019), inconsistent and inadequate pain assessment documentation (Sahyoun et al., 2021; Senger et al., 2021; Wilding et al., 2021), competing priorities, demanding workloads (Hu et al., 2020; Senger et al., 2021) and problems of knowledge translation (KT) (Gagnon et al., 2016; Gagnon et al., 2020). The Australian Department of Health advocates for embracing the digital revolution to support children and young people's health (Department of Health, 2021a), and best practices standards on paediatric pain management call for engaging children and families as active partners in pain care during hospitalisation (Health Standards Organization, 2023; Larocque et al., 2021; Vasey et al., 2019). Research described within this thesis was designed to address the needs outlined in these policies.

1.2.3 Hospital Electronic Medical Records Systems

Electronic medical records are replacing hospital paper-based medical records (Australian Digital Health Agency, 2019b; Unwin & Sanzogni, 2013) and comprise functionality including electronic documentation, ordering, and embedded clinical decision

support (CDS) and secure messaging systems (The Office of the National Coordinator for Health Information Technology, 2015). Associated patient portal systems are tethered to the EMR, providing patients online access to physician-selected hospital medical records (i.e., medications, laboratory results, and notes) and facilitating patient-clinician communication through secure messaging. Despite the extensive uptake of EMRs in the United States of America (USA) since the early 2000s, health services outside the USA are largely in the earlier stages of implementing these digital systems (Slovis et al., 2017; Sullivan et al., 2016). Since 2015, some Australian hospitals have begun introducing EMR systems. As of 2020, an estimated one-third of Australian hospitals had an EMR system (Healthcare Information and Management Systems Society, 2021a). Yet, many are still in the early stages of EMR rollout (Australian Digital Health Agency, 2019b).

International evidence demonstrates that adopting EMRs in paediatric hospitals can facilitate compliance with evidence-based practices and improve care quality, safety, and outcomes (Horton et al., 2020; Pageler et al., 2013; Teufel et al., 2013). Electronic medical record systems have made it possible to create care pathways that actively guide clinicians using CDS features such as alerts, prompts, and reminders for care (Sutton et al., 2020). For example, an EMR automated CDS system comprising a checklist linked to CPGs and colour-coded indicators conveying task completion improved clinician adherence to evidence-based central catheter care and reduced central line-associated bloodborne infections in critically ill children (Pageler et al., 2014). Similarly, Nerissa and colleagues found that implementing an automated screening process for autism spectrum disorders facilitated paediatric clinician adherence to best practice guidelines (Bauer et al., 2013).

Extensive work has focused on the impact of EMR electronic medication management systems (also known as computerised provider order entry – CPOE) with CDS to improve medication safety. Alerts can be triggered to warn clinicians of safety issues (i.e., dosing errors, drug-drug interactions) and the need for therapeutic drug monitoring. Order sets, a collection of orders aggregated for a given condition, clinical situation, or process (McGreevey et al., 2020), have also supported safe medication practices. Horton’s team found that instituting a post-tonsillectomy EMR order set that presented four medications (paracetamol, ibuprofen, oxycodone, and dexamethasone) on postoperative recovery room discharge resulted in standardised and improved pain control regimens and consistency in opioid prescription for children (Horton et al., 2020). This study did not examine the effects of the order set on children's pain outcomes.

There is a lack of evidence regarding the impact of EMR systems on hospitalised children's pain care, particularly in Australia, where much of what is known about children's pain care has been derived from research in hospitals using paper-based records. Studies conducted in adult acute care have demonstrated the potential of EMRs to improve pain care practices. For example, Gilberston-White and Shapiro reported increased pain assessment documentation for adult patients following the introduction of the hospital EMR (Gilbertson-White & Shapiro, 2007). Similarly, an improved frequency of pain assessment documentation was reported in a later study examining pain care documentation across three adult tertiary hospitals in the USA; however, inconsistencies and omissions in pain care documentation were also identified (Samuels & Kritter, 2011).

1.2.4 Patient Portal Systems

The focus on safety and quality of care has also accelerated the adoption of patient-facing health technologies, such as patient portal systems. Patient portals are digital tools linked to an EMR that can be accessed via the web or using mobile phone applications and give patients secure access to their health information and facilitate communication with providers. Patients can access their medication lists, immunisation history, and pathology results through the portal, request and view appointments and prescriptions, and communicate with healthcare providers using secure messaging (Australian Digital Health Agency, 2019a). Most experience with patient portals has been in ambulatory care settings. Consolidated evidence from an umbrella review, including 14 systematic reviews focused on patient portals used in ambulatory settings, demonstrates that portals can improve safety and quality of care, outcomes, and increase patient empowerment and satisfaction (Antonio et al., 2020).

Recently there has been an increasing focus on the use of patient portals to give inpatients (adults and children) and families access to selected health information and support their engagement in care during hospitalisation (Kelly et al., 2018; Schofield et al., 2019). Emerging evidence demonstrates that well-designed inpatient portals can facilitate patient and family engagement and patient-clinician communication and can be used to deliver education to advance safe, coordinated, family-centred care. In their systematic review, that included 58 studies, Dendere's team found having access to health information helped patients better understand, monitor, and be involved in their care (Dendere et al., 2019). Much of the evidence regarding inpatient portals has focused on adult acute care; there is less evidence regarding their use in children's hospitals.

From 2017 to 2019, a project comprising three studies explored inpatient portal use in a tertiary paediatric hospital in the USA. Clinicians were surveyed before and after the inpatient portal was implemented, with most reporting fewer challenges than anticipated (Kelly et al., 2017). Parent use and perceptions of the inpatient portal were captured via an online survey (Kelly, Hoonakker, et al., 2017) and qualitative interviews (Kelly et al., 2019). Almost all parents reported that the portal improved care (Kelly, Hoonakker, et al., 2017). Parents with access to the portal were more able to monitor, understand and make decisions about their child's care (Kelly et al., 2019). Although these findings offer preliminary insights into inpatient portals, the generalisability of results is limited, given that these studies were undertaken in a single setting. As of December 2021, no Australian tertiary paediatric hospital had implemented an inpatient portal system, and only a few have introduced their use for outpatient settings.

1.3 Problem Statement and Study Purpose

Pain is a common problem for hospitalised children that is known to have negative immediate impacts and is associated with harmful lifelong consequences impacting children, families, and communities. A growing evidence base demonstrates that EMRs and patient portal systems can improve care quality and safety, child and family engagement, and outcomes during hospitalisation. Despite this knowledge, research into EMRs and patient portal systems in hospitalised children's pain care is limited. Thus, the work described in this thesis focused on the intersection between hospitalised children's pain and the use of acute care digital health technology. It aimed to explore how EMR, and patient portal systems can be designed, optimised, and used to improve pain care practices and outcomes for hospitalised children and their families. While these systems show promise, there is little evidence about how these systems are used and how they can be optimised to support evidence-based pain care. The purpose of the work conducted here was to gather evidence about EMR and patient portal systems in paediatric pain care. An exploratory multiphase, mixed-methods design, as described by Creswell and Clark (2011), was selected for this project. Chapter Three of this thesis describes and provides a rationale for this design. Three studies were designed to address the overall aim. Situated within a pragmatic paradigm, each study addressed individual, interrelated objectives, discussed in detail in their respective chapters and presented below:

1. The first study explored EMR designs necessary to drive optimal pain care practices for hospitalised children. This qualitative descriptive study examined the perspectives

of international paediatric clinical pain experts' perspectives on how to capitalise on hospital EMR designs to drive evidence-based child and family-centred pain care.

2. The second study explored the role of patient portal systems in pain care. Primary caregivers of hospitalised children and hospitalised youth at the Royal Children's Hospital (RCH), Melbourne, engaged in face-to-face qualitative interviews to share their perspectives on their potential role using an inpatient portal to support their engagement in pain care during hospitalisation.
3. The third and final study examined clinical practice using EMRs in hospitalised children's pain care. A national, cross-sectional survey collected perceptions of clinician EMR users in Australian tertiary paediatric hospitals to understand the current and potential use of EMRs in children's pain care.

1.4 Thesis Structure

This thesis comprises eleven chapters. This chapter presented an introduction to this thesis topic, focusing on pain prevalence in hospitalised children, the short and long-term impacts of undertreated pain, and EMR and patient portal systems. The aim and objectives of this project were presented. In Chapter Two, a critical literature review provides context for the study and identifies evidence and practice gaps. First, evidence on evolving pain theories, children's pain, and pain care practices are summarised. Subsequently, literature regarding EMR, and patient portal systems is presented. The review concludes that while there is growing evidence of the potential benefits of EMRs and patient portals to improve paediatric patient outcomes, insufficient evidence exists about how to harness these systems to drive improved pain care and outcomes for hospitalised children and their families. Chapter Three describes the methodological approach, philosophical position, and conceptual framework underpinning this Ph.D. project.

Chapter Four describes Study One methods, and Chapter Five includes a published manuscript reporting Study One findings. Participants, recruitment, data collection, and analysis processes are articulated. Ethical considerations are described.

Chapter Six presents a detailed description of the methods used in Study Two, including information on the research setting, participants, qualitative data collection and analysis, and ethical considerations. Methods are described further in the published manuscript reporting Study Two results, presented in Chapter Seven.

Chapters Eight and Nine explain the methods and results of Study Three, respectively. Chapter Eight presents methods and procedures, including details on study promotion, sampling, data collection, and analysis. Results are presented in Chapter Nine as a manuscript currently under review in an international journal.

Chapter Ten describes data integration processes and positions the work described in this thesis within the conceptual framework to inform future recommendations and research directions regarding using and designing EMRs and patient portal systems in pain care. Key findings are summarised, and new contributions to knowledge are presented. Reflexive perspectives from the researcher are presented, and the strengths and limitations of the Ph.D. project are outlined. The chapter concludes with a description of the knowledge mobilisation plan. Concluding remarks close the thesis.

Chapter Conclusion

In this chapter, an orientation of the thesis was presented. Pain is a frequent symptom for children during hospitalisation, which can lead to short-term and lifelong biopsychosocial consequences. Government, national and international policies recognise the importance of addressing inadequate pain management for hospitalised children. Hospital-based digital technologies are promising tools to improve pain care practices and outcomes for hospitalised children and families. This chapter presented the aims and purpose of the thesis and the knowledge gap it aims to address. The thesis organisation is provided to orient the readers to this work's structure and content. The following chapter provides an overview of the literature on pain experienced by hospitalised children and pain management.

Chapter Two

2

Literature Review

The preceding chapter explained how the undertreatment of hospitalised children's pain and hospital-based technologies intercept and briefly introduced this project's scope. In this literature review chapter, evidence pertaining to pain theory, children's pain and pain care practices, and the use of EMRs and patient portal systems in children's hospitals is synthesised and critiqued. A critical review of existing literature within this chapter intends to offer a general background to the thesis and demonstrate how knowledge and practice have evolved within the field of children's pain and pain care. This review of the literature was not exhaustive and is not considered a systematic review. The chapter concludes with a summary of the gap in the literature and how this dissertation will address this gap.

2.1 Pain

The International Association for the Study of Pain (IASP) defines pain as: 'An unpleasant sensory and emotional experience associated with or resembling that associated with actual or potential tissue damage' (Raja et al., 2020). This definition rejects the premise that pain is solely caused by tissue insult, emphasising pain's various causes, mediators, and moderators (Hadjistavropoulos et al., 2011). Pain is influenced in varying degrees by biological, psychological, and social factors and is much more complex than our traditional understanding, which focused on nociceptive pain and was reflected in early pain theories and definitions. These evolving pain theories are described in the following section.

2.1.1 Pain Theories

Cartesian notions of pain dominated scientific literature for hundreds of years. A 17th-century French philosopher, Renee Descartes, hypothesised that pain could result from *either* physical or psychological harm, but these two harms were mutually exclusive, i.e., they could not combine or influence each other (Decartes, 2013; Hatfield, 2003). In current literature, this theory is called the Cartesian dualism theory of pain (Eccleston et al., 2021; Raja et al., 2020). Despite being 400 years since its inception, dualistic views of pain, which ignore the multiplicity of mind-body interactions, persist today and impede modern scientific inquiry and clinical practice, including how children's pain is assessed and managed (Eccleston et al., 2021).

During the 19th century, scientists and philosophers continued to postulate pain theories. Specificity theory delineated distinct pathways sensitive to four separate somatosensory modalities (cold, heat, touch, and pain) (Dubner, 1978). After some time, Pattern theory rejected the existence of distinct receptors for sensory modality. It proposed that each sensation relayed a specific pattern to the brain, which was decoded to produce sensations (Moayedi & Davis, 2013). While these theories contributed to early understandings of pain, these purely sensory accounts of pain were inconsistent with pain reports in the presence and absence of physiological injury. In 1965, Melzack and Wall announced the first theory that viewed pain through a mind-body perspective, the gate control theory (GCT) of pain (Melzack & Wall, 1965).

The GCT revolutionised our understanding of pain, integrating both psychological and physiological dimensions of pain modulation. Melzack & Wall propose that thin

diameter nociceptive fibres, called Aδ and C fibres, and large diameter non-nociceptive fibres, called Aβ fibres (sensitive to touch, pressure, and vibration), transmit information from the injury site to the spinal cord dorsal horn. Transmission cells carry pain signals to the brain within the dorsal horn, and inhibitory cells impede transmission cell activity. Activity in nociceptive Aδ and C fibres *impedes* inhibitory cells, and painful sensations are perceived. Whereas stimulation of Aβ fibres *excites* inhibitory cells, inhibiting transmission and painful sensations (Melzack & Wall, 1965). Nerve impulses that descend from the brain's higher centres, such as the limbic system, hypothalamus, and cerebral cortex, can also modulate the transmission of pain impulses (Melzack & Wall, 1965). As an extension of the GCT, Melzack later distinguished the Neuromatrix Theory of Pain, proposing that pain perception results from the activation of a distributed network of brain regions. According to this theory, previous experiences, context, and cognitive, emotional, and motivational factors modulate pain (Martucci & Mackey, 2018).

2.1.2 Pain Classification

Pain can be described or classified in several ways, including by somatosensory mechanism, time, and context or location (Eccleston et al., 2021). Somatosensory pain includes; 1) nociceptive pain, where noxious stimuli (tissue damage) activate nociceptors, and pain resolves with healing (Friedrichsdorf & Goubert, 2020); 2) neuropathic pain, resulting from dysfunction of, or injury to, the somatosensory nervous system caused by disease or lesion. This results in pain in the absence of painful stimulus, and pain does not resolve with healing (Eccleston et al., 2021); and 3) nociplastic pain, caused by altered nociception in the absence of actual or potential tissue damage, and without somatosensory nervous system damage or dysfunction (Eccleston et al., 2021).

When classified by time, pain is acute (a time-limited response to a painful stimulus lasting less than three months) or chronic (pain persisting beyond three months which can involve nociceptive, neuropathic, or nociplastic mechanisms) (Raja et al., 2020). When classified by context or location, pain may be disease-related (i.e., cancer pain), iatrogenic (i.e., pain caused by medical procedures, treatments, and interventions), functional (no clearly identified cause), or tissue or organ related (i.e., musculoskeletal, visceral) (Eccleston et al., 2021). Although they help convey our broader understanding of pain and pain mechanisms, these various pain classifications may be perceived as complicated and confusing, leading to inconsistent use of pain terminology, and potentially confounding the assessment and treatment of children's pain.

2.2 Research on Pain Consequences

In addition to the developing theoretical understanding of pain, key discoveries and events in the last 50 years have advanced the field of paediatric pain science. As McGrath proposes in an article on the history of pain sensitivity, misconceptions about pain sensitivity put forth by scientists and clinicians until the 1970s were widespread in paediatric healthcare (McGrath, 2011). This resulted in widespread neglect of pain treatment for neonates until the 1970s (Olmstead et al., 2010), with reports of infants undergoing surgical procedures with no analgesics or anaesthetic (Swafford & Allan, 1968). By the 1980s, research confirmed that neural pathways responsible for pain processing and perception form in early foetal development, and while not fully mature, these structures are functional at birth (Loizzo et al., 2009). Since then, many studies have focused on examining neonatal pain exposure, management, and consequences of undertreated pain, including neurodevelopmental outcomes.

An abundant evidence base is focused on long-term neurodevelopmental consequences associated with neonatal pain exposure and subsequent behavioural, psychological, cognitive, and somatosensory outcomes (Duerden et al., 2018; Valeri et al., 2015; Walker, 2019a; Walker et al., 2018). Early pain exposure is associated with persistent changes in brain composition (reduced white matter and subcortical grey matter), growth and development (delayed growth, poor cognitive and motor function), stress regulation (high cortisol activation), and poorer psychosocial and behavioural outcomes later in life (Valeri et al., 2015; Walker, 2019). Premature neonates cared for in intensive care units (NICUs) are especially vulnerable because they are critically unwell and exposed to repeated painful procedures (Cruz et al., 2016) during a delicate and critical phase of very rapid brain development (Ranger & Grunau, 2014).

There is also evidence that repeated pain exposure in neonates is associated with short and long-term pathophysiological changes in pain processing (Grunau et al., 2021). For example, Slater et al. (2010) showed that premature infants (7 infants; born 24-32 weeks) who spent at least 40 days in PICU and underwent several painful procedures each day had an increased neuronal response to painful heel lance procedures compared to healthy newborns (n=8 infants; born 37-40 weeks) at the same corrected age. A longitudinal study followed children born very preterm from birth to school age (n=56) to examine the association between painful procedure exposure in NICU and self-reported pain intensity during venepuncture at school age (Valeri et al., 2016). After adjusting for neonatal clinical and concurrent psychosocial factors, findings showed that higher pain ratings by

very preterm children at school age were significantly associated with a greater number of neonatal invasive procedures (Valeri et al., 2016). Studies of children and adults demonstrate that pathophysiological changes in pain processing lead to peripheral and central sensitisation, heightening the risk of chronic pain (Feizerfan & Sheh, 2015; Fortier et al., 2011; Woolf, 2010). However, further longitudinal studies examining factors that initiate and maintain pain sensitisation, and the transition from acute to chronic pain is required to advance understanding of these pathophysiological processes (DiLorenzo et al., 2016; Eccleston et al., 2021; Stone & Wilson, 2016).

Alongside early neurodevelopmental effects, undertreated pain in children is also an important predictor of immediate and life-long physiological and psychological consequences. For example, undertreated pain in hospitalised children is associated with delayed recovery (Williams et al., 2015), prolonged hospital admissions, and increased risk of complications, such as infections (Rosenbloom et al., 2021). Greater psychological consequences, such as catastrophic thoughts of pain, needle fears and phobias, and subsequent avoidance of medical care, have also been reported (McMurtry et al., 2015; McMurtry et al., 2016). Unrelieved childhood pain is a risk factor for the development of chronic and persistent pain and is associated with sleep issues, functional disability, substance misuse, social isolation, depression, and anxiety (Page, Stinson, et al., 2012; Pielech et al., 2014; Stone & Wilson, 2016). Pain can have negative implications for a child's life trajectory, so its treatment must be a priority for all paediatric health services.

In addition to a clinical priority, effective pain care for children is an ethical imperative. This is underscored in the United Nations Declaration on the Rights of the Child (United Nations, 1989) and the Declaration of Montreal (International Association for the Study of Pain (IASP), 2015). According to these declarations, ethical pain care requires indiscriminate access to pain treatment information and effective multimodal pain relief facilitated by trained clinicians (IASP, 2015). Indeed, parents of hospitalised children expect and trust clinicians to provide clear and understandable pain information and access to timely, effective pain treatment (Twycross & Finley, 2013). Hospitalised children have similar expectations of pain care. A study of children's experiences of pain within an Australian paediatric emergency department (ED), which included 14 children aged 4-8 years, showed that all children expected truthful and understandable information about their pain care and multimodal pain relief (Pope et al., 2018). Children undergoing surgery and their families also expect understandable preparatory information about their/their child's surgery and about medicine and non-medicine pain treatment options

(Smeland et al., 2019). These findings support recommendations endorsed in best practice guidelines (RCH, 2020; UCSF Benioff Children's Hospital, 2016) and outline the importance of children and family engagement in pain care during their hospitalisation (Pope et al., 2017; Rao-Gupta et al., 2018).

2.3 Pain in Hospitalised Children

Despite the ethical imperative of effective pain relief and knowledge of the consequences of undertreated childhood pain, children's pain remains undertreated in hospitals worldwide (Birnie et al., 2014; Friedrichsdorf et al., 2015; Harrison et al., 2014; Postier et al., 2018; Velazquez Cardona et al., 2019; Walther-Larsen et al., 2017; Wilding et al., 2021). Worldwide studies demonstrate that most hospitalised children experience moderate to severe pain associated with injury, disease, or painful procedures required for clinical care (Birnie et al., 2014; Harrison et al., 2014). Needle procedures (heel lance, venepuncture, and peripheral venous catheter insertion) are among the most frequent and painful sources of pain and one of the most distressing hospital experiences for children and their families (Senger et al., 2021). Pain and distress are also amplified by fear, anxiety, lack of control, and restraint (Khadij et al., 2021; Pope et al., 2018; Velazquez Cardona et al., 2019). A study examining oral sucrose in hospitalised toddlers (12-36 months) found that most (n=76/85) toddlers were crying before the needle when they were laid flat in preparation for venepuncture (Modanloo et al., 2021).

In 2011, a Canadian study involving eight paediatric hospitals identified that in 24 hours, 78% (n=322/515) of children underwent painful procedures, with an average of 6.3 painful procedures per child (Stevens et al., 2011). More recently, a cross-sectional pain prevalence study involving three wards at another Canadian paediatric hospital showed that 82% (n=69/84) of children experienced pain in the past 24 hours. Most reported their pain as moderate to severe (78%: n=29/37) and commonly from needle procedures (n=23/53) (Senger et al., 2021). Similarly, a European pain prevalence study, including 579 hospitalised children, found 87% (n=504/579) of hospitalised children experienced pain during admission (Vejzovic et al., 2020). Many of these children (n=365/579) reported their pain as moderate to severe, but the source of their pain was not captured (Vejzovic et al., 2020).

Similar findings have also been reported in other regions of the world. A cross-sectional, single-day study of pain prevalence and severity in hospitalised children (n=63) aged one month to 17 years (mean age 9.7 years) was undertaken in a tertiary hospital in

South Africa. Findings showed that 87% (n= 55/63) of children experienced pain, and 37% (n=23/63) reported their pain as severe (Velazquez Cardona et al., 2019). Linhares et al. (2012) interviewed hospitalised children (n=34) and their parents (n=82) to examine pain prevalence in children admitted to a tertiary hospital in Brazil. More than half of the children interviewed (n=20/34) reported pain, and close to half of the parents (n=40/82) said their child experienced pain.

Critically unwell neonates are particularly vulnerable to pain and are commonly exposed to multiple painful diagnostic and therapeutic procedures, often without adequate pain relief (Courtois, Droutman, et al., 2016; Cruz et al., 2016). A systematic review of 18 epidemiological studies that represented 13 countries from all regions of the world reported that, on average, neonates are exposed to between 7.5 to 17.3 painful procedures per day, and the sickest neonates received the fewest interventions to prevent or manage procedural pain compared to older infants (Cruz et al., 2016). Similarly, a survey undertaken as part of a large prospective observational study, Epidemiology of Procedural Pain In Neonates (EPPIPAIN 2), conducted in 16 neonatal and paediatric ICUs in France showed that neonates (n=562) underwent an average of 16 heel lance procedures daily (Courtois, Droutman, et al., 2016). Only half (n=5236/8995) were performed with specific pre-procedural analgesia (Courtois, Droutman, et al., 2016). Another analysis of the EPPIPAIN 2 data focused on venepuncture. It showed that neonates (n=495) underwent an average of 3.8 venepunctures per day during an average eight-day ICU admission (Courtois, Cimerman, et al., 2016). While 76% (n= 1478/1887) of venepunctures were performed with pre-procedural pain relief, only 61.7% were successful on the first attempt (n=1164/1887); 38.3% (n=722/1887) needed more than one attempt, and 20% (n=377/1887) needed three or more attempts to successfully complete the procedure (Courtois, Cimerman, et al., 2016).

Compared to adults, children are less likely to have their pain assessed or documented and are less likely to receive interventions for pain (Cruz et al., 2016; Furyk & Sumner, 2008), even when there are physician orders for pain relief (Birnie et al., 2014). This is despite the evidence of low-cost, effective pre-emptive strategies available to reduce pain in children (Fisher et al., 2022; Friedrichsdorf & Goubert, 2020; Schug et al., 2020). This highlights the lack of universal application of this knowledge in clinical practice (Eccleston et al., 2021; Senger et al., 2021; Vejzovic et al., 2020; Velazquez Cardona et al., 2019; Walther-Larsen et al., 2017).

2.4 Pain Assessment and Measurement

An important step in effective pain care is pain assessment and measurement and ongoing evaluation of the effectiveness of treatment. Pain measurement generally quantifies pain intensity (Manworren & Stinson, 2016). In comparison, pain assessment is a broader concept involving understanding the significance of pain and its social and contextual influences to capture biopsychosocial dimensions (Andersen et al., 2021; Franck et al., 2000; Herr et al., 2019). Pain intensity is most commonly measured by self-report, behaviour observations, and physiological measures (Manworren, 2020; Tomlinson et al., 2010). Both self-report and behaviour observation pain measures can be evaluated via psychometrically sound and validated pain scales (Crellin, Babl, et al., 2018; Crellin et al., 2015).

2.4.1 Self-Report Pain Scales

Because pain is an individual, personal experience modulated by biopsychosocial factors, children's self-reports should be the primary source of pain intensity wherever possible (Birnie et al., 2019; Raja et al., 2020). Most children aged three years and older can provide meaningful self-reports of pain when developmentally appropriate pain scales are used (Palmer & Alcock, 2020; von Baeyer et al., 2013). Self-report measurement tools include numerical rating scales (NRS), visual analogue scales (VAS), colour analogue scales (CAS), and faces scales. These tools have been extensively reviewed for use in children (Birnie et al., 2019; Tomlinson et al., 2010).

Faces pain scales are widely recommended and used self-report measures. The most studied scales include Wong-Baker FACES Pain Scale (WBFPS) (Wong & Baker, 1988), the Faces Pain Scale-Revised (FPS-R) (Hicks et al., 2001), and the Oucher scale (Beyer & Aradine, 1986). These scales consist of a sequence of faces arranged horizontally, expressing increasing degrees of pain intensity. The pain intensity corresponds to scores ranging from 0 to 10. The child is asked to select the face that most closely denotes their pain. Faces pain scales are validated for use in children four years and older and are generally preferred by children over other self-report tools (Tomlinson et al., 2010).

The FPS-R and WBFPS are the most studied self-report faces pain scales. These tools have been subjected to extensive psychometric testing, translation, and cross-cultural adaptation (Birnie et al., 2019; Voepel-Lewis et al., 1997). The facial expressions incorporated vary between scales; the FPS-R includes a neutral facial expression for 'no

pain' (Hicks et al., 2001), while the WBFPS uses a smiling face for 'no hurt' and a crying face for ‘most/maximum hurt’ (Wong & Baker, 1988). Although psychometric data support scores from both scales, studies have shown that a smiling anchor (as in the WBFPS) produces higher pain scores than other faces scales, including FPS-R (Chambers et al., 1999; Tomlinson et al., 2010). However, children prefer the WBFPS over different faces scales (Tomlinson et al., 2010). There is also evidence young children (aged 3-6 years) prefer and manage better with self-report scales that use fewer faces (Bayram et al., 2020; von Baeyer et al., 2013), such as the Simplified Faces Pain Scale (S-FPS). The S-FPS applies a 3-point scale with faces signifying mild, moderate, and severe pain intensity (Emmott et al., 2017).

The NRS and VAS are recommended for acute, procedural, and chronic pain for children six to eight years and older, according to a systematic review that examined self-report properties of pain intensity measures in children (3-8 years) and included 80 publications (Birnie et al., 2019). The child is asked to rate their pain using the NRS from zero, indicating no pain, to ten, indicating worst pain. The VAS, first designed for adults, incorporates a graphic representation of the numerical scale comprising a horizontal line with endpoints defining the limits (no pain and worst pain). The child is asked to indicate the severity of their pain using the horizontal line (Stinson & Jibb, 2013). Evidence shows that numerical scales can make measuring children's pain more complex than other self-report measures because they rely on the child’s cognitive ability to understand quantitative information and reason numerically (Page, Stinson, et al., 2012). These scales are often the least preferred among children and clinicians (Page, Katz, et al., 2012; Tomlinson et al., 2010).

Children's verbal reports of pain intensity are not possible in infants and very young children and not always possible in children with cognitive disabilities or critical illness. Observational pain scales are one of the most used alternatives to facilitate pain measurement in these children.

2.4.2 Observational Pain Scales

Observational pain scales require clinicians and parents to examine the child for parameters indicative of pain, including behaviours and physiological reactions. More than 65 observational pain scales are available for children of different ages and cognitive abilities (Andersen et al., 2017) and with varying degrees of psychometric evaluation

(Meesters et al., 2019). Each scale parameter is assigned a score based on descriptors for the parameter, and the sum of these scores indicates pain intensity. The most studied and used scales include the Faces, Legs, Activity, Cry, Consolability (FLACC) scale and its revised versions (Merkel et al., 1997), the COMFORT scale (Ambuel et al., 1992), and the Modified Behavioural Pain Scale (MBPS). While evaluation of psychometric properties supports the reliability and sensitivity of scores derived from the application of behavioural observation scales (Crellin, Babl, et al., 2018; Crellin, Harrison, et al., 2018), some evidence suggests that these scales are limited in their capacity to differentiate between non-pain-related distress and procedural pain in children (Crellin et al., 2021). For example, when applying the MBPS, a child who is not 'smiling', 'giggling', 'laughing', ' resting', or 'relaxed' would be assessed as having pain. Many children feel scared and anxious in hospital environments (Pope et al., 2018), and pre-procedural fear is common, which would make smiling unlikely (Buttner & Finke, 2000; Crellin et al., 2021).

2.4.2.1 Observer Assessment of Children's Pain

Studies of children of various ages have revealed differences in pain evaluations between clinicians, parents, and children (Brudvik et al.; Khin Hla et al., 2014; Rajasagaram et al., 2009; Senger et al., 2021). There is evidence that clinicians sometimes underestimate children's pain, and bias toward underestimating pain may contribute to the undertreatment of pain in children (Andersen et al., 2021; Senger et al., 2021). A study was undertaken in the day-stay surgical unit of an Australian tertiary paediatric hospital to investigate differences in postoperative pain scores by children and nurses (Khin Hla et al., 2014). Results showed that nurses' NRS assessments were significantly lower than self-reported pain scores by children using the WBFPS (young children) or an NRS (older children) (Khin Hla et al., 2014). Among the children who could self-report, the median pain score reported by the child was 2/10, whereas the nurses' median pain score was 0/10. Another study was undertaken across three clinical settings within one tertiary care centre in Canada (paediatric ward, ED, and maternal services). Findings showed maximum pain scores differed between child-reported and clinician-documented pain scores by an average of 4.5/10 (SD = 3.1, $P<0.0001$), with higher pain scores reported by children (Senger et al., 2021).

Similarly, a Norwegian ED study including 243 child-parent dyads and doctors (n=51) found that doctors using an NRS reported significantly lower scores than children using the FPS-R (aged 3-8 years) (Brudvik et al., 2017). However, there were less significant differences in children with fractures (Brudvik et al., 2017). This highlights

how pain may be more evident to clinicians in the context of an obvious injury (Brudvik et al., 2017). Studies of adult patients also show that clinicians tend to discount pain without clear medical evidence for the pain (De Ruddere et al., 2013; De Ruddere et al., 2012). Similar findings are echoed in studies examining children with chronic pain conditions (Betsch et al., 2017)

Collectively, these studies imply a persistence by clinicians to seek, expect, and depend on biomedical explanations for pain (Eccleston et al., 2021). However, pain without an obvious medical explanation is a common phenomenon. For example, in nociplastic conditions, pain is caused by altered nociception, in the absence of actual or potential tissue or somatosensory system damage (Eccleston et al., 2021). Relying on nociceptive explanations for pain fails to account for the complexities of pain. It leaves children feeling misunderstood (Wakefield et al., 2018) and clinicians uncertain about the genuineness of children's pain symptoms (Neville et al., 2019).

There is mixed evidence regarding the validity of parent reports of children's pain. A study in outpatient clinics of four USA paediatric hospitals compared postoperative pain scores between children using the FPS-R and their parents who used the NRS for three consecutive days following surgery (Kaminsky et al., 2019). Results showed that a significant proportion of child-parent dyads disagreed on pain ratings. Of the dyads in disagreement, parents' pain scores were significantly higher than their children across all postoperative days (Kaminsky et al., 2019). In contrast, Matziou et al. (2016) study involving 92 oncology patients and 159 orthopaedic patients (aged 5-13 years) from two children's hospitals in Greece found that parents reported lower pain scores than their children using the WFBPS, particularly with acute procedural pain.

Despite these differences, parental pain reports of their child's pain remain integral to measuring and assessing pain because parents know their child best and may be better than clinicians at recognising changes in their child indicative of pain (Vasey et al., 2019). Children and parents benefit from parental engagement in all aspects of children's care. Parental presence helps foster a sense of security for children in pain (Pope et al., 2018), which promotes positive psychological outcomes in children with pain (Barone et al., 2016). Therefore, forming partnerships with parents is central to effective pain care for children (Vasey et al., 2019).

2.4.3 Physiological Measures

Physiological responses can provide helpful information in pain measurement, particularly when combined with self-report and behavioural observation measures (Schug et al., 2020). Routine physiological measures include monitoring for indicators of stress associated with pain, such as elevated respiratory rate and blood pressure, altered heart rate, and pupil dilation. Other physiological measurements used for research purposes include monitoring for cortical (near-infrared spectroscopy, electroencephalography, and functional magnetic resonance imaging), autonomic (skin conductance), and hormonal (salivary cortisol) evoked responses (Relland et al., 2019). The validity of physiological measures is debated, given their lack of specificity for pain (Franck et al., 2000). In hospitalised children, physiological measurements can be compromised by the effects of medications administered, such as vasoactive agents, or by manifestations of disease processes (Palmer & Alcock, 2020). Therefore, physiological measures are recommended as part of a multimodal pain assessment rather than as a stand-alone indicator of pain (Hu et al., 2021).

2.5 Documentation of Pain

Compliance with and accuracy of pain assessment documentation is an important problem in paediatric hospitals. Documentation of pain by clinicians is frequently below the requirements mandated in hospital standards and is fraught with omissions and inconsistencies. For example, a Canadian study of pain assessment and treatment practices in a paediatric hospital found that in 24 hours, only 27% of children (n= 57/212) had a documented pain score (Taylor et al., 2008). In a later study conducted at a different Canadian paediatric hospital, pain scores were documented for only 34 of the 62 hospitalised children in 24 hours. Only 17 of the 62 children (27%) had a pain score recorded using a pain scale within the first hour of admission, per the hospitals' pain management policy (Harrison et al., 2014). Persistent inadequacies in pain documentation are reported in other more recent studies from both high (Friedrichsdorf et al., 2015; Wilding et al., 2021) and low to middle-income countries (Velazquez Cardona et al., 2019) and across various clinical areas (Andersen et al., 2021) using both paper-based and electronic systems for documentation (e.g., EMR systems).

Lack of routine pain assessment and measurement led to a campaign initiated in the 1990s by the American Pain Society to make pain the 'fifth vital sign' (Lucas et al., 2007). This campaign aimed to increase awareness, utilisation, and documentation of routine pain

assessment and measurement in clinical settings. This campaign underscored that pain should be viewed with the same regard as physiological signs such as blood pressure and heart rate. Senger and colleagues' examination of pain practices in a Canadian hospital showed that pain score documentation was higher when pain was captured with routine vital signs (every four hours). There is mixed evidence on the effectiveness of the fifth vital sign campaign in improving pain outcomes (Manworren, 2020; Schug et al., 2020).

Although pain assessment and measurement are important to guide pain treatment, they are not enough to ensure it. A systematic review of 32 studies examined the association between pain scale use and outcomes for hospitalised children. It concluded that increased pain scale use did not result in better patient outcomes (Andersen et al., 2021). Findings from an integrative review of 20 studies examining interventions to improve children's pain care practices in EDs demonstrated that significant improvement in pain documentation does not consistently translate to timely analgesic administration or better pain outcomes for children (Williams et al., 2019). In another study (not included in the two previous reviews), Stocki et al. (2018) used a plan-do-study-act methodology to improve pain assessment documentation in a post-anaesthetic care unit (PACU) of a quaternary paediatric hospital in Canada. Although interventions, which were staff education sessions, visual reminders, audits, and feedback, improved pain score documentation, they did not decrease the proportion of children with moderate to severe pain (Stocki et al., 2018). These examples highlight that pain score documentation is not necessarily a suitable proxy for children's pain outcomes. The way forward is to find ways to improve pain assessment and documentation to ensure assessment leads to actions to manage pain effectively.

2.6 Pain Treatment

Effective pain treatments combine age and developmentally appropriate multimodal approaches, including pharmacological (i.e., analgesics, anaesthetics), physical (i.e., comfort positioning, massage), and psychological strategies (distraction, CBT). These strategies are recommended for immunisations (Friedrichsdorf et al., 2018; World Health Organization, 2015), procedural pain (Birnie et al., 2018; Harrison et al., 2016), disease or illness-related pain, and chronic and persistent pain in infants and children (Birnie et al., 2018; Fortier et al., 2016).

2.6.1 Pharmacological Treatments

Pharmacological interventions involve using medications to prevent, relieve, and eliminate pain. Appropriate pharmacological interventions can contribute to effective pain relief for various types of childhood pain. However, there remains a dearth of high-quality evidence on pharmacological interventions targeting chronic non-cancer pain in children (Eccleston et al., 2017).

2.6.1.1 Simple Analgesics

Simple (basic) analgesics, such as paracetamol (acetaminophen) and non-steroidal anti-inflammatory drugs (NSAIDs), are recommended as first-line treatments for children's pain (Bueno et al., 2013; Friedrichsdorf & Goubert, 2020; Palmer & Alcock, 2020). Paracetamol is the most widely used analgesic, and therapeutic doses are safe, effective, and can reduce opioid requirements, thus reducing opioid-related side effects (Ohlsson & Shah, 2020; Palmer & Alcock, 2020). For this reason, paracetamol should be available on a regular scheduled basis to all hospitalised children with moderate to severe pain, regardless of type. Some evidence suggests that this recommendation has been adhered to in practice. For example, over a decade ago, an Australian study of babies cared for in NICU (n=55) showed that 92% (n=51/55) received paracetamol for a median of 16 days (Harrison et al., 2009). Harrison et al. (2014) also found that 42% (n=26/62) of hospitalised children were prescribed paracetamol in their study examining pain prevalence, assessment, and practices in Canadian tertiary paediatric hospitals. In a follow-up study in the same hospital, paracetamol was, again, the most frequently administered analgesia in a pre-post quality improvement study (pre- n=20/48, 41%; post n= 39/48, 45%) (Wilding et al., 2021).

In contrast, other studies have shown that very few hospitalised children are prescribed regularly scheduled paracetamol. Groenewald and colleagues' USA study examining pain severity and treatment showed that only 22% (n=70/321) of children with moderate to severe pain were prescribed scheduled paracetamol, and 53% (n=170/321) were prescribed it on an as-needed, *pro re nata* (PRN) basis (Groenewald et al., 2012). A later pain prevalence study involving four Danish paediatric hospitals found that 13% (n=18/134) of children with moderate to severe pain were administered regular paracetamol, and only 5% (n=7/134) received paracetamol prescribed as PRN (Walther-Larsen et al., 2017).

Paracetamol is well-established for postoperative pain in terms of opioid-sparing. Baarslag et al. (2018) reported that adherence to a protocol that implemented intravenous paracetamol as first-line pain treatment after major non-cardiac surgery in neonates and infants resulted in low morphine needs. Similarly, a double-blinded randomised study of postoperative morphine use in infants (n=71, aged 0-12months) found that infants who received intravenous paracetamol as the primary analgesic after major surgery (n= 33/71) received significantly less morphine than those receiving a continuous morphine infusion (n =38/71). Pain scores and adverse effects were not significantly different between groups (Ceelie et al., 2013).

Despite its widely recognised safety profile, paracetamol should be prescribed cautiously in paediatric patients. Neonatal case reports have shown hepatotoxicity from a single high oral dose of paracetamol (> 150 mg/kg/dose) and doses that exceed the maximum daily limit (Bucaretchi et al., 2014; Locci et al., 2021). Intravenous dosing in hemodynamically unstable children of all ages is linked to clinically significant hypotension (Chiam et al., 2015). The analgesic efficacy of paracetamol for painful procedures in neonates is not well-established, according to findings from a systematic review (n=9 studies; n=728 neonates) (Ohlsson and Shah, 2020).

Non-steroidal anti-inflammatory drugs (NSAIDs) have similar (Shepherd & Aickin, 2009) or superior (Tan et al., 2020) efficacy to paracetamol in treating acute paediatric pain. Ibuprofen is the most widely used NSAID for treating inflammation and mild to moderate pain in children. A study examined patterns of pharmacological agent prescription for paediatric musculoskeletal pain in two tertiary EDs, one paediatric and one mixed, in Canada (Kircher et al., 2014). Ibuprofen was the most common analgesic used (n=126/241; 59%) in both settings (Kircher et al., 2014). Ibuprofen was the second most frequently administered analgesic in Wilding et al. (2021) pre-post quality improvement study undertaken in inpatient departments in a Canadian children's hospital (pre- 10/48, 20%; post n= 14/48, 16%). While NSAIDs are effective for many painful conditions, there is uncertainty about their efficacy in treating chronic non-cancer pain in children (Eccleston et al., 2017). Other NSAIDs commonly used in adults are used infrequently for paediatric pain management, and aspirin is specifically contraindicated in children (Palmer & Alcock, 2020).

Adverse effects of NSAIDs may include gastrointestinal (diarrhoea, constipation, abdominal pain, nausea), rash, dizziness, and renal implications for dehydrated children (Cravero et al., 2019; Fisher et al., 2022). Close monitoring for adverse effects is advised

(Tobias, 2014). Non-steroidal anti-inflammatory drugs are not approved for infants < 3 months old but are considered generally safe for infants over six months old (Palmer & Alcock, 2020). There is limited safety data on NSAID use in infants 3-6 months old. Close monitoring for adverse effects is advised (Tobias, 2014).

2.6.1.2 Opioids

Opioids are powerful pharmacological agents recommended for moderate to severe acute pain combined with simple analgesia (Palmer & Alcock, 2020). Morphine and Fentanyl are among the most common conventional opioids used in acute paediatric pain and are most effective as part of a multimodal regimen (Friedrichsdorf & Goubert, 2020). However, there is a lack of evidence supporting the use of opioids for chronic, non-cancer pain in the absence of new tissue injury (Schechter & Walco, 2016). Opioid use is associated with adverse short-term (nausea, vomiting, constipation, cognitive dysfunction, respiratory depression) and long-term (tolerance, dependence) effects (Palmer & Alcock, 2020). Careful titration of opioids according to the individual child's response is required.

Morphine administered via various routes (oral, intravenous (IV), epidural, intramuscular (IM)) is an effective analgesic for children but with a high incidence of side effects (Palmer & Alcock, 2020). Over one and a half decades ago, a systematic review that included 36 randomised, double-blinded control trials with 49 comparisons examined analgesic efficacy and side effects of different paediatric post-operative morphine regimens (Duedahl & Hansen, 2007). Findings showed that morphine alone did not have superior analgesic effects and had a higher incidence of side effects (vomiting and sedation) than active controls (Duedahl & Hansen, 2007). A later study examining oral morphine regimens for children also showed a lack of analgesic superiority of morphine over ibuprofen, and oral morphine was associated with more adverse side effects than ibuprofen (Poonai et al., 2014).

Despite these adverse side effects, morphine and other opioids remain important to adequate pain control, particularly for acute, severe pain. Combining various analgesic agents with different mechanisms of action optimises analgesic effects and reduces opioid dosing. This reduces opioid side effects in paediatric patients (Duedahl & Hansen, 2007; Palmer & Alcock, 2020). All children receiving opioids require appropriate dosing and surveillance for opioid-related side effects.

Fentanyl has been administered for paediatric perioperative, procedural, and breakthrough cancer pain by multiple routes (i.e., IV, IM, epidural, transbuccal, intranasal,

nebulised, and transdermal). The non-invasive nature and rapid onset of effects have made the intranasal route increasingly popular in paediatric acute pain treatment (Schug & Ting, 2017). Studies comparing intranasal fentanyl (INF) with parental morphine have demonstrated INF's effectiveness in children (Murphy et al., 2014). It has minimal severe adverse effects and causes minimal distress for children (Murphy et al., 2014). A systematic review including ten studies reporting the efficacy of INF found that although it was not superior to other opioids, it provided analgesia with rapid onset, with a clinically significant decrease in time to pain medication administration compared to intravenous opioids (Setlur & Friedland, 2018).

Finally, access to medically prescribed opioids is limited in many settings and for different patient cohorts (Kunnumpurath et al., 2018), and children suffer from this inequity. Eighty percent of the global supply of opioids is distributed to less than 10% of the world's population; the USA and Canada receive the highest supply per capita, followed by Austria and Germany (Manjiani et al., 2014). Other inequities to patient access driven by race, sex, gender, and disability have also been cited, even in countries with access to medicinal opioids (Fleegler & Schechter, 2015; Goyal et al., 2015; Malviya et al., 2001). For example, over twenty years ago, a USA study of postoperative pain care in children following spinal fusion surgery revealed that children with disabilities (n=23) received smaller doses of opioid therapy and for shorter durations than children without disabilities (n=19) (Malviya et al., 2001). Similarly, a more recent survey of parents of children with cerebral palsy (CP) (n=95 children) showed that almost half lived with pain, yet only half of these children (n= 25/49) had their pain addressed at physician visits; NSAIDs and paracetamol were prescribed, but opioids were never used (Tedroff et al., 2021). Effective pain treatment remains a priority for children with disabilities, especially since they are more vulnerable to pain from underlying medical conditions and medical interventions. Their pain is also more likely to be under-recognised than children without disabilities (Quinn et al., 2015).

Racial and ethnic disparities in paediatric opioid administration are also reported. A retrospective cross-sectional analysis of analgesia administration among children presenting to a USA paediatric ED with limb fractures (n=8374) and suspected appendicitis (n=4780) showed that black and Hispanic children were less likely to receive an opioid treatment than white, non-Hispanic children (Guedj et al., 2021). Similarly, non-Hispanic black children were less likely to receive any analgesic (opioid and non-opioid) and were more likely to have a prolonged hospital stay than non-Hispanic white children presenting with abdominal pain (Johnson et al., 2013).

2.6.1.3 Topical Anaesthetics

Evidenced summarised in systematic reviews demonstrates the effectiveness of topical anaesthetics, administered via gels, creams, and patches, in reducing needle-related pain in adults and children with minimal adverse effects (Lander et al., 2006; Pywell & Xyrichis, 2015; Schug et al., 2020; Taddio et al., 2015). Tetracaine (amethocaine) 4% gel and a eutectic mixture of local anaesthetics cream (EMLA®, lidocaine, 2.5%, and prilocaine, 2.5%) are the most commonly used agents in paediatric venepuncture and venous cannulation (Pywell & Xyrichis, 2015). Both are applied to the needle insertion site and sealed with an occlusive dressing. EMLA® should be applied 60 minutes before a procedure (Aspen Group, 2021). Tetracaine can be applied 30 minutes before venepuncture and 45 minutes before intravenous cannulation (Pywell & Xyrichis, 2015). The shorter duration of action makes tetracaine more feasible and desirable than EMLA® in time-critical circumstances, such as needle-related pain in ED settings.

A systematic review conducted 15 years ago that included six randomised controlled trials (n=534 children, three months to 15 years of age) compared the anaesthetic efficacy of tetracaine gel and EMLA® cream (Lander et al., 2006). Findings showed tetracaine was superior to EMLA® in reducing needle-related pain (self-report and observer assessment) (Lander et al., 2006). Lander and colleagues reported that tetracaine resulted in vasodilation and improved successful intravenous cannulation (Lander et al., 2006); however, this was dispelled in a more recent systematic review (n=85 studies) that found tetracaine cream did not significantly facilitate successful cannulation in children compared to EMLA® cream (Pywell & Xyrichis, 2015).

Despite evidence of the effectiveness and safety of topical anaesthetics in reducing needle-related pain, a lack of routine use and inconsistency in the documentation of their use have been described. A hospital-wide survey of pain care in a USA paediatric hospital following the implementation of an initiative targeted at needle pain showed that topical anaesthesia was only administered to five out of 24 (21%) infants and 11 out of 16 (69%) children (>1 year of age) whose parents identified needles as the cause of their child's worst pain (Postier et al., 2018). Three studies at one paediatric hospital in Canada in 2004, 2014, and 2021 showed that topical anaesthetic creams were not routinely used or documented for children undergoing painful needle procedures. In 2004, most needle procedures were performed without topical anaesthetic (n=313/387; 81%) (Ellis et al., 2004). Ten years on, topical anaesthetics use had improved marginally, but less than a quarter of children (n=14/61; 23%) received topical anaesthetics, and only two of these

cases were documented (Harrison et al., 2014). In 2021, only one-quarter of infants and children eligible for topical anaesthetic cream had it prescribed (n=6/25). However, topical anaesthetics use without a prescription was reported (Senger et al., 2021).

2.6.1.4 Inhaled Anaesthetics

Procedural sedation and analgesia are widely recommended for managing pain and anxiety in children undergoing diagnostic and therapeutic procedures outside the operating theatre (OT). Nitrous oxide (N2O) is one of the most widely used inhaled anaesthetic agents for conscious sedation in children (Sahyoun et al., 2021; Tsze et al., 2016; Zafirova et al., 2018). Its rapid onset and offset, analgesic, amnesic, and anxiolytic properties, and safety record make N2O well-suited for painful and anxiety-producing procedures (i.e., laceration repair, fracture manipulation, venous cannulation) (Pedersen et al., 2013; Zafirova et al., 2018). Nitrous oxide is also effective for intramuscular injection in fearful children or children with developmental or behavioural delays (Cheng et al., 2018).

Evidence from a systematic review (n=26 studies) supports the sedative efficacy of inhaled N2O during brief, but painful paediatric procedures (Pedersen et al., 2013). However, because of its low analgesic potency, it is rarely used as a single agent. A retrospective analysis of Paediatric Sedation Research Consortium (PSRC) data of children (n=1632) receiving N2O as the primary sedative (outside the OT and dental practices) across 40 children's hospitals in the USA found that when N2O was the sole agent, only 1.2% of children (n=195/1632) had adequate sedation (Tsze et al., 2016). Similarly, over a decade ago, an Australian study demonstrated that N2O (oxygen/N2O ratio = 50:50) used as a sole agent had limited analgesic efficacy for children (n=124; 1-17 years old) undergoing very painful procedures, such as fracture reduction and laceration repair (Babl, Oakley, Puspitadewi, et al., 2008). Pain scores reported by children (5 to 17 years) and parents (of children <5 years) showed that over one-third of children (n=42/124) had increased pain during the procedure compared to baseline, and more than half of the children (n=63/124) had no change in their pain (Babl, Oakley, Puspitadewi, et al., 2008). This emphasises the need for adjunct analgesia when using N2O sedation for painful and distressing procedures.

Although the analgesic efficacy of N2O may be sub-optimal, it is safe, with a low prevalence of adverse events. Vomiting is the most common adverse event in children (Pedersen et al., 2013; Tsze et al., 2016; Zafirova et al., 2018), and concomitant opioid administration increases vomiting risk (Tsze et al., 2016). The prevalence of serious adverse events with N2O is very low, even with high doses of N2O (50-70%) (Gall et al.,

2001; Pasaron et al., 2015; Srinivasan & Carlson, 2013). A prospective observational study enrolled 762 children (aged 1-17 years) and examined the incidence of adverse events associated with various concentrations of N2O (Babl, Oakley, Seaman, et al., 2008). The children received either N2O 50% or N2O 70%. Results showed that only 63 (8.3%) children experienced mild and self-resolving adverse events, such as vomiting (n= 43 children), and there was no significant difference in adverse event rates between N2O 50% and N2O 70% (Babl, Oakley, Seaman, et al., 2008). Risk reduction guidelines for procedural pain sedation are recommended to reduce the risk of N2O sedation-related adverse events in children (Babl et al., 2010).

From 2012-2016, a comprehensive immunisation service offered immunisations under sedation for children with needle phobia, anxiety, and developmental or behavioural disorders in an Australian tertiary paediatric hospital day medical unit (Cheng et al., 2018). One hundred and thirty-nine children had 213 vaccination encounters, and 400 vaccinations were administered. Nitrous oxide was used in almost all vaccination encounters (n=208/213; 97.5%) and as the single agent in more than half of encounters (n=117/213; 54.7%). The immunisation under sedation service was regarded as highly successful, with 203 (95.3%) vaccinations safely and effectively administered (Cheng et al., 2018). There has been little further research on N2O use for immunisation.

Finally, despite N2O administration being safe and effective in paediatric care, evidence has shown that its availability is limited in many settings. A multi-national European survey involving 172 sites across 19 countries investigated analgesia, anxiolysis, and sedation practices in children presenting to ED and found that N2O was only available in 56% of sites (n=96/172) (Sahyoun et al., 2021). Further inquiry is necessary to understand why staff did not have access to N2O for children in these settings.

2.6.1.5 Sweet Solutions

Evidence for analgesic effects of oral sweet solutions, such as glucose and sucrose, for neonatal and infant procedural pain has been established for almost three decades (Blass & Shah, 1995; Bueno et al., 2013; Harrison, Larocque, Bueno, et al., 2017; Stevens et al., 2001). Sweet taste is believed to initiate an oral-mediated release of endogenous opioids; this promotes calm and reduces pain in neonates (Blass & Shah, 1995). Sucrose is the most extensively studied sweet solution, and its safety and analgesic efficacy for single minor painful procedures for newborns is well established in systematic reviews and meta-analyses (Harrison, Larocque, Bueno, et al., 2017; Stevens et al., 2016). A systematic review including 74 studies (n=7049 neonates) demonstrated that sucrose

reduces pain during heel lance, venepuncture, and intramuscular injection in preterm and term neonates with minimal to no adverse effects (Stevens et al., 2016). The review also found moderate evidence that combining sucrose with non-nutritive sucking (pacifier dipped in sucrose) is more effective than sucrose alone (Stevens et al., 2016). The analgesic effects of sucking are explained by the stimulation of orogustatory and mechanoreceptors during sucking (Blass & Ciaramitaro, 1994). Only small volumes of sucrose are required; the effective dose for pain in a single heel lance is 0.1 ml of 24% sucrose (Stevens et al., 2018). However, repeated doses throughout prolonged, painful procedures are recommended to ensure a sustained analgesic effect (Harrison, Larocque, Bueno, et al., 2017).

In another systematic review (38 RCTs; n=3785 neonates), Bueno et al. (2013) demonstrated that glucose (20% to 30%) reduced pain scores and crying during single venepuncture and heel lance procedures. These findings confirm glucose as an effective alternative to sucrose for healthy and preterm infants. Both systematic reviews also demonstrated that sucrose and glucose do not provide adequate analgesia during more major procedures such as circumcision (Bueno et al., 2013; Stevens et al., 2016). There is conflicting evidence supporting the efficacy of sweet solutions for other painful procedures, such as nasogastric tube insertion and bladder catheterisation (Stevens et al., 2016).

Finally, because of robust evidence supporting the efficacy of sucrose and glucose for acute procedural pain in newborn infants, a state of equipoise has not existed for some time in the analgesic effects of sweet-tasting solutions. Experts call for future research to focus on the dissemination and implementation of knowledge and argue that it is unethical to continue to conduct placebo or no-treatment controlled trials relating to the treatment of pain during commonly performed painful procedures in newborn infants (Harrison, Larocque, Bueno, et al., 2017)

Beyond the neonatal period, evidence also supports the analgesic effects of oral sucrose and glucose in infants up to one year of age. A systematic review of 14 RCTs found the administration of oral sucrose or glucose before immunisation moderately reduced the incidence and duration of crying in infants aged one to 12 months (Harrison et al., 2010). However, the optimal analgesic dose could not be determined. There is insufficient evidence of the analgesic effects of sweet solutions for needle-related pain in young children between one and four years of age, as demonstrated in Harrison et al. (2015) systematic review (8 studies, n=808 children). Results of three subsequent RCTs show mixed evidence regarding the efficacy of sucrose in young toddlers. In Despriee and

Langeland (2016) study, statistically significant shorter crying time was reported in children (15 months) who received sucrose compared to water during immunisation. Similarly, Kassab et al. (2020) reported statistically significant lower pain scores, using the MBPS and crying time in 10-18-month-old toddlers undergoing immunisation. In 2022, Modanloo's team found that sucrose did not effectively reduce distress in toddlers aged 12-36 months undergoing venepuncture (Modanloo et al., 2021). Sub-analysis showed that analgesic effects were evident in the younger age group (12-24 months) (Modanloo et al., 2021).

2.6.2 Physical and Psychological Treatments

While the most commonly reported pain interventions are pharmacological, there is growing research interest in physical and psychological treatments for children's pain. Combining pharmacological with physical and psychological interventions acts synergistically for more effective treatment of acute, chronic, and needle-related pain and discomfort (Friedrichsdorf & Goubert, 2020). These interventions are recommended because they are safe, require minimal or widely available resources, are feasible, and draw on children's coping tendencies (Birnie et al., 2018; Fisher et al., 2022; Friedrichsdorf & Goubert, 2020). Most physical and psychological strategies can be applied and modified by clinicians, families, and children (Fisher et al., 2022; Ismail et al., 2019), increasing their appeal and feasibility.

Research on physical treatments for acute pain has focused mainly on neonates, infants, and young children during painful procedures. Robust evidence demonstrates the efficacy of breastfeeding, non-nutritive sucking (i.e., pacifier), skin-to-skin contact, rocking, and comfort positioning to reduce needle pain in neonates and infants (Harrison et al., 2016; Johnston et al., 2017; Pillai Riddell et al., 2015; Taddio et al., 2015). A systematic review including ten studies and 1066 infants examining the efficacy of breastfeeding in reducing vaccination pain in infants beyond the neonatal period up to 1 year found that breastfeeding significantly reduced cry time and pain scores compared to water or no treatment (Harrison et al., 2016). Evidence of the effectiveness of non-nutritive sucking, swaddling/facilitated tucking, and rocking/holding to manage pain behaviours associated with acute painful procedures in neonates born preterm, term, and older infants are also well established, as demonstrated in another systematic review of 63 randomised control trials (Pillai Riddell et al., 2015). A separate systematic review (n=31 studies) focused on immunisation pain and distress found evidence supporting the effectiveness of

non-nutritive sucking, skin-to-skin contact, and holding or upright positioning for acute infant vaccination pain and distress (Taddio et al., 2015).

For psychological interventions, various cognitive and behavioural strategies have been deemed efficacious in reducing children's needle pain and distress. Psychological therapies aim to manage the adverse consequences of pain by focusing on the cognitive (thoughts) and behavioural processes that underlie or contribute to pain, distress, or disability (Birnie et al., 2020). Cognitive behavioural therapy for pain uses a combination of strategies to target thoughts, behaviours, or both, such as distraction, relaxation, deep breathing, hypnosis, and using positive reinforcement (Birnie et al., 2018). Psychological interventions with robust evidence for reducing needle pain and distress in children (aged 2 to 19 years) include distraction, hypnosis, combined CBT, and breathing interventions, as determined in a systematic review that included 59 randomised control trials (Birnie et al., 2018). The efficacy of psychological interventions are influenced by other factors, such as child pain-related fear (Birnie et al., 2017) and parent distress and behaviours (Campbell et al., 2017).

Most psychological interventions have been studied in chronic pain, particularly in older children (Birnie et al., 2020). A systematic review and meta-analysis (n=63 studies; 5025 participants) found that psychological treatments, including CBT, hypnosis, music therapy, noise reduction, and distraction, have some benefits in reducing pain intensity in paediatric chronic pain (Fisher et al., 2022). However, the effects were not maintained over time (Fisher et al., 2022). Some psychological interventions, in particular CBT, reduced functional disability, and these effects were maintained over time (Fisher et al., 2022).

Evidence for physical treatments in chronic childhood pain is less common (Birnie et al., 2020). Results from a systematic review that included 15 studies suggest that exercise may be related to decreased pain intensity for children with chronic pain. However, further high-quality evidence is necessary to substantiate these findings, given the low methodological quality and high risk of bias in the included studies (Kichline & Cushing, 2018). In Fisher's systematic review, physical therapies showed a moderate beneficial effect of reducing pain and functional disability; however, the certainty of these outcomes effects was rated very low (Fisher et al., 2022).

2.7 Sociocultural Factors Impacting Pain Care

Despite long-standing guidance on the use of multimodal strategies to address pain in children, worldwide reports show inconsistent use of these strategies and highlight the risk

of undertreatment of paediatric pain (Birnie et al., 2014; Friedrichsdorf et al., 2015; Postier et al., 2018; Twycross & Collis, 2013; Vejzovic et al., 2020; Velazquez Cardona et al., 2019; Whitley et al., 2021). In addition to issues in pain measurement, assessment, and documentation and the (under) use of multimodal analgesics, several broader sociocultural factors contributing to the complexity of children's pain care have been described. Societal views of pain, dualism, and pain-related stigma are three important sociocultural factors presented in the following subsection.

2.7.1 Societal Views of Pain

Pain is a social phenomenon; culture influences how a person expresses pain and how people view and react to another person's pain (Hadjistavropoulos et al., 2011). However, societal views of pain are limited. The pervasive misconception that pain is temporary, purely physical, and should be endured are embedded in societal norms (Eccleston et al., 2021). When people cope with pain, they are esteemed as 'strong,' amplified by phrases such as 'no pain, no gain' or 'big boys don't cry.' For many people, pain is self-limiting, with obvious underlying aetiologies. However, pain is often dismissed or devalued when pain conditions do not have clear causes or trajectories (De Ruddere et al., 2013; Eccleston et al., 2021). The dismissal or devaluation of pain by clinicians and caregivers predisposes sick, hospitalised children to suffer repeated painful procedures without analgesics (Eccleston et al., 2021; Wakefield et al., 2021).

Children with chronic pain are particularly vulnerable to having their pain devalued by others, including family, friends, and clinicians, and this contributes to poor health outcomes (Wakefield et al., 2021). In their study examining chronic pain injustice (the negative appraisal of the severity of pain related-loss and sense of unfairness) and functioning in adolescents (n=139, mean age 15 years), Miller et al. (2016) found higher levels of perceived pain injustice were associated with adverse outcomes; including higher pain intensity, poor social and emotional functioning, and overall functional disability. Similar findings were reported in a qualitative study by Forgeron et al. (2013) examining the challenges faced by adolescents (n=16,14-18 years) living with chronic pain. In that study, adolescents expressed feeling judged and disbelieved, and all but one adolescent described social losses, including changes to the closeness of their friendships and friendship breakups (Forgeron et al., 2013). Adolescents with chronic pain have also reported the loss of friends in a quantitative longitudinal study examining friendship stability and factors contributing to friendship breakups (Forgeron et al., 2022). This is important given the evidence that stable friendships can be protective to adolescents with

chronic pain (Forgeron et al., 2013; Meldrum et al., 2009) and provide pain-related social support (Forgeron et al., 2022).

2.7.2 Dualism and Stigma

Dualistic views of pain, where pain is declared as the result of either a medical or psychological condition, also stubbornly pervade clinical practice (Wakefield et al., 2018) and impact how children's pain is assessed and managed. The conviction that pain can only be objectively measured and explained in terms of biological constructs blinds clinicians to the psychosocial elements of pain and misdirects pain assessment and treatment (Eccleston et al., 2021). Pain is assessed based on intensity alone in these cases, neglecting broader social, behavioural, emotional, and functional impacts of pain (Eccleston et al., 2021).

When pain is regarded purely through a biological lens, clinicians focus on pharmacological pain interventions and often overlook physical and psychological therapies. This limited approach to pain care fails to address the complete scope of pain (Fisher et al., 2022; Friedrichsdorf & Goubert, 2020; Ismail et al., 2019). A call for greater focus on multimodal pain treatments has been endorsed in the World Health Organization's (WHO) new guideline for the management of chronic pain in children (The World Health Organization, 2021) and the Health Standards Organization, Paediatric Pain Management policy (Health Standards Organization, 2023). These guidelines inform best practice protocols and are essential in promoting appropriate multimodal pain relief for children.

Then again, deeming pain as (solely) psychological contributes to poor pain care for children. Pain is often considered psychological when there is a perceived uncertainty or lack of medical explanation for pain. This is associated with pain-related stigma (Betsch et al., 2017). In Australia in 2021, the National Strategic Action Plan for Pain Management identified pain-related stigma as a public health priority owing to its negative implications on health outcomes, quality of life, and healthcare utilisation (Department of Health, 2021b). Alongside poor outcomes, children and families feel insulted, frustrated, and isolated due to pain-related stigma. Wakefield et al. (2018) used focus group interviews to explore the pain experiences of four adolescent women with chronic pain. These adolescents described frequent exposure to pain-related stigma enacted by clinicians, teachers, and their families and peers. These harmful attitudes contributed to their feelings of social isolation (Wakefield et al., 2018).

Similarly, studies of children with sickle cell disease (SCD) acknowledge the experience of stigmatisation and treatment inequalities when seeking pain treatment. Higher stigma was associated with lower quality of life, more loneliness, and less pain reduction among hospitalised adolescents (n=92) aged 12-18 with SCD admitted for vaso-occulsive pain episodes (Martin et al., 2018). Pain-related stigma also predisposes children and adolescents to delayed diagnosis, treatment bias, and prolonged illness (Wakefield et al., 2018). Families often seek several medical evaluations in pursuit of tangible explanations for their child's pain (Wakefield et al., 2018). These factors increase healthcare utilisation and cost (Birnie et al., 2020; Friedrichsdorf et al., 2016). To date, the issue of pain-related stigma in children with chronic pain has received little attention (Wakefield et al., 2018). A better understanding of the sources, social pressures, and challenges children face because of stigma and the impact on health outcomes is needed.

These dualistic views of pain are often engrained in the clinical practice culture and society more broadly. This highlights an urgent need to raise knowledge and awareness about the biopsychosocial features of pain, particularly given that clinicians have insufficient pre-service and in-service training on pain education (Eccleston et al., 2021). Efforts to educate and raise awareness of pain must also extend to other stakeholders involved in interdisciplinary pain care as well as children, families, and society. Still, although education is essential, it has historically been insufficient to ensure improvements in clinical practice and pain outcomes for children (Chambers, 2018). A broader approach that harnesses digital health technology is needed to ensure paediatric pain is prioritised and all hospitalised children and their families can benefit from improved pain care.

2.8 Prioritising and Improving Childhood Pain

An important challenge in improving children's pain has been moving the focus beyond the individual clinicians knowledge deficits to addressing upstream causes at organisational and cultural levels (Gagnon et al., 2016). Many initiatives to date have focused on education (Gagnon et al., 2016; LaRocca et al., 2012) but not on the social aspects of knowledge translation (KT). Although essential, these efforts have been insufficient to improve clinical practice and children's health outcomes (Chambers, 2018). The number and frequency of clinician-targeted education initiatives have also had little sustained effect on improving clinical practice (Forsetlund et al., 2021; Mansouri & Lockyer, 2007). Broader KT strategies targeting clinicians, patients, and their families, or those with combined interventions, are generally more effective than single strategies

(LaRocca et al., 2012). Evidence also demonstrates that CPGs are infrequently used in practice (Correa et al., 2020), including CPGs addressing the prevention and treatment of children's pain (Harrison et al., 2015; Losacco et al., 2011).

System-level interventions are necessary and should evaluate relationships between interventions and patient outcomes and incorporate follow-up periods to evaluate the sustainability of changes (Gagnon et al., 2016). Multi-stakeholder collaboration (comprising policy and decision-makers, knowledge users, and patient partners) is critical to ensure research relevance and applicability and generate widespread and faster impact (Chambers, 2018; Gagnon et al., 2016). Evaluating previous KT initiatives to understand if, how, and why they have worked (or not) to improve pain care is also essential to advancing the field (Gagnon et al., 2016).

One example of a successful KT initiative is Friedrichsdorf et al. (2018) multiyear, multidimensional initiative called Children's Comfort Promise, which aims to reduce children's needle pain across multiple US paediatric health service settings. The intervention integrated research evidence, ward-specific customisations, staff training, and continuous quality improvement methods using 'plan, do, study act' (PDSA) cycles. Early evaluations showed significant improvements in reducing or eliminating children's needle pain. Although the intervention was resource-intensive, Children's Comfort Promise has become each institution's standard of care for needle procedures integrated into all organisational policies, the EMR, and new staff orientation (Friedrichsdorf et al., 2018). Bonnie Stevens et al. (2014) led another multifaceted and multi-site KT initiative targeting children's pain which also involved tailored strategies and PDSA cycles to improve pain assessment and treatment for hospitalised children in Canada. Moderate improvement in pain practices was seen and sustained in most settings 12 months after the intervention (Stevens et al., 2014).

Children's Comfort Promise is endorsed by ChildKind, an international initiative addressing challenges in paediatric pain through hospital certifications[1]. Conceived by the International Association for the Study Pain's (IASP) Special Interest Group on Pain in Childhood, ChildKind aims to improve children's pain care quality by supporting, educating, evaluating, and recognising healthcare facilities that have developed the highest standards for paediatric pain care (Schechter et al., 2009). To achieve ChildKind status, the hospital must demonstrate a clear organisational commitment to pain relief. This includes;

[1] www.childkindinternational.org

ongoing education for staff, children, and families, consistent use of developmentally appropriate pain assessment and treatment strategies, and regular self-monitoring within quality improvement frameworks (Schechter et al., 2009). As of June 2023, there were 17 ChildKind accredited hospitals across the US (n=12), Canada (n=4), and Singapore (n=1)[2]. Reaccreditation processes ensure the institution remains committed to maintaining optimal pain care practices for children.

As well as clinician-targeted initiatives, there are opportunities to direct KT initiatives toward other knowledge users, including children, primary caregivers, policymakers, and the public. Parent-targeted KT interventions focused on children's pain are increasingly being developed and evaluated. In a systematic review (n=12 studies), Gagnon et al. (2020) found that most KT programs for parents focused on procedural pain among infants. Many parent-targeted KT interventions use social media platforms like Twitter, YouTube, and Facebook to reach parents. For example, the YouTube video for parents, "Strategies for Helping Children with Shots and Needles," demonstrates how parents can help minimise needle pain (Chambers et al., 2013). Five years after its launch, an evaluation of the video showed it had over 240,000 unique views from 182 countries (Chambers et al., 2020). Parents reported the video helpful for seeing techniques to minimise needle-related pain (Chambers et al., 2020). Other campaigns target both parents and clinicians, such as 'The Power of a Parent's Touch in Reducing Baby's Pain During Medical Procedures" led by Campbell-Yeo et al. (2014), focused on newborns, and the suite of Be Sweet to Babies videos which address reducing infant pain during needle procedures (Harrison, Larocque, Reszel, et al., 2017).

Other organisational-based initiatives have helped raise awareness of childhood pain. For example, in 2019, the IASP's Global year initiative focused on vulnerable populations, including pain in infants and young children (International Association for the Study of Pain, 2021). A Canadian mobilisation network, Solution for Kids in Pain (SKIP), was launched in 2019 to unite paediatric pain specialists, clinicians, consumers, KT experts, and over 100 government, business, and healthcare sector partners to improve children's pain care across Canada[3]. In Australia and New Zealand, the Paediatric Electronic Persistent Pain Outcomes Collaboration (PaedePPOC) initiative collectively captures,

[2] www.childkindinternational.org

[3] https://kidsinpain.ca/skip

measures, and benchmarks pain care practices across ten centres to improve specialised pain services (Lord et al., 2019).

Mass media campaigns aimed at reducing childhood mortality and injury-related morbidity have targeted the impact of injuries on children. These include burns prevention, playground safety, and child passenger safety campaigns (Centers for Disease Control and Prevention, 2019; Kidsafe, 2020). While pain is not the focus of these campaigns, these morbidities include pain. Health promotion campaigns to reduce comorbidities associated with persistent and chronic pain, such as obesity, depression, and unhealthy sleep, have also been cited (Centers for Disease Control and Prevention, 2020; National Youth Mental Health Foundation, 2021). However, the effectiveness of these campaigns in reducing childhood pain has not been widely evaluated.

2.9 Healthcare Digitisation

Healthcare facilities worldwide are increasingly adopting digital technologies to support sustainable healthcare systems that deliver high-quality, safe, and efficient care. Alongside promises for better and more accessible healthcare, digital innovations provide significant economic and business development opportunities. These gains account for the considerable financial investment devoted to implementing transformative digital technologies, with estimates predicting the global digital health market size will reach USD 295.4 billion by 2028 (Newswire, 2021). The Coronavirus 2019 pandemic (COVID-19) has prompted an unprecedented acceleration in the adoption and mainstreaming of digital health and increased the use of new care delivery models. There has been a global upsurge in the use of telecommunications for delivering healthcare and increasing implementation of virtual care solutions for remote monitoring and managing chronic disease (Newswire, 2021).

Despite the extensive uptake of digital solutions in the USA since the early 2000s, health services outside the USA are largely in the earlier stages of digital transformation (Slovis et al., 2017; Sullivan et al., 2016). The enthusiasm for digital transformation has also been tempered by previous failures. For example, the demise of the UK's National Programme for Information Technology (NPfIT) in 2012 halted a fully digital National Health Service (NHS). With an initial budget of £6.2 billion, the NPfIT aimed to revolutionise the NHS' use of technology by introducing an integrated electronic patient record system (Crompton, 2007). However, insufficient end-user engagement, the absence of a phased change management approach, and underestimating the project's scale

contributed to its failure (Justinia, 2017). In 2016, the NPfIT was relaunched (Wachter, 2016), but publicly available formal evaluations of the NPfIT have not been accessible. In 2022, the UK's Department of Health and Social Care presented four transformative goals to secure the NHS's digital future by 2025 (National Health Service, 2022).

In Australia, digital transformation has made steady progress. Since 2016, Australian hospitals have begun introducing EMR systems and developing platforms for future digital innovations (Australian Digital Health Agency, 2019b). Australia's multi-tiered healthcare sector has contributed to complexities in designing and implementing digital technologies (Australian Institute of Health and Welfare, 2017). The following sections offer a brief overview of the Australian healthcare system and the implementation of digital health technologies.

2.9.1 The Australian Healthcare System

The Australian healthcare system is governed both federally and by the states and territories. Australian states and territories are primarily responsible for the extensive public hospital network and providing a portion of these hospitals' funding; the remainder comes from the federal government. Additional federal government healthcare funding is delivered under a universal public health insurance scheme called Medicare, which subsidises patient healthcare costs (Australian Institute of Health and Welfare, 2017). Out-of-hospital specialist services, general practice (GP), and some allied health are fee-for-service practices, which Medicare fully or partially subsidises (Australian Institute of Health and Welfare, 2017). Medicare funding is derived through a mix of state and federal taxes.

States and territories use various levels of centralisation to govern health services. Individual hospitals, healthcare networks, and state and territory health departments make decisions regarding hospital operations, which can result in inconsistencies in hospital operations across Australian hospitals. These inconsistencies impact the designing and implementing of digital initiatives within and across Australian states and territories and add to the complexities of digital health in Australia (Australian Digital Health Agency, 2019a). However, each state and territory has prioritised digital health to improve healthcare outcomes while lowering costs (Australian Digital Health Agency, 2019b)

2.9.2 The Australian Digital Health Landscape

Digital technologies are well established in primary care, private specialist settings, and clinical areas of some hospitals. In primary settings, these technologies are generally known as electronic health record (EHR) systems. The Australian GP sector is nearly

100% digitised, and pharmacies have been computer-assisted for some time (Sullivan et al., 2016). Similarly, most allied health services have used computerised systems for patient scheduling, rebates, reviewing diagnostic results, and accessing online clinical reference tools (Department of Health and Ageing, 2011).

In 2012, Australia launched a personally controlled EHR called *My Health Record*. This national system is a longitudinal collection of patient health information shared between patients and clinicians involved in their care and accessed via a web-based consumer portal (Pearce & Bainbridge, 2014). *My Health Record* allows clinicians to share patient information, such as prescribed and dispensed medications, diagnostic imaging and pathology reports, and immunisation history with patients. Patients can also request medications digitally, and pharmacists can access electronic prescriptions (Australian Digital Health Agency, 2019b). In 2019, an estimated 90% of Australians had access to their *My Health Record*, and many Australian hospitals are connected to the *My Health Record* system (Australian Digital Health Agency, 2019b). Other digital solutions have also been implemented in states and territories, such as SafeScript in Victoria, which provides clinicians access to a patient's prescription history for high-risk medicines to enable safer clinical decisions (Department of Health and Human Services, 2020).

The National Children's Digital Health Collaborative is another Australia-wide digital initiative proposed to overcome challenges associated with children's health records (Australian Institute of Health and Welfare, 2021). Children's interactions with hospital and primary care settings are captured in multiple paper-based and electronic systems, which vary between and within states and territories. Since 2021, development work has been underway for a proof of concept for the 'Child Digital Health Record,' which will capture information currently collected in a child's hard copy infant health record ('Baby Book') (Australian Institute of Health and Welfare, 2021). The Baby Book is given to parents at birth and contains information about the child's growth, vaccination, and health history. Once developed, the Child Digital Health Record will link to the *My Health Record* system (Australian Digital Health Agency, 2019b).

In addition to primary care initiatives, Australia has directed substantial health expenditure toward digitising hospitals, specifically adopting EMR and patient portal systems. While electronic information systems have been used in hospital areas such as EDs (Gerdtz & Bucknall, 2001), these legacy systems were primarily flow-management tools with limited functionality and did not replace paper-based clinical records. Many of these systems are now outdated and are no longer in use.

2.10 Hospital Electronic Medical Record Systems

Electronic medical records replace paper-based patient record systems (Australian Digital Health Agency, 2019b; Unwin & Sanzogni, 2013) and are used to document, monitor, and manage all events during a patient's visit to a healthcare facility (The Office of the National Coordinator for Health Information Technology, 2015). A complete EMR consists of a suite of integrated digital components. The core EMR components are clinical documentation and electronic medication administration records (eMAR) (Garets & Davis, 2006). Other functionalities include CPOE, used to enter, modify, review, and communicate radiology and laboratory orders and referrals; electronic medication prescribing (ePrescribing); and CDS tools to provide real-time alerts or prompts to guide and improve clinical decision making at the point of care (Black et al., 2011).

Hospital EMR adoption and maturity can be categorised according to the eight stages (0-7) of the Healthcare Information and Management Systems Society (HIMSS) EMR Adoption Model (EMRAM) (Furukawa & Pollack, 2020) (Table 2.1). The EMRAM is helpful as it provides staged guidance on EMR adoption, maturity, and use, although not all hospitals using EMRs undergo HIMSS accreditation.

The eight stages of HIMSS adoption are shown in Table 2.1, and it can be seen that stage 0 has no elements of the three key ancillary department systems (laboratory, pharmacy, and radiology); these are installed by stage 1. By stage 2, basic security is in place, and internal interoperability is possible. At stage 3, 50% of nursing and allied health documentation, the eMAR, and basic CDS are implemented. By stage 4, nursing and allied health documentation have reached 90%, advanced CDS tools support clinicians, and CPOE replaces 50% of all medical orders with CDS. Complete physician documentation is implemented for at least 50% of the hospital by stage 5. Stage 6 has closed-loop processes for administering medication and blood products and full CDSS functions. By stage 7, the hospital no longer uses paper charts. Barcode scanning for closed-loop administration of medications, blood products, and breastmilk and documentation of all medications is via the eMAR (Furukawa & Pollack, 2020; Healthcare Information and Management Systems Society, 2021).

Table 2.1

HIMSS EMR Adoption Model Cumulative Capabilities by Stage

Cumulative Capabilities
Stage 0
No major ancillary department systems (laboratory, pharmacy, and radiology).
Stage 1
All major ancillary clinical systems are installed.
A full complement of radiology, pharmacy, and cardiology systems provides medical images to physicians via an intranet and displaces all film-based images.
Patient-centric storage of 90% of all digital imaging and communications in Medicine (DICOM) and non-DICOM images is also available.
Stage 2
Major ancillary clinical systems are enabled with internal interoperability, feeding data to a single clinical data repository (CDR) or fully integrated data stores that provide seamless clinician access from a single user interface for reviewing all orders, results, and radiology and cardiology images.
The CDR/data stores contain a controlled medical vocabulary, and a CDS rule for rudimentary conflict checking supports order verification.
Information from document imaging systems may be linked to the CDR.
Basic security policies and capabilities addressing physical access, acceptable use, mobile security, encryption, antivirus/anti-malware, and data destruction are in place.
Stage 3
50% of health professional documentation (e.g., vital signs, flowsheets, nursing notes, nursing tasks, care plans) is implemented and integrated with the clinical data repository.
Capability must be used in the ED, but the ED is excluded from the 50% rule.
eMAR is implemented.
Role-based access control is implemented.
Stage 4
50% of all medical orders are placed by CPOE.
CPOE is supported by a CDS rules engine for rudimentary conflict checking, and orders are added to the nursing and clinical data repository environment.
CPOE is in use in the ED but not counted in the 50% rule.
Nursing/allied health professional documentation has reached 90% (excluding the ED).
Where publicly available, clinicians have access to a national or regional patient database to support decision-making.
During EMR downtimes, clinicians have access to patient allergies, problem/diagnosis list, medications, and lab results.
A network intrusion detection system is in place.
Nurses are supported by a second level of CDS capabilities related to medicine protocols.

Cumulative Capabilities
Stage 5
Full physician documentation (e.g., progress notes, consultation notes, discharge summaries, problem/diagnosis list, etc.) with structured templates.
Discrete data is implemented for at least 50% of the hospital capability must be in use in the ED, but the ED is excluded from the 50% rule.
Can track and report on the timeliness of nurse orders/task completion.
Intrusion prevention system in use to both detect and prevent possible breaches.
Hospital-owned portable devices are recognised and authorised to operate on the network and can be remotely wiped if lost or stolen.
Stage 6
Closed-loop process for administering medications, blood products and human milk, and for blood specimen collection and tracking; fully implemented in 50% of the hospital. Capability must be in use in the ED, but the ED is excluded from the 50% rule.
eMAR and technology in use are implemented and integrated with CPOE, pharmacy, and laboratory systems.
Advanced CDS provides for the "five rights" of medication administration and other "rights" for blood product, human milk administrations, and blood specimen processing.
At least one advanced level of CDS provides guidance triggered by physician documentation related to protocols and outcomes in the form of variance and compliance alerts.
Mobile/portable device security policies and practices are applied to user-owned devices. Annual security risk assessments and a report is provided to a governing authority.
Stage 7
Complete EMR.
Data warehousing is used to analyse patterns of clinical data to improve the quality of care, patient safety, and care delivery efficiency.
Clinical information can be readily shared via standardised electronic transactions with all entities authorised to treat the patient and external health information exchange.
Summary data continuity for all hospital services (i.e., inpatient, outpatient, ED).
Physician documentation and CPOE have reached 90% (excluding the ED), and the closed-loop processes have reached 95% (excluding the ED).

NOTE: Source HIMSS EMRAM from https://www.himss.org/what-we-do-solutions/digital-health-transformation/maturity-models/electronic-medical-record-adoption-model-emram

As of February 2021, there were 576 stage 6 and 309 stage 7 HIMSS-validated hospitals worldwide, most of which were in the USA (Stage 6 n=392/576 and Stage 7 n=257/309). Only four Australian hospitals have reached stage 6 (Healthcare Information and Management Systems Society, 2023). In 2015, Princess Alexandra Hospital (PAH) in Queensland (QLD) became Australia's first adult tertiary hospital to adopt an EMR system consisting of eMAR integrated with CPOE and preliminary CDSS functionalities (Eden et al., 2020). Their EMR was implemented using a phased approach, and by 2017, PAH was accredited as HIMSS EMRAM stage 6.

The Royal Children's Hospital, Melbourne (RCH), was the first Australian paediatric hospital to achieve stage 6 HIMSS EMRAM accreditation following its launch of a comprehensive EMR. The EMR system went live after an 18-month project using a 'big bang' methodology (Owens, 2008), which involved a single-day transfer from predominantly paper-based records to EMR across every department (South et al., 2022). The EMR system included electronic documentation, eMAR (closed-loop barcode scanning), blood management, referrals, and scheduling. As of 2021, five of the nine Australian tertiary paediatric hospitals have an EMR, but RCH is the only site to have undergone HIMSS EMRAM accreditation.

In Australia, the potential economic benefit of EMR systems is an estimated AUS$1.76 billion annually (Forsythe et al., 2016). However, because the EMR rollout is still in its early stages, little has been published about the impact of EMR on care in the Australian context. While EMR implementation may differ worldwide, examining international experience in paediatric hospitals may highlight the long-term impacts of EMR systems and expose potential benefits and challenges associated with their use.

2.11 Electronic Medical Record Systems in Paediatric Hospitals

In addition to barriers common to adult hospitals, such as cost and navigating challenges in early EMR adoption, children's hospitals have a unique challenge in finding digital technologies that meet the needs of children's healthcare (Teufel et al., 2013). For example, paediatric medications are often prescribed off-label and based on weight, requiring more complex EMR medication prescribing tools and workflows than EMR products standardised for the adult population (Ferranti et al., 2011). Most available EMR products have been developed specifically for the adult population (Teufel et al., 2012). The limited availability of paediatric-specific EMR functionality can contribute to the slower progression of EMR adoption in paediatric hospitals (Teufel et al., 2012), often fraught with periods of success and regression (Goldstein et al., 2014).

Despite customisation issues, international evidence has demonstrated that adopting EMRs in paediatric hospitals can facilitate compliance with evidence-based practices and improve care quality, safety, and outcomes (Horton et al., 2020; Pageler et al., 2013; Teufel et al., 2013). Electronic medical record systems have made it possible to create care pathways that actively guide clinicians using CSD features such as alerts, prompts, and reminders for care (Sutton et al., 2020). For example, an automated CDS system comprising checklists linked to CPGs and visual indicators to convey task compliance improved clinician adherence to evidence-based central catheter care and reduced central line-associated bloodborne infections in critically ill children (Pageler et al., 2014). Central line-associated bloodborne infections (CLABSIs) decreased from 2.6 CLABSIs per 1000-line days before the CDS intervention to 0.7 CLABSIs per 1000-line days after the intervention (Pageler et al., 2014). Similarly, improved patient outcomes were observed by implementing an automated EMR malnutrition screening tool in a paediatric oncology unit. This saw significant advancements in screening efficiency and early diagnosis and treatment of malnutrition among hospitalised children (Phillips et al., 2020). Baurer and colleagues found that implementing an automated screening process for autism spectrum disorders in the EMR facilitated paediatric clinician adherence to recommended screening guidelines (Bauer et al., 2013).

Positive effects related to implementing a comprehensive EMR system were reported in a before and after study examining in-hospital deaths at RCH in Melbourne, Australia (South et al., 2022). Over the two-year intervention period, a decrease of approximately 22% in in-hospital mortality rate from 2.20 to 1.72 per 1,000 discharges was reported. Although no causal relationship could be established, a post hoc analysis of mortality rates for an additional two-year pre-intervention period showed the changes were not part of a pre-existing downward trend (South et al., 2022).

A large body of work illustrating the impact of EMR systems has concentrated on improving medication safety in paediatric patients using electronic medication management systems (CPOE) with CDS. Alerts can be triggered to warn clinicians of safety concerns (i.e., dosing errors, drug-drug interactions) and the need for therapeutic drug monitoring. Order sets, a collection of orders aggregated for a given condition, clinical situation, or process (McGreevey et al., 2020), also support safe medication practices. Horton et al. (2020) found instituting a standardised post-tonsillectomy EMR order set that guided clinicians to prescribe four medications (Paracetamol, Ibuprofen, Oxycodone, and Dexamethasone) resulted in standardised and improved pain control regimens and consistency of opioid prescription for children (Horton et al., 2020). While

these were positive outcomes related to pain management, the study did not examine the effects on children's pain outcomes; therefore, this information remains unknown.

2.11.1 Electronic Medical Records in Children's Pain Management

To date, few studies have examined the role of EMRs in hospitalised children's pain care (Aldekhyyel, Melton, Lindgren, et al., 2018; Brenn et al., 2016). Studies conducted in adult acute settings demonstrate the potential of EMRs to improve pain care practices. Gilberston-White and Sharpiro reported an average increase of 1.6 pain assessments documented per day when clinicians used the EMRs compared with the previous paper-based documentation (Gilbertson-White & Shapiro, 2007). Improved frequency of pain assessment documentation was also seen in a later study examining documentation of pain care across three adult tertiary hospitals in the USA; however, inconsistencies, duplications, and omissions in pain care documentation, particularly reassessments of pain, were also identified (Samuels, 2012). Inadequate and inconsistent documentation complicates the extraction and use of EMR pain data, thus impeding quality improvement initiatives and benchmarking efforts (Samuels & Kritter, 2011).

In their pilot study in a USA paediatric hospital, Aldekhyyel, Melton, Lindgren, et al. (2018) implemented a pain management interface (PMI) workflow that integrated the inpatient television (TV), the EMR, nurse call bell, and pharmacy inventory systems to allow patient/parent reporting of pain assessments. Pain medication dispensed from the pharmacy inventory system triggered a timer based on the medication route (15 minutes for IV, 30 minutes for oral). Once the time had elapsed, a pop-up window displayed on the patient's TV prompting them to self-report their pain by selecting one of the pop-up options: (a) hurts more, (b) hurts the same, or (c) hurts less. Pain reports were automatically documented in the EMR and sent to the nurse's phone, prompting the nurse to perform a face-to-face pain assessment. A follow-up message was then displayed on the patient's television, linking them to resources on non-pharmacological pain interventions (Aldekhyyel, Melton, Lindgren, et al., 2018). Patient/parent (n=608) engagement with the pain reassessment TV prompt was low (6.5%); of 27 224 TV prompts triggered, only 1767 were responded to by patients/parents. However, patients'/parents' use of the PMI was associated with a statistically significant improvement in pain reassessment documentation (a 26% increase compared to the previous year). Data regarding changes in pain interventions were not reported (Aldekhyyel, Melton, Lindgren, et al., 2018). Aldekyyel also led a separate study examining parents' and nurses' perceptions of the PMI. Parents were satisfied with the PMI and regarded it as an important

communication tool for reassessing pain (Aldekhyyel, Melton, Hultman, et al., 2018). Nurses also reported that the PMI increased patient engagement in care and indicated that timely reassessments were valuable. However, nurses were uncertain about its clinical utility in reporting pain because they were concerned that patients/parents would dismiss the pop-up pain rating question so that they could continue watching TV (Aldekhyyel, Melton, Hultman, et al., 2018). This is interesting, given the evidence of the efficacy of distraction for reducing children's pain and distress, particularly when used as part of a multimodal pain regimen (Pillai Riddell et al., 2015). Ignoring a pop-up may indicate that watching TV helped distract the child from their pain. Nonetheless, to address the nurses' concerns, the authors modified the pop-up question so that the default display was 'hurts more,' in the hopes that this would increase patient engagement with PMI and emphasised the need for patient/parent education on the benefits of using the tool (Aldekhyyel, Melton, Hultman, et al., 2018).

To our knowledge, no further published studies have examined the influence of hospital EMR systems on assessing and treating hospitalised children's pain, which may reflect the relatively new status of EMR systems in paediatric settings.

2.11.2 Patient Portals

As digital technology evolves, there is a central focus on leveraging technology to connect and empower people to manage their own health and wellness. The COVID-19 pandemic has drastically stimulated the use of patient-enabled portals to facilitate remote consultation, monitoring, communication, and treatment (Greenhalgh et al., 2020; Lindsay et al., 2021; Vandekerckhove et al., 2020), particularly for people living with chronic diseases.

Patient portals provide patients with secure online access to their personal health information contained within the EMR, such as medication lists, immunisation history, and pathology results (Australian Digital Health Agency, 2019a). They allow patients to view and book appointments, request and review prescriptions, and facilitate patient-clinician communication via secure synchronous messaging. For example, an overview of 14 systematic reviews demonstrates that patient portals used in ambulatory settings can increase patient empowerment and improve care quality and outcomes (Antonio et al., 2020).

Similarly, a growing evidence base demonstrates that inpatient portals (linked to hospital EMRs) enhance child and family engagement and improve safety, quality, and care outcomes during hospitalisation (Kelly et al., 2019; Kelly et al., 2018). Hospital-based portals can give patients real-time access to their EMR data, such as vital signs,

medications, and test results. They can also give patients the ability to communicate with clinicians via messages, and order meals and access entertainment (Aldekhyyel, Melton, Lindgren, et al., 2018; Antonio et al., 2020; Kelly et al., 2018). However, best practice recommendations regarding the amount and timing of information released to patients/parents (i.e., clinical notes and pathology results), hardware decisions (i.e., hospital-owned tablets vs. bring your own device), and the scope of messaging systems are scant (Dendere et al., 2019; Kelly et al., 2018).

Like portals used in ambulatory care, preliminary evidence supports that inpatient portals may improve patient/parent engagement, knowledge, and the quality and safety of care. Evidence from a systematic review (n=58 studies) demonstrates that having access to health information helps patients and families better understand, monitor, and make decisions about their care (Dendere et al., 2019). Patients and families have shared their desire for an inpatient portal with features that allow them to communicate with clinicians and access real-time clinical information (Greysen et al., 2020; Kelly et al., 2019). However, clinicians are concerned that increased information transparency may confuse or cause anxiety for patients/parents (Dendere et al., 2019; Kelly et al., 2018). They also worry that patient-clinician communication via synchronous messaging may establish unreasonable expectations and increase their workload (Dendere et al., 2019; Kelly et al., 2018). However, these concerns have not materialised in studies exploring the impact of inpatient portals in adult settings (Dendere et al., 2019).

To date, much of the evidence on inpatient portals has focused on interim outcomes such as user perceptions; however, whether the use of inpatient portals ultimately translates to demonstrable improvements in meaningful health outcomes, such as morbidity and mortality, is largely unknown. While there is emerging evidence regarding portals in adult hospitals, there is less evidence of their use in inpatient paediatrics settings.

2.11.3 Inpatient Portals in Paediatric Care

From 2017 to 2019, Kelly led a project comprising three studies that explored inpatient portal use in a USA tertiary paediatric hospital (Kelly et al., 2019; Kelly, Hoonakker, et al., 2017; Kelly, Hoonakker, et al., 2019). Doctors were surveyed before and six months after an inpatient portal was implemented, and most reported fewer challenges than anticipated. Only 17% (n=12/70) of clinicians agreed that their workload increased, and 3% (n=2/70) reported spending more time answering parent questions (Kelly, et al., 2017). Parent use and perceptions of the portal were captured via an online

survey (Kelly, Hoonakker, et al., 2017) and qualitative interviews (Kelly et al., 2019). Almost all parents reported that using the portal improved care (n=85/90). More than half (n=54/90) said that the portal improved communication with the clinical team, and some (n=7/90) found errors in their child's medication list (Kelly, Hoonakker, et al., 2017). Qualitative study findings showed that parents wanted more portal functions, especially synchronous messaging, and unrestricted access to their medical notes to support their involvement in care (Kelly et al., 2019). Together, these studies offer preliminary insights into the use of inpatient portals; however, the generalisability of findings is limited, given that these studies were conducted in a single setting in the USA. Few Australian hospitals have implemented patient portals. In 2016, the Royal Children's Hospital, Melbourne (RCH), was the first in Australasia to implement an outpatient portal (Epic MyChart) system (Glogolia et al., 2019). In 2022, RCH was the first Australian hospital to implement an inpatient portal system (Epic, Bedside), rolled out across two hospital departments as part of a pilot implementation process preceding a hospital-wide project. As of July 2023, no Australian tertiary paediatric hospital has fully implemented an inpatient portal system.

2.12 Summary

Despite how frequently hospitalised children are exposed to pain, the ramifications of unrelieved pain, and evidence supporting the effectiveness of multimodal pain treatments, children's pain remains under-recognised and undertreated in most children's hospitals. Adopting acute care digital health technologies, such as EMRs and patient portal systems in international hospitals, has improved adherence to evidence-based practices, care quality and safety, and outcomes. While promising, little is known about how these systems can be used to improve pain care practices and outcomes for hospitalised children and their families. This research program is focused on examining recommendations, practices, and perspectives regarding EMR and patient portal use and designs to facilitate optimal pain care for hospitalised children and their families to address this critical knowledge gap.

Chapter Conclusion

Evidence presented in this chapter highlighted advancements in the fields of pain theory, science, and practice. The inconsistent use of pain treatments for hospitalised children worldwide was discussed, and the short and long-term consequences of undertreated childhood pain were briefly highlighted. Multifaceted issues related to assessing and treating children's pain were illustrated. Commitments to improve pain outcomes through KT initiatives were presented. The impact of digital technologies on clinical practice and outcomes was outlined.

The following section outlines and explains the context in which this research program sits. The mixed methods design applied in this project is illustrated, and the purpose of collecting and analysing quantitative and qualitative data is explained and justified.

Chapter Three

3

Research Design & Conceptual Framework

This chapter outlines the research aim and provides a rationale for selecting a multi-phase, mixed-methods design for this study. The philosophical approach underpinning this study is outlined, and the selection, rationale, and description of the conceptual framework underpinning this research is presented. The chapter concludes by explaining how stakeholders were actively involved throughout the project. The methods for each study are described in their respective chapters, Chapters Four, Six, and Eight, and supplemented by the information outlined in their respective manuscripts in Chapters Five, Seven, and Nine.

3.1 Research Aim

The aim of research described in this thesis is to examine recommendations, practices, and perspectives regarding EMR and patient portal use and designs to optimise pain care and outcomes for hospitalised children and their families.

Three specific research objectives underpin this aim;

1. To explore the perspectives of international paediatric clinical pain experts about EMR designs that drive optimal child and family-centred pain care practices in hospitalised settings.
2. To examine the perspectives of primary caregivers of hospitalised children (0-18 years) and of hospitalised youth (12-18 years) about their potential use of an inpatient portal to support their engagement in their/their child's pain care.
3. To examine how paediatric clinicians use EMRs in hospitalised children's pain care in Australian tertiary paediatric hospitals.

3.2 Research Design

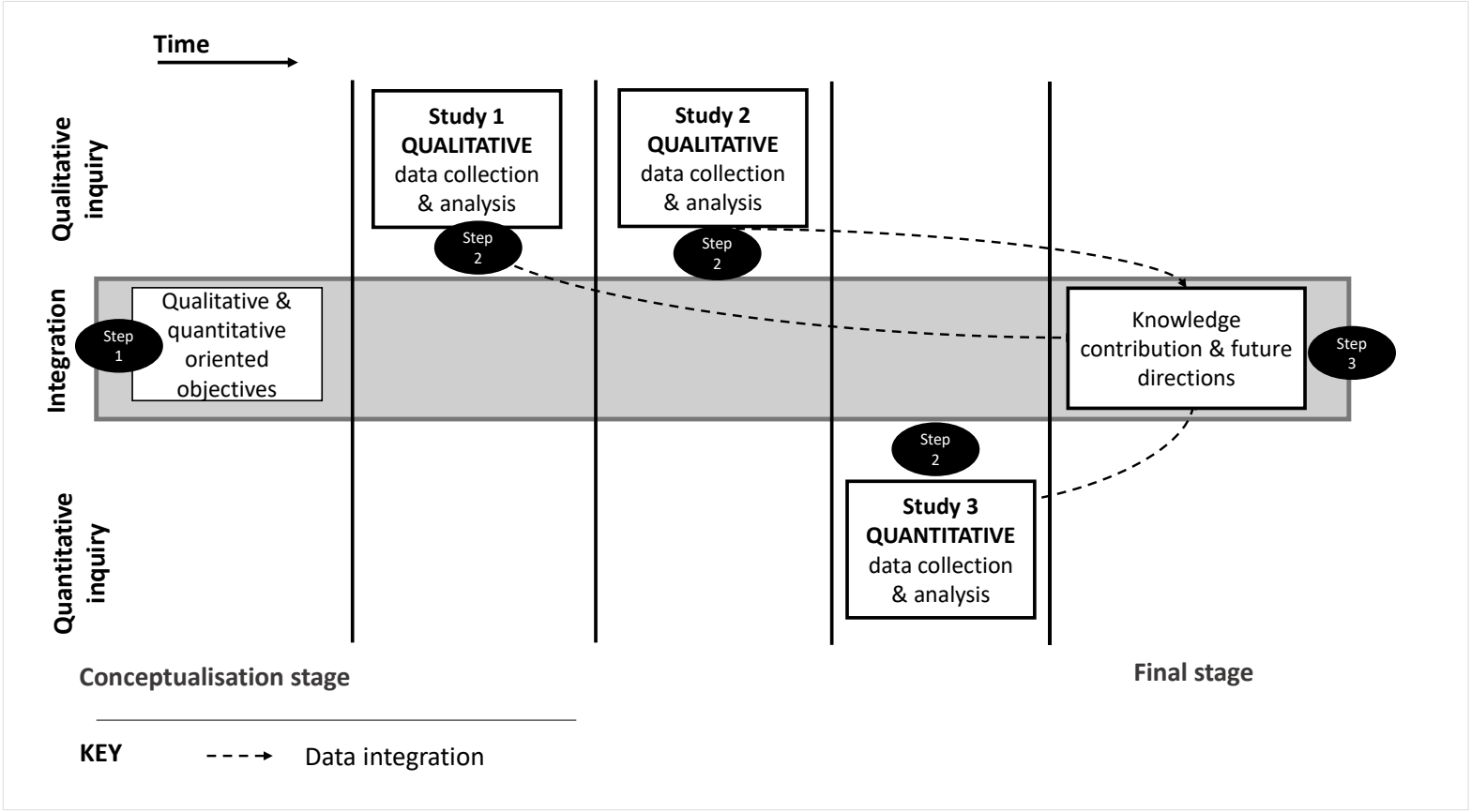
This project explores an area of hospitalised children's pain care about which little is known. The project is underpinned by a pragmatic research paradigm (Morgan, 2014) and aligned with an inquiry framework (Mitchell et al., 1998). Neither quantitative nor qualitative aspects alone could provide a complete understanding of the research objectives, so a mixed methods approach was adopted. This multiphase mixed-methods design (Creswell & Clark, 2011) included three sequential, independent, equal-status studies. Specific designs, methodologies, and research objectives exist for each study, outlined in their respective thesis chapters. Qualitative interviews were used to explore clinical pain experts' recommendations on EMR designs to drive optimal pain care practices (research objective 1). Interviews were also used to examine the perspectives of PCGs and of youth about using a portal to support their engagement in pain care during hospitalisation (research objective 2). Quantifiable data collected via a clinician-targeted cross-sectional survey provided insight into current practices using EMRs in hospitalised children's pain care (research objective 3). Mixed methods facilitated breadth and depth of examination of distinct but related aspects of the complex phenomena (Tashakkori & Creswell, 2007).

3.2.1 Integration of Qualitative and Quantitative Components

Using Creswell and Clark's (2011) multiphase mixed methods design, integrating quantitative and qualitative components in this study involved three steps, outlined in Figure 3.1. Firstly, the decision to integrate quantitative and qualitative components began during the project's conceptualisation; when the aim, associated objectives, and scope were defined (step 1). To address the aim, both quantitative and qualitative-oriented objectives were formulated (step 1). Secondly, qualitative and quantitative data were collected independently across different time points to address the distinct but related objectives; no integration occurred at this point (step 2). Qualitative data were collected from clinician experts about EMRs (Study One) and PCGs and youth about patient portal systems (Study Two), and quantitative survey data were collected from clinicians in Australian paediatric hospitals (Study Three). Data from each study were analysed separately and handled in a traditional manner as dictated by methodological considerations (step 2). Lastly, findings from qualitative and quantitative components were drawn together at the project's final stage (step 3) to address the research aim, outline important knowledge contributions, and provide insights into future directions in EMR and patient portals systems in hospitalised children's pain care (Creswell et al., 2011).

Figure 3.1

Steps and integration of the multiphase mixed methods study



NOTE: Figure illustrates the points of integration of quantitative and qualitative components. Mixed methodology based on design types proposed by Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C. (2011). Best practices for mixed methods research in the health sciences. *Bethesda (Maryland): National Institutes of Health, 2013*, 541-545. (Adapted from Tashakkori and Teddlie (2010).

3.3 Philosophical Position: Pragmatic Paradigm

A researcher's theoretical position influences their research and how it is defined and contextualised (Morgan, 2014). It is critical to identify paradigms that align with the researcher's philosophy to bring awareness to how the researcher influences the research and to mitigate any biases. As a clinical nurse scientist with over 14 years of experience and an interest in paediatric pain, I conceptualised and designed this research from the knowledge and insights I gained throughout my career. My experiences as a registered nurse and researcher guided this project's development into a meaningful whole, incorporating clinical, research, and theoretical understanding, steering the ultimate goal of translating knowledge into practice (LaRocca et al., 2012). Pragmatism aligns with the proposed research and is the underpinning philosophical position guiding this thesis.

This research acknowledges that the use of EMRs and portal systems in paediatric pain care is a complex phenomenon. For this reason, the study has been designed to ensure that multiple views contribute to a comprehensive understanding of the phenomenon. As previously described, both qualitative and quantitative methods are used to fully meet the research aim. This section describes the philosophical implications of combining qualitative and quantitative methods. The paradigms associated with each research type are presented, and philosophical considerations of mixing qualitative and quantitative research are outlined. Pragmatism is presented as a paradigm that unifies the conflicting philosophical underpinnings and justifies using mixed methods.

Many paradigms exist, but positivist and constructivist paradigms are discussed as they strongly align with quantitative and qualitative research. Quantitative inquiry is rooted in a positivist paradigm. The term 'positivism' originates from the Latin word "positum" meaning that facts are "posited" in front of the researcher (Alvesson, 2009). Positivists argue that knowledge can be empirically measured and understood. When appropriately developed, knowledge is truth that is certain, accurate, and congruent with a single reality. Epistemological assumptions deriving from this contend that knowledge can and must be objectively developed using value-free methods (McEvoy & Richards, 2006). Experimental designs and closed-ended techniques such as questionnaires are favoured in the positivist paradigm (McEvoy & Richards, 2006).

Qualitative research is aligned with the constructivist paradigm, also known as the interpretivist paradigm. Constructivists believe that multiple realities exist, that human behaviour is complex, and that knowledge can only be created by interpreting meanings

that people place on their behaviours or events (Maxwell, 2012). Epistemological assumptions emanate from this claim that knowledge must be subjectively, holistically, and inductively obtained (Maxwell, 2012). The researcher(s) inevitably shape and influence the knowledge they create. Constructivist methodologies depend heavily on naturalistic methods such as interviews and observations and require interaction between the researcher(s) and the participant(s) to understand the research phenomenon.

Quantitative purists who argue that inquiry should be objective and qualitative purists who defend the benefits of relativism, hermeneutics, and constructivism in favour of positivism have jointly agreed that their methods should not be mixed (Zhang & Creswell, 2013). However, the emergence of mixed methods is said to have appeased these warring parties (Tashakkori & Teddlie, 1998). Using mixed methods acknowledges that opposite paradigms are not all-inclusive and other factors are at play (Greene, 2007). Pragmatists reject the 'either-or' decision points associated with the paradigm wars and postulate a *compatibility thesis* (Tashakkori & Teddlie, 1998) in which quantitative and qualitative methods are, indeed, compatible, and combining these methods complements the advantages and disadvantages present within each.

This unification of the philosophical underpinnings was required to proceed with the research discussed in this thesis. This research was therefore positioned within the pragmatic paradigm. The ontological and epistemological stance for pragmatism combines quantitative and qualitative paradigms as two integrated philosophies and justifies using the most appropriate methods to address the research aims (Morgan, 2014). In this research, the pragmatic ontological stance warranted the investigation of pain care practices and experiences, and experiences of using digital health technologies in pain care. A mixed methodology was required for this research project because neither quantitative nor qualitative methods alone could investigate these components of EMR and patient portal systems in pain care. Using mixed methods would allow broad scope and breadth of examination by including multiple overlapping components (Morgan, 2014). Components of design mixing, including how and where data are mixed, are debated among mixed methods researchers (Tashakkori & Teddlie, 1998). A discussion on design mixing in this project is presented in detail in Chapter Eight of this thesis.

3.4 Conceptual Framework Search and Selection

Theory-based conceptual frameworks inform thinking and offer meaning and direction to research (Fawcett & Gigliotti, 2001). Each conceptual framework facilitates

the grounding of a distinctive cognitive orientation for viewing phenomena and provides a foundation to examine interactions and relationships among concepts, which, when considered together, can describe a more complex and complicated phenomenon (Nilsen, 2015). Research has found that interventions for children with pain are more effective with clear theoretical underpinnings (Andersen et al., 2021). The nursing discipline is informed by many conceptual models that offer a framework for inquiry to describe, examine, evaluate, and empirically test contextual elements that influence practice (Fawcett, 2016). Each conceptual model provides a different way of thinking about what Fawcett termed the nursing meta-paradigm: person, environment, health, and nursing (Fawcett, 1984).

The literature review in Chapter 2 revealed that addressing the undermanagement of hospitalised children's pain is a complex, multifaceted issue. Background literature also suggests the potential for hospital-based technology to improve practice and outcomes, but multifarious institutional and individual factors influence their implementation, design, and use. A deeper understanding of how pain care quality and outcomes are influenced by the dynamic interplay between the care context, including people (staff), processes and systems, and patients, is required. The search for a conceptual framework to guide this research revealed the Quality Health Outcome Model (QHOM) to be frequently cited in nursing care. Many contexts and patient-related factors important in examining EMRs and portal systems in pain care can be drawn from this model. The QHOM is considered in greater detail in the following subsection.

3.5 The Quality Health Outcomes Model

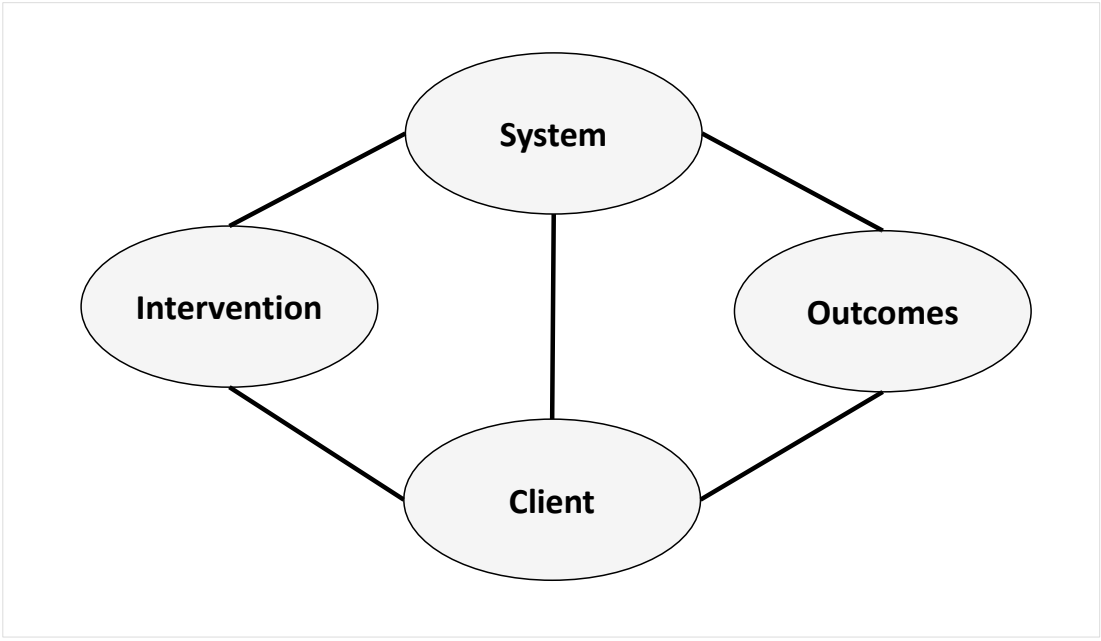
The QHOM (Mitchell et al., 1998) is depicted in Figure 3.2. It was developed by the American Academy of Nursing in 1998 as an extension of The Donabedian Model of quality assessment in healthcare (Figure 3.3) (Donabedian, 1988). The Donabedian Model (1966) implies a linear relationship between structures (healthcare context), processes (interventions and treatments), and outcomes (effects of care). Structures are attributes of the care setting, such as material and human resources, including hospital ward equipment, technology, available staff, their knowledge and skill levels, and policy and practice. Processes are healthcare activities and tasks, such as comprehensive assessments and subsequent multimodal treatments. The results of the process are outcomes, including patient states of health or events that follow care, such as patient outcomes, satisfaction and safety, and clinician documentation. The underlying premise is that good performance in one domain increases the likelihood of good performance in the subsequent domain.

The model suggests that interventions directly produce expected outcomes. A key limitation of the Donabedian Model is that the implied relationships among the three variables usually remain linear and unidirectional and do not reflect the feedback that occurs among patients, the system or context in which the care is provided, and interventions.

As an extension of the Donabedian Model, the QHOM posits a non-linear model depicting the reciprocal interaction among the four constructs: system characteristics (healthcare context), interventions, client characteristics, and outcomes (Mitchell et al., 1998). Unlike the Donabedian Model, the QHOM does not include a direct connection between intervention and outcomes (Figure 3.2). Healthcare interventions are mediated and moderated by system and client characteristics. The path from interventions to outcomes is also conceived to be moderated by both system and client characteristics. Although the QHOM includes nursing meta-paradigm constructs (person, environment, health, and nursing care), it applies to all health services research and quality improvement activities.

Figure 3.2

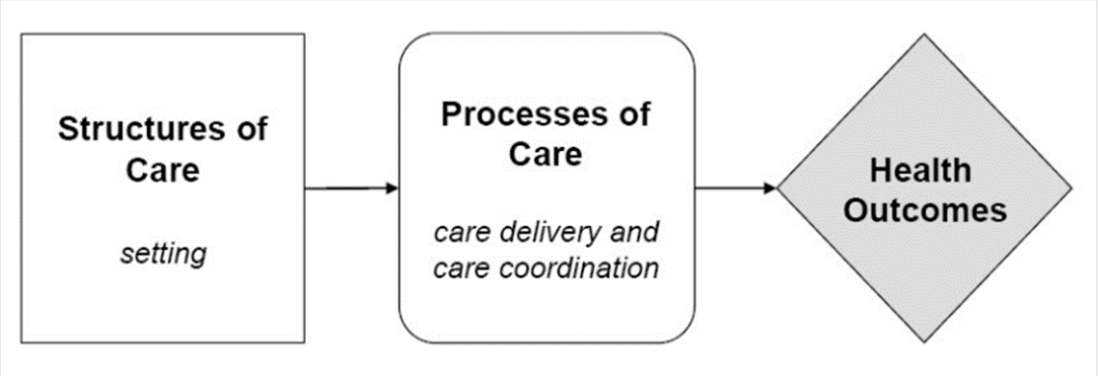
The Quality Health Outcomes Model (Mitchell et al., 1998)



NOTE: The Quality Health Outcomes Model. From Mitchell, P. H., Ferketich, S., & Jennings, B. M. (1998). Quality Health Outcomes Model. *Image: The Journal of Nursing Scholarship, 30*(1), 43-46. https://doi.org/10.1111/j.1547-5069.1998.tb01234.x

Figure 3.3

The Donabedian Model in quality assessment in healthcare



NOTE: From The Donabedian Model. From Donabedian, A. (1966, Jul). Evaluating the quality of medical care. Milbank Mem Fund Q, 44(3), Suppl:166-206.

3.5.1 Use of The Quality Health Outcomes Model in the Literature

Since its development, the QHOM has served as a theoretical framework for research projects and as an impetus for developing other related models. A literature review identified 19 studies that used the QHOM to varying extents (Boyle & Baernholdt, 2021). The most common systems studied using the QHOM were hospitals, particularly nursing units, and various patient groups, interventions, and outcomes were studied (Boyle & Baernholdt, 2021). Not all studies examined all four QHOM constructs (Boyle & Baernholdt, 2021).

The QHOM has been used to study several patient groups, including the care of children and their families. For example, Hallowell and colleagues used the QHOM to examine the association between the NICU environment, staffing levels, staff education, lactation consultant availability, and breastfeeding support on infant receipt of human milk at discharge (Hallowell et al., 2016). The QHOM was also used to examine the impact of early-term infant birth rates, elective labour induction, and caesarean section on NICU admission of early-term infants (McAlister et al., 2013). Both studies identified practice patterns amenable to improvements in infant quality of care and outcomes.

Studies have also used the QHOM to describe health information technology interventions. For example, Jost examined how implementing an EMR-based CDS system impacted nurses' perceptions of their ability to efficiently practice, communicate, and share information and the impact of the CDS on nursing practice environments (Jost, 2016). Study results informed CDS system designs that drive evidence-based practice while preserving the impact of nurses' expertise, intuition, and holistic care (Jost, 2016).

Another study used the QHOM to guide the implementation of a patient acuity software system that generated patient acuity scores, which were subsequently used to guide staffing decisions (Badger, 2017).

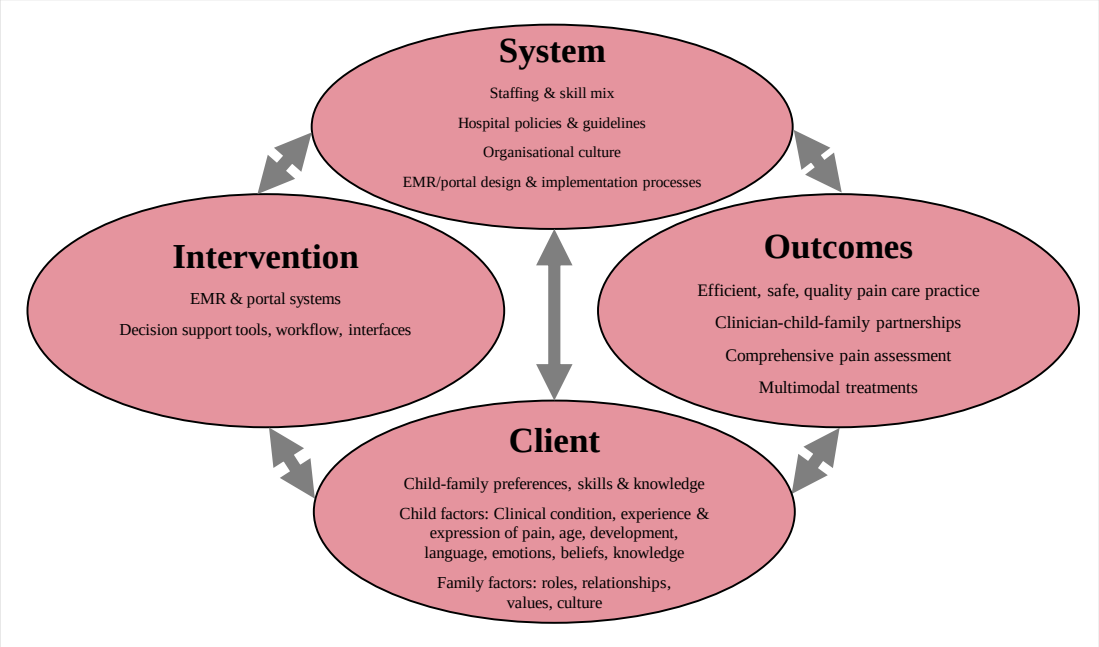
Various outcomes have been examined in studies using QHOM, including patient-reported outcomes, patient safety, and nursing processes. Patient symptom management, including pain and function, was examined in a study by Baernholdt et al. (2015), who used the QHOM to assess the influence of specific hospice interventions on hospice care quality in rural and urban areas. Berry et al. (2018) used the QHOM to frame their study reporting acceptability and utilisation of the iCancerHealth app as an adjunct to usual patient education among adult cancer patients.

3.5.2 Application of The Quality Health Outcomes Model to this Thesis

The use of EMRs and patient portal systems in hospitalised children's pain care is a complex phenomenon involving a reciprocal interplay of institutional and individual factors that influence system implementation, design, and use. The QHOM is deeply embedded within a pragmatic worldview and was selected to underpin this thesis. The model is built on the principle of quality care, an essential concept for clinical research. The QHOM provided a meaningful frame of reference to examine meta-paradigm constructs (person, environment, health, and clinical care) in the quality of pain care for hospitalised children and their families. Hospitalised children and their families are intricately tied to clinical practice and the hospital environment. The QHOM created a framework on which the three studies in this multiphase project are mapped to offer a comprehensive lens to examine the role of EMR and patient portal systems in hospitalised children's pain care. Figure 3.4 represents study constructs with the QHOM. Figure 3.5 provides an overview of the project encapsulating the overarching theoretical framework, methodology, and the three independent, interrelated studies.

Figure 3.4

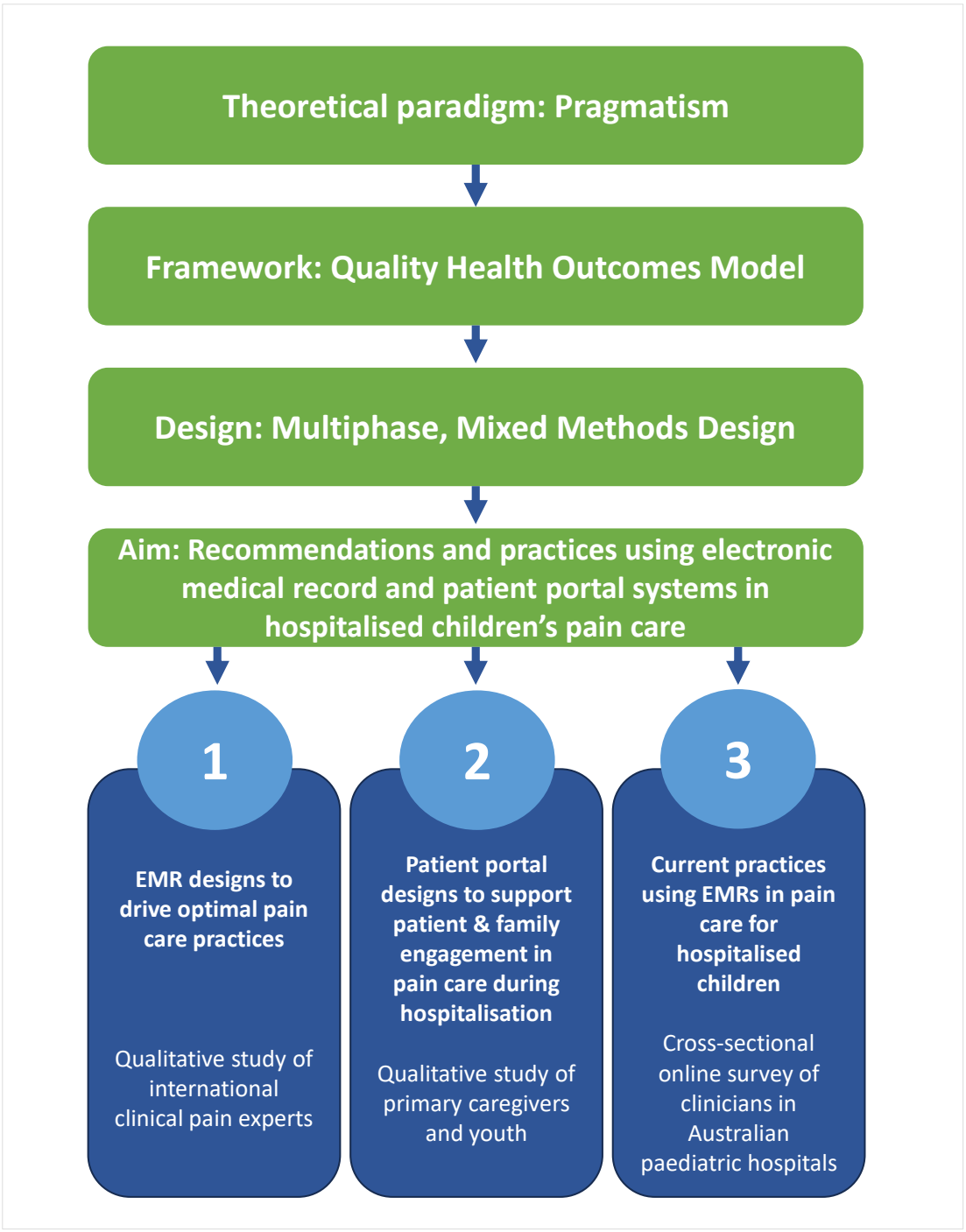
Study constructs examined as applied to the Quality Health Outcomes Model



NOTE: Adapted from The Quality Health Outcomes Model. From Mitchell, P. H., Ferketich, S., & Jennings, B. M. (1998). Quality Health Outcomes Model. *Image: The Journal of Nursing Scholarship, 30*(1), 43-46. https://doi.org/10.1111/j.1547-5069.1998.tb01234.x

Figure 3.5

Thesis overview outlining the framework and study components



3.6 Stakeholder Engagement

The research team comprised a diverse group of researchers, clinicians, and patient partners. The team has expertise in quantitative (DH, DC, SJ, LC, MS, GP) and qualitative methods (NP, DH, DC, SJ, LC), implementation science (DH), paediatric pain care (NP, DH, DC, LC, MS, GP, JK), patient engagement and knowledge mobilisation (DH, SJ, NP), information technology, including EMRs and patient portal systems (SJ, MS). The team collaborates with medical, nursing, and research directors at the Royal Children's Hospital, Melbourne, the University of Melbourne, and the Murdoch Children's Research Institute. The primary supervisory committee (DH, DC) met fortnightly, and full supervisory team meetings (DH, DC, MS, GP) 4-5 times yearly. We actively engaged youth (female, aged eight; male aged 14) and PCGs (mother and father) patient partners with recent hospitalisation with a painful condition to guide aspects of study conduct from youth and PCG perspectives. This group met virtually two times per year.

Chapter Conclusion

In this chapter, the overall multiphase mixed methods study design was described and justified. The underpinning philosophical assumptions were presented. The search for a suitable conceptual framework was described, and an in-depth account and consideration of the Quality Health Outcomes Model was presented, including evidence of its previous use and rationale for its selection for this research. Stakeholder engagement was discussed. Chapters Four, Six, and Eight present the methods of each of the three studies.

Chapter Four

4

Study One Methods

This chapter describes the methods used to conduct Study One, consisting of qualitative online interviews. Recruitment procedures, data collection and analysis, and ethical considerations are described. The information in this chapter summarises the study methods and supplements details provided in the peer-review publication reporting study findings, which is incorporated in Chapter 5.

4.1 Study One Objective

Guided by the general principles of naturalistic inquiry situated within a constructivist worldview (Lincoln & Guba, 1985), this study employed a qualitative exploratory interview design to address the first objective; which was to examine the perspectives of international clinical paediatric pain experts regarding EMR designs needed to facilitate optimal pain care practices for hospitalised children.

4.2 Study One Participants

The sample comprised English-speaking nursing and medical experts (hereafter 'experts') who worked in hospitals using a comprehensive EMR and were primarily responsible for caring for children with pain. A comprehensive EMR was defined as a system comprising the essential functions to support pain care: electronic documentation of vital signs, pain assessment and documentation of pain care-related interventions, and order entry for actionable items. The HIMSS EMRAM (Healthcare Information and Management Systems Society, 2021) was not used to define eligibility criteria because not all hospitals with an EMR undergo a HIMSS assessment and accreditation.

The experts purposively targeted had experience caring for hospitalised children with acute pain and were conversant with evidence-based patient and family-centred pain care practices and how to capitalise on EMR designs to drive these practices. As this research was focused on nursing and medical experts, other clinicians (i.e., allied health and child life specialists) were not included. Clinicians from hospitals that did not use a comprehensive EMR were excluded.

4.3 Study One Sampling and Recruitment

Theoretical purposive and snowball sampling was applied to target experts with knowledge and experience of the phenomena of interest (Polit & Beck, 2021). Unlike stratified purposive sampling, where the researcher establishes homogenous subpopulations *before* sampling, theoretical sampling is applied *during* the data collection and analysis to help build heterogeneity into the sample (Robinson, 2014). Using theoretical purposive sampling in the initial stages of recruitment ensured expert participants from various clinical settings with comprehensive EMRs were represented (Polit & Beck, 2021). A secondary snowball strategy was applied to extend the reach and, therefore, the diversity and number of potential participants. Participants were encouraged

to promote the study to their networks via email or social media (Twitter). These sampling methods enabled a heterogeneous sample representative of the expert population.

To target clinicians with interest and expertise in paediatric pain, expert participants were recruited via email invitations distributed to self-subscribing members of the Paediatric Pain Mailing List (PPML). Since 1993, the PPML has brought together a community of more than 1000 paediatric pain clinicians from many countries to share clinical and research experiences (Stewart et al., 2010). However, the PPML originated in Canada; therefore, there is the potential that it over-represents North American clinicians. Strategies were included to reach clinicians beyond Canada. The email invitation (Appendix O) outlined the study purpose, the intended target population, and the research procedures. The participant information sheet and consent form were included as email attachments (Appendix P and Appendix Q) to further detail the study's aim, significance, and recruitment processes.

The study was also promoted via social media. A brief (24-second) video and associated text outlining the study aim was posted on Twitter with an embedded link to the participant information statement. This approach was considered an effective recruitment tool, given the interconnected nature of social media and the ability to extend communication reach to potential participants (Gelinas et al., 2017). Only two follow-up emails and two posts were distributed via PPML and Twitter to ensure recipients were not inundated with reminders (National Health and Medical Research Council, 2018). This was especially important given that the study was undertaken during the COVID-19 pandemic.

The principal investigator (PI) (NP) contacted potential participants who expressed an interest in taking part in the study to assess eligibility, discuss the project further, and answer any questions before scheduling the online one-to-one interview at a time convenient to the participants. Eligible participants were sent an email with a link to collect informed electronic consent (e-consent) and demographic data using Research Electronic Data Capture (REDCap®) hosted by the University of Melbourne, Health and Biomedical Informatics Centre (Harris et al., 2009). A link to access the web-based video conference meeting using the Zoom platform was also included in the email. The PI completed all interviews during December 2021 and March 2022.

4.4 Study One Data Collection

4.4.1 Demographic Data

A 17-item demographic REDCap® survey captured participants' roles, years of experience, workplace, and hospital EMR. The questionnaire was developed in consultation with the stakeholder committee and pre-tested before use for clarity and relevance of questions and time taken to complete the survey. Survey questions were modified based on the feedback, adding two pain assessment scales as options in one of the questions. The final questionnaire is included in Appendix R. Questions were multiple choice, tick box, and short answer. Adaptive questioning was used, where items were conditionally displayed based on responses to other questions. Respondents could review and change their answers before submitting the survey using a back button. Demographic data were summarised using means and standard deviations for continuous factors (i.e., mean for years of experience) and frequencies and percentages for categorical factors (i.e., type of EMR).

4.4.2 Interview Guide

An interview guide was constructed from a review of literature and consultation with the stakeholder committee and pre-tested with a pain specialist nurse who was not a study participant. Pre-testing addressed the content and clarity of questions, time to complete, and to what degree the questions could capture expert perspectives about using EMRs in children's pain care. Pre-testing led to adjustments for clarity and removing a question considered redundant. This final version of the interview guide was used for the participant interviews (Appendix S).

Interview questions invited participants to draw on their experiences using EMRs to assess and treat pain, including how families and children are involved in this process. Three further interview questions asked about using EMR data in quality improvement activities and sought recommendations for EMR designs and system optimisations to enhance children's pain care. Using the interview guide helped ensure data collection was conducted within an appropriate timeframe and allowed participants to express their experiences without prolonging the interview. It also helped to ensure the interview addressed the domains of interest. Interview questions were iteratively modified based on an analysis of preliminary interviews to address the participant's needs, enhance clarity and comprehension of questions, and explore new concepts as they unfolded, such as the

use of patient-facing digital health technologies in pain care and perceived benefits and burdens related to these systems.

4.4.3 Online, One-to-One Interviews

The PI, a woman, and a paediatric registered nurse with experience in qualitative research methods, conducted the online semi-structured interviews. The PI had no previous relationships with the participants. Before the interviews, the participants were advised to ensure they had access to a secure internet connection and a quiet space during the interview to minimise disruptions. The PI recorded reflexive notes in a journal immediately following each interview (See Chapter 12, section 12.5). This journaling allowed the PI to reflect on and clarify any biases that may have influenced the interview process (Holloway & Wheeler, 2010). Given her professional work, her interest in digital technology, and her experience using an EMR, the PI needed to be cognisant of how her assumptions, values, and experiences may have influenced data production and interpretation (Braun & Clarke, 2021; Trainor & Bundon, 2021). Reflexivity was also enhanced through collaborative discussions with the research team at regular meetings to help NP increase her awareness of her subjectivity (e.g., opinions, values, biases). See Chapter 10, Section 10.4 for a detailed account of reflexivity.

With permission from participants, interviews were video recorded using the Zoom functionality. The audio recordings associated with the video recording were transcribed verbatim by the PI, which helped maximise data immersion (Creswell, 2014). All identifying information was removed during transcription. Transcription was undertaken within two days of the interview to enhance recall and accuracy. A research team member (LC) checked the transcriptions' reliability before deleting the audio recordings.

4.5 Study One Data Analysis

Qualitative content analysis (QCA) (Elo & Kyngas, 2008) was conducted in parallel with ongoing recruitment and data collection. This involved a systematic, iterative process of inductive and deductive coding, categorizing, and conceptualization. Qualitative content analysis suited this exploratory work because the project focused on phenomena in which little was known (Elo & Kyngas, 2008). In contrast to grounded theory or hermeneutic phenomenology, QCA employs a relatively low inference interpretation (Vaismoradi et al., 2013), where researchers do not move far into or beyond their data. In this way, QCA is well suited to qualitative descriptive research, which strives for in-depth

understanding but with emphasis *first* on literal description (Sandelowski, 2000). This level of interpretation enabled the researchers to showcase expert descriptions of EMR designs that supported optimal pain care without unduly transforming them (Lambert & Lambert, 2012).

This study's analysis unit was the interview text, and the analysis focused on manifest content. Guided by Creswell's (2014) approach, data analysis involved the researchers (NP and LC) first immersing themselves in the transcript data, examining, re-examining, and cross-referencing the material to develop a sense of the data as a whole and making preliminary coding notes (Elo & Kyngäs, 2008). LC is a woman and clinician researcher with expertise in qualitative research, an interest in optimising family-centred pain care for hospitalised children and infants, and experience using EMRs in caring for hospitalised children with pain. During the process, the reflexive researchers remained close to the data yet cognisant that some degree of interpretation was involved (Varpio et al., 2017). As health researchers, NP and LC inherently influenced data analysis. They consciously mediated their own expectations about how EMRs could be used in pain care, allowing them to uncover participant's perspectives.

Data were reviewed again and divided into meaning units that contained related aspects, which were subsequently condensed, abstracted, and labelled with a code. Coders reviewed each transcript independently, and transcript coding was verified by the second coder for correctness to ensure that the entire context was considered when coding. What differed between coders was their judgment about what comprised unintended consequences of sharing EMR information. Reflection and consensus discussions (NP, LC, DH) resulted in agreement about how to sort these codes. Codes were aggregated and grouped into exhaustive and mutually exclusive candidate categories, which were subsequently reviewed, refined, and named as final broad categories. Verbatim quotations from research participants were incorporated in results reporting to exemplify conceptualised categories. Trustworthiness was further enhanced through collaborative debriefing discussions with the entire authorship team throughout data collection and analysis. Working through data analysis reflexively with this experienced team of clinician researchers and constantly returning directly to the data assured the study's rigor.

Data were indexed using NVivo 10© software (QRS International, 2014). Participants were not asked to review transcripts or provide feedback on the findings. This avoided unnecessarily prolonging their research engagement (Varpio et al., 2017). An

audit trail was constructed throughout the study, including information about interview guide development and methodological, analysis, and synthesis processes.

Sample size requirements were guided by the principles of information power (Malterud et al., 2016), in which five items (study aim, sample, theory, dialogue quality, and analysis strategy) were iteratively assessed throughout the research processes. The research team jointly agreed that the final sample of 14 participant interviews provided adequate information power to address the research question. The richness of information was based on the combination of sampling approach, the narrow study aims, the dense sample of clinician expert participants from diverse settings, and the biopsychosocial pain theory underpinnings that explained important aspects of paediatric pain care. The dialogue was strong (i.e., rapport was established, participants were engaged, and conversations flowed naturally) and focused. The data were suitably rich in depth and breadth to address the research aim and provide an understanding of EMR designs needed to drive optimal paediatric pain care practices.

4.6 Ethical Considerations

Human Research Committee Ethics (HREC) approval was obtained through the University of Melbourne (HREC: 2021-22171-23430-6). Ethics approval documents are included in Appendix T. This study was conducted as per the University of Melbourne HREC guidelines and the Declaration of Helsinki.

4.6.1 Consent and Data Management

Online interviews were undertaken at a time convenient to the participants. In addition to obtaining e-consent, consent was recorded within the interview before data collection commenced.

4.6.1.1 Informed Consent

The following consent procedure was undertaken prior to starting the interview where the researcher outlined;

1. The possible effects of participation.
2. Participation was for research purposes.
3. The voluntary nature of participation and that participants were free to withdraw from the interview at any time without explanation, with the assurance that any unprocessed data would be withdrawn.

4. Data would be stored at the University of Melbourne for five years and subsequently destroyed.
5. Confidentiality of information was safeguarded subject to legal requirements and only accessible to named researchers.
6. Given the small number of participants, anonymity may not be guaranteed.
7. Pseudonyms would be used when referring to participants in presentations and/or publications.
8. A copy of the research findings could be forwarded to participants upon request.

4.6.1.2 Data Management

Data were managed in accordance with University of Melbourne procedures and the Australian Code for the responsible conduct of research (National Health and Medical Research Council- Australian Research Council, 2018). Processes were outlined in a Data Management Plan (Appendix U) developed at the commencement of this project. All data collected were de-identified during transcription to protect participants' privacy; identifiers were stored separately and securely on password-protected computers on the University of Melbourne's server in password-protected files. An external hard drive provided backup storage and was kept in a locked filing cabinet at the University of Melbourne, only accessible by the researcher and associate investigators. These data were kept for the duration of the study and will be destroyed five years after the research has been published.

Chapter Conclusion

This chapter describes the methods and procedures used to undertake Study One. Recruitment, data collection, and analysis processes were presented, and ethical considerations were outlined. Findings from the study will be presented in the following Chapter, the accepted version of the publication of this study. Methods for Studies Two and Three are described in Chapters Six and Eight.

Chapter Five

5

Study One Findings

Since 2015, Australian hospitals have begun introducing EMR systems, and by 2021, approximately one-third had an EMR, yet many were in the early stages of implementation (Healthcare Information and Management Systems Society, 2021a). International hospitals, particularly in the USA, have more experience with EMRs, with some hospitals having implemented their EMRs for over 20 years (Slovis et al., 2017; Sullivan et al., 2016). This provided an invaluable opportunity to explore how expert pain clinicians (nurses and doctors) in these hospitals used EMRs to care for hospitalised children with pain. Given their clinical expertise in children's pain care and EMR experience, these clinicians were anticipated to offer valuable insights and recommendations into advanced knowledge on EMR designs for pain care. In this chapter results of the first study in this research program were presented. This addressed the first objective to explore the perspectives of international paediatric clinical pain experts about EMR designs that support optimal child and family-centred pain care practices in hospitalised settings.

PUBLICATION 1 – A CALL TO FOCUS ON DIGITAL HEALTH TECHNOLOGIES IN HOSPITALISED CHILDREN'S PAIN CARE: CLINICIAN EXPERTS' QUALITATIVE INSIGHTS ON OPTIMIZING ELECTRONIC MEDICAL RECORDS TO IMPROVE CARE.

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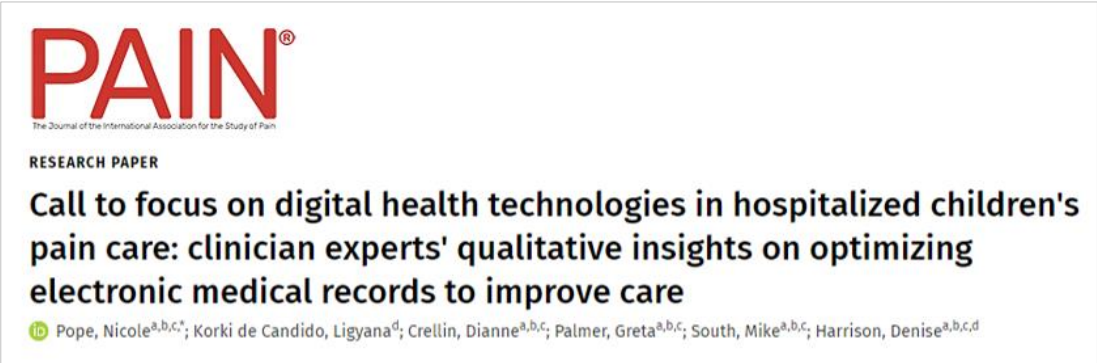
PAIN®
The Journal of the International Association for the Study of Pain
RESEARCH PAPER
Call to focus on digital health technologies in hospitalized children's pain care: clinician experts' qualitative insights on optimizing electronic medical records to improve care
Pope, Nicole[a,b,c,*]; Korki de Candido, Ligyana[d]; Crellin, Dianne[a,b,c]; Palmer, Greta[a,b,c]; South, Mike[a,b,c]; Harrison, Denise[a,b,c,d]

This chapter contains the manuscript reporting results published in an international peer-reviewed journal, *PAIN*. Reference formatting is modified to align with the thesis referencing style, and references are provided at the end of this thesis. There are no changes to the manuscript text as it appears in the journal before typesetting. All authors read and approved the final manuscript. The bibliographic details for the following manuscript accepted in *PAIN* are:

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Author Contribution: My contribution was to all aspects of this study. This included my involvement in conceptualising and planning the project, preparation, ethics submission, and study coordination. I undertook all online interviews and transcribed audio-recorded interviews verbatim. I worked with co-investigator LC in applying qualitative content analysis to interpret the data. I was first and corresponding author and drafted and prepared the manuscript for publication, addressed manuscript revisions, including responses to reviewers, and approved the final manuscript for submission.

Abstract

Most hospitalized children experience pain which is often inadequately assessed and undertreated. Exposure to undertreated childhood pain is associated with negative short and long-term outcomes, and can detrimentally impact families, health services, and communities. Adopting electronic medical records (EMR) in pediatric hospitals is a promising mechanism to transform care. As part of a larger program of research, this study examined the perspectives of pediatric clinical pain experts about how to capitalize on EMR designs to drive optimal family-centered pain care. A qualitative descriptive study design was used, and fourteen nursing and medical experts from five countries (USA, Canada, UK, Australia, Qatar) were interviewed online using Zoom for Healthcare. We applied reflexive content analysis to the data and constructed four broad categories: 'capturing the pain story', 'working with user-friendly systems', 'patient and family engagement and shared decision making', and 'augmenting pain knowledge and awareness'. These findings outline expert recommendations for EMR designs that facilitate broad biopsychosocial pain assessments and multimodal treatments and customized functionality that safeguards high-risk practices without overwhelming clinicians. Future research should study the use of patient and family-controlled interactive bedside technology to and their potential to promote shared decision-making and optimize pain care outcomes.

Keywords

electronic medical/health record systems; pediatric pain; qualitative; pain management

5.1 Introduction

Worldwide studies demonstrate that most hospitalized children (78%-94%) experience acute pain (Cruz et al., 2016; Grunau et al., 2021; Senger et al., 2021; Vejzovic et al., 2020; Velazquez Cardona et al., 2019) which is often inadequately assessed and undertreated. In 2011, research involving eight Canadian pediatric hospitals demonstrated the regular occurrence of painful procedures, yet less than one-third of these children had a documented pain intervention (Stevens et al., 2011). More recent studies from Canada`, Europe`, and South Africa show the continued high prevalence (24% to 63%) of moderate to severe acute pain reported in hospitalized children`, commonly from needle procedures and often performed without adequate analgesic strategies (Cruz et al., 2016; Senger et al., 2021; Vejzovic et al., 2020; Williams et al., 2015). Critically unwell neonates are particularly vulnerable to undertreated pain. A recent systematic review showed that neonates in a neonatal intensive care unit underwent up to 17 painful procedures each day (Cruz et al., 2016), the vast majority performed without pain relief. Overall, these studies show that many pediatric patients suffer undertreated acute pain despite advances in knowledge of effective assessment and multimodal treatments.

Exposure to severe pain in childhood without adequate treatment is associated with adverse short and long-term biopsychosocial outcomes for children (Grunau et al., 2021), which can have detrimental impacts on families and, more broadly, on health services and society. Undertreated acute pain in hospitalized children is associated with delayed recovery (Williams et al., 2015), prolonged hospital admissions, and increased risk of complications, such as infections (Rosenbloom et al., 2021). Research demonstrates that unrelieved and poorly managed acute pain in childhood is linked to psychological consequences such as catastrophic thoughts of pain, fear of needles, subsequent vaccine hesitancy, and avoidance of medical care (McMurtry et al., 2015; McMurtry et al., 2016). It also increases the risk of developing problems in adulthood, such as chronic pain and depressive and anxiety disorder (Page, Stinson, et al., 2012).

The use of electronic medical records (EMR) (also known as electronic health records) in pediatric hospitals is a promising mechanism to transform care by improving guideline implementation, facilitating compliance with evidence-based practices, and improving care quality and outcomes (Boonstra et al., 2014; South et al., 2022; Teufel et al., 2013). These systems replace hospital paper-based medical records and include functionality such as electronic documentation, ordering, medication management, and decision support tools. Electronic medical record systems have made it possible to create

care pathways that actively guide clinicians using clinical decision support (CDS) features such as alerts, prompts, and reminders for care (Kharbanda et al., 2021). These systems have great potential to improve pain care practices for hospitalized children and families.

Digital health technologies are becoming increasingly important in improving access to and quality of pediatric acute pain care. While the world has seen a rapid rise in the use of remotely delivered digitally based interventions for pediatric pain in outpatient settings, the focus on digital technology for children's acute pain in inpatient settings has received less attention. Few studies have examined the role of EMRs in hospitalized children's pain care (Aldekhyyel, Melton, Lindgren, et al., 2018; Brenn et al., 2016). This study aimed to explore the perspectives of pediatric clinical pain experts using hospital EMRs, and their perspectives on how to capitalize on hospital EMR designs to drive optimal child and family-centered pain care practices in inpatient settings.

5.2 Methods

This study employed a qualitative exploratory design to illustrate the perspectives of pediatric clinical pain experts (hereafter 'participants') about EMR designs that support optimal pain care for hospitalized children and families. This research was approved by the University of Melbourne Human Research Ethics Committee (Protocol number 2021-22171-23430-6). Reporting is in accordance with the Consolidated Criteria for Reporting Qualitative Research checklist (Tong et al., 2007).

5.2.1 Recruitment and data collection

English speaking nurse and medical participants who worked in hospitals using an EMR and who were primarily responsible for caring for children with pain were purposively targeted. Clinicians from hospitals that did not use an EMR were excluded. Study advertisements were distributed via email invitation to self-subscribing members of the Pediatric Pain Mailing List (Stewart et al., 2010), subscribed by over 1000 pediatric pain clinicians from various countries, and Twitter posts by NP and DH. Membership of the Mailing List was considered indicative of self-declared interest in pediatric pain. Interested people could click on a link to access a participant information statement and consent information. All participants consented to participate using an online consent form accessible via Research Electronic Data Capture (REDCap) hosted at the University of Melbourne (Harris et al., 2009).

An interview guide was developed from a review of literature and consultation with a stakeholder committee comprising of academics and clinicians and was pretested with a pediatric pain expert who was not a study participant. Interview questions related to EMR use in assessing and treating pain, the involvement of children and families, and the use of EMR data. The interviewer (NP) used prompts to elicit detail and clarity from participants regarding their responses (e.g., 'Tell me more about that'), and interview questions were iteratively modified based on an analysis of preliminary interviews to incorporate specific questions.

Individual semi-structured interviews were conducted virtually (using Zoom for Healthcare ©) between November 2021 and March 2022 by NP, a female registered nurse, and a Ph.D. candidate with training and experience in qualitative research. Audio-recorded interviews were transcribed verbatim [NP]. Transcripts were proofread alongside the original recordings to ensure their accuracy. To avoid unnecessarily prolonging participant engagement with the research and ensuring participants' initial perspectives were captured, participants were not asked to validate their transcripts.

5.2.2 Data Analysis

Reflexive content analysis (Elo & Kyngas, 2008) was conducted in parallel with ongoing recruitment to evaluate sample size requirements in relation to the principles of information power (Malterud et al., 2016); an alternative to data saturation (Braun & Clarke, 2019) where five items (aim, sample specificity, established theory, dialogue quality and analysis strategy) are iteratively assessed throughout the research process to guide sample size (Malterud et al., 2016). Data were managed in NVivo (QRS International, 2014). In the early stages, two authors (NP and LC) met weekly to reflexively discuss data collection and patterns of early analysis. A coding matrix was iteratively developed through descriptive open coding and independent and careful review of initial interview transcripts and comparing the consistency of concepts. Codes were refined, and the matrix was restructured with the coding of subsequent data. Any differences between the coders were resolved through consensus (NP, LC, and DH). The final matrix informed the development of broad categories, which were reviewed, refined, and named with input from the full research team. Categories were finalized through the results writing process and incorporated a range of participant narratives to ensure the representation of diverse perspectives across each category. Minor alterations to narratives were made to replace brand names for EMR platforms.

5.3 Results

Fourteen participants were recruited, and their interview data was included in the analysis (Table 5.1). The sample comprised nine nurses and five medical doctors from ten pediatric hospitals across five countries who had no previously established relationship with the interviewer (NP) before the study's commencement. The duration of each interview ranged between 29 and 59 minutes (mean 42 minutes). The researchers developed four broad categories during qualitative content analysis (Table 5.2). They were labelled; (1) capturing the pain story, (2) working with user-friendly systems, (3) patient and family engagement and shared decision making, and (4) augmenting pain knowledge and awareness. These categories and their corresponding subcategories are presented below with supporting participant quotes. All potential participant and EMR platform identifying information has been removed.

Table 5.1
Participant characteristics (n=14)

Characteristic	Value n (%)
Role, n (%)	
Clinical nurse consultant/nurse practitioner (pain)	7 (50%)
Bedside nurse	2 (14%)
Pain specialist physician	5 (36%)
Gender, n (%)	
Male	3 (21%)
Female	11(79%)
Country, n (%)	
USA	5 (36%)
Canada	4 (29%)
UK	2 (14%)
Australia	2 (14%)
Qatar	1 (7%)
Hospital type, n (%)	
Urban pediatric tertiary centre	10 (100%)
EMR, n (%)	
Epic	6 (43%)
Cerner	5 (36%)
Other	3 (21%)
Time since EMR implementation, (y)	
<1-5	8 (57%)
6-10	1 (7%)
11-15	3 (21%)
16+	1 (7%)
Unsure	1 (7%)

NOTE: Percentages may not calculate to 100 due to rounding.

Table 5.2
Qualitative results

Category		Sub-Category	
1	Capturing the pain story	1.1	Functionality that facilitates biopsychosocial assessments
		1.2	Functionality that facilitates comprehensive interventions.
2	Working with user-friendly systems	2.1	Evolving EMR practice
		2.2	Balanced decision support for standardized safe practice
3	Patient and family engagement and shared decision making	3.1	Harnessing bedside technology
		3.2	Concerns about shared access
4	Augmenting pain knowledge and awareness	4.1	Leveraging pain data for quality improvement.
		4.2	Highlighting pain as a priority

5.3.1 Broad Category 1: Capturing the pain story

The first category centers on the EMR designs that guide clinicians to undertake and record detailed pain assessments and initiate and document multimodal interventions. This was organized into two subcategories as follows;

5.3.1.1 Subcategory 1.1: Functionality that facilitates biopsychosocial pain assessment

Participants advocated that EMR designs should incorporate functionality that drives clinicians to undertake, and record detailed, individualized pain assessments that support child and family engagement. Recommendations included integrating electronic self-and parent report pain scales for clinicians to use to measure pain intensity and various pain assessment tools available for different clinical scenarios. Participants felt that electronic pain scales were more valuable than paper-based systems because they allowed clinicians to view specific details of pain measurement, such as various components of pain scores and different pain locations. Participants suggested that electronic pain scales should be integrated in a manner that supports clinicians to efficiently and consistently select the most appropriate scale. One participant described how their EMR pain scales were integrated to support appropriate scale use:

> *We have all of our pain assessment tools separated by neonatal and pediatric. When* [nurses] *click on neonatal pain assessment, they only get the tools that are appropriate to neonates. The same with pediatric assessment.* (Participant 3, Nurse)

However, participants acknowledge the limitations of pain intensity scores to understand the child's total pain experience. They described how many of their original EMR workflows were not designed for detailed pediatric pain assessments and advocated for tailoring EMRs to help guide clinicians to undertake and record comprehensive pain assessments:

> *We replaced things that had never been documented with more kid-friendly options like sleep, mood, behavior, activity level, mobility, to give a more detailed assessment. We also added parent reports and expanded the patient-stated goals.* (Participant 4, Nurse)

Participants also advocated for EMR designs to incorporate functionality that allowed for visual representations of pain data:

> *If I could track it and trend pain, like put it on a graph, to see any difference. Especially because many of the kids I see are neurologically impaired, so they could get a really bad functional score, but if that is their baseline, it wouldn't be as helpful as knowing if it is different than what their 'usual' is.* (Participant 11, Doctor)

5.3.1.2 Subcategory 1.2: Functionality that facilitates comprehensive interventions

Participants recommended that EMR designs guide clinicians to employ age and developmentally appropriate multimodal pain treatments. This was related to treatment plans that combined pharmacological, physical, and psychosocial interventions. Regarding pharmacological interventions, participants perceived the electronic medication administration record (eMAR) as essential to support safe medication practices. They felt the eMAR and pharmacological interventions were well-established elements of their EMR. The eMAR supported guideline adherence to safe prescription and accurate documentation of pharmacological interventions:

> *Infusion and medications are very well documented. These electronic medication systems are very much driven by pharmacy and medication safety. I would say 99% of the time medications administrations are signed and documented.* (Participant 8, Nurse)

While participants were mostly satisfied with how their EMRs supported pharmacological interventions, many provided recommendations for optimizing their EMRs to better support clinicians to use and document physical and psychological interventions. Participants reported that these non-medicine interventions were infrequently documented. Some attributed this to the lack of routine use; others suggested

that non-medicine interventions were being used but not documented. Competing clinical priorities, such as clinicians' workload and patient acuity, contributed to the under-documentation of physical and psychological interventions.

Participants advocated for EMRs to include physical and psychological intervention options. Customizing EMR workflows so non-medicine options could be efficiently navigated was essential to help guide busy clinicians to consider, provide and record these interventions. One expert suggested:

> *If we could order the integrative medicine techniques similar to the medicines, so when the nurses look through the availability of what they had, things like aromatherapy, breathing, what apps we have recommended, if that was in there and they saw it, I think they would think about it more.* (Participant 11, Doctor)

5.3.2 Broad Category 2: Working with user-friendly systems

Participants discussed their experiences working with EMRs and the interdisciplinary teams' ongoing, iterative work to tailor their EMRs to support end-users and drive optimal pain practices. These two sub-categories are described in the following sections.

5.3.2.1 Subcategory 2.1: Evolving electronic medical record practice

Participants noted that because many EMR designs were conceived for adult patients, they needed to customize their EMRs for pediatric healthcare and, more specifically, pediatric pain care. Participants acknowledged that customizing EMRs was a time and resource-intensive and iterative process. Examining the impact of EMR customizations was integral to ensuring customizations were relevant and valuable to clinical practice.

> *When you make a change, you might think it is working amazingly, but you need to circle back because you don't want to assume that just because changes are made that this will correlate to uptake or change in practice.* (Participant 5, Nurse)

5.3.2.2 Subcategory 2.2: Balanced decision support for standardized, safe practice

Participants described how various CDS features, such as prompts and alerts, were integrated into their EMR workflows to guide practice. Some CDSs were regarded as helpful, while others were not. Those safeguarding high-risk practices, such as medication prescription, were also considered essential to responsible and safe pain care. Medication order sets, a collection of orders aggregated for a given condition, clinical situation, or process (McGreevey et al., 2020), offered an efficient way for clinicians to provide standardized, safe prescriptions:

> *Order sets certainly have improved our standardization and everybody getting their orders right. No one is going off rogue and doing different things. It is ensuring from a safety perspective that they always have a naloxone order, for example.* (Participant 8, Nurse)

Some participants regarded critical alert colors, such as severe pain, displayed in red font as valuable to guide practice. Templated notes, dropdown menu options, and embedding content such as links to guidelines and policies were considered helpful. As was combining alerts with automated interdisciplinary referrals:

> *Dropdown options serve as a prompt. If you've focused on the medication interventions and haven't really thought about how you engaged with physiotherapy, it is sort of a prompt to say ok, let's follow up on that.* (Participant 2, Nurse)

While subtle prompts were helpful to guide some aspects of pain care, all participants warned that excessive alerts such as pop-up reminders were disruptive, stressful, and often ignored. Participants described how clinicians felt 'saturated', 'overwhelmed', and 'overloaded' with prompts, reminders, and documentation. Prompts burdened an already over-burdened workforce, who are weighing up their competing priorities in their daily work. Participants recommended that prompts should be preserved to safeguard high-risk practices:

> *Any prompts and alerts need to be pertinent and important, so you're not getting pinged too often or constantly scrolling through prompts that aren't relevant. We spent a lot of time filtering out and discussing prompts, and drilling down the key ones that are important from a safety perspective.* (Participant 14, Nurse)

While participants advocated capitalizing on EMR designs to drive optimal care, they agreed that well-designed EMRs would not guarantee adherence to best practices and did not replace ongoing education, training, and advocacy efforts. Optimal pain care relies on skilled clinicians undertaking detailed assessments and using clinical judgment:

> *I think there is so much going on, especially in the EMR and in the pediatric intensive care unit, and ward nurses are busy too. I mean, you have the child in front of you, don't you, so that is your prompt, hopefully.* (Participant 13, nurse)

5.3.3 Broad Category 3: Patient and family engagement and shared decision making

This broad category reflects participants' views on the potential role of families using EMR-integrated technology to view and report pain-related information. This was considered necessary for the future of pain care for hospitalized children. Potential issues

associated with shared access to the EMR data needed thoughtful consideration. The two subcategories within this category are presented below.

5.3.3.1 Subcategory 3.1: Harnessing bedside technology

Most participants identified that their EMR included mechanisms to capture the child's and family's perspectives on pain and interventions. Some hospitals' EMR designs comprised a specific section for clinicians to record parental pain reports, including pain intensity scores and subjective descriptions documented in free text fields. Interfaces to promote and support child and family engagement, such as displaying EMR information screens that families could see, were regarded as important to engage children and families in open communication.

Participants advocated for more advanced technology with interfaces that allow children and families to view and contribute to EMR pain information in real time. Family and patient-controlled bedside interactive technology such as touch screens and audio-dictation devices that automatically and wirelessly transferred information to the EMR were suggested as possible options to engage families in care.

Inpatient portal systems were frequently discussed as advanced technology to engage children and families in pain care. Most participants worked in hospitals that used outpatient portal systems that allowed patients to view clinical information such as pathology results. Some hospitals used inpatient portal systems that allowed families access to similar clinical information, but no hospital used an inpatient portal system with the functionality that allowed hospitalized children or families to view or enter their own pain-related data. This was identified as an important practice gap to address. In addition to capturing rich, contemporaneous reports of pain, the possibility of having children and families provide pain reports using EMR integrated technology was considered important to understand the effectiveness of pain treatments and trends of pain over time.

> *Having a better understanding of the time continuum of pain and treatment and how things have evolved together, I think that would be very helpful. Because I always get the feeling that we are often too late. We try to anticipate, but we don't necessarily capture it at the right moment.* (Participant 7, Doctor)

Some participants spoke about the potential for inpatient portal systems to be used as education and coping tools by including resources to teach children and families strategies to cope with pain, and functionality, such as games, to help distract them from pain.

If that patient had a device, and you can have them use that device, not only to report but also to learn strategies to help with the pain, that might be really beneficial. (Participant 10, Doctor)

5.3.3.2 Subcategory 3.2: Concerns about shared access

Participants also cautioned that giving children and families access EMR pain data could have unintended consequences. There were concerns that access to too much information could overwhelm children and families. Participants also felt that addressing children's and families' expectations of pain and pain treatment would be necessary. One participant shared their apprehensions:

My only concern is there is this perception that a pain score of a specific number should automatically equal medication. We have a lot of struggles having families understand the concept of total pain and that a lot of our interventions don't have to be medication. So, I worry that having the ability to enter pain scores, people would just put 10 10 10 10 10 until they get medication. (Participant 11, Doctor)

Having robust mechanisms to support the appropriate and timely escalation of care was critical.

What happens if [parents] *enter information that is time critical that should be actioned? What would an appropriate way to enter information like, my pain is getting worse, and I am getting fevers and it's a sign that they are getting an infection or some sort of complication?* (Participant 6, Doctor)

5.3.4 Broad Category 4: Augmenting pain knowledge and awareness

The final category captures participants' perceptions about how the introduction of EMRs has presented opportunities to enhance pain knowledge and awareness among clinicians, children, and families. Two subcategories were apparent. Participants regarded EMRs as a rich data source to examine pain care practices, identify quality improvement opportunities, and inform education priorities for clinicians and families. The EMR was viewed as a catalyst in raising awareness among clinicians and families about children's pain and highlighting pain care as a priority. This was organized into two subcategories as follows;

5.3.4.1 Subcategory 4. 1: Leveraging pain data for quality improvement

Many participants routinely interrogated EMR data for high-risk pharmacological interventions to safeguard practice and to examine pain prevalence and severity data. They used this data to inform quality improvement priorities.

> *We can quickly look up who are the patient groups that have the worst pain scores in the hospital and target interventions on those types of patients. It really is helpful and makes a difference. It allows us to do quality improvement efforts much more rapidly than we were able to before.* (Participant 9, Nurse)

> *Looking at that data has been very good in guiding us as to where our deficits are and where more education is needed.* (Participant 1, Doctor)

However, many participants also described barriers to accessing and using EMR data. Extracting EMR data in meaningful ways was acknowledged as a time and resource-intensive process that required skills and capacity beyond their scope. Skilled informatics specialists were, therefore, integral members of interdisciplinary pain teams. Human resources and competing priorities were also described as barriers to accessing EMR pain data:

> *It took us eight months to get a one-month report. Part of that will be the hierarchy of IT support, where they are allocated. I think that was the biggest thing.* (Participant 7, Doctor)

Problems in extracting meaningful EMR data also related to the volume of data collected and how it was recorded. Some participants felt that EMR designs forced clinicians to chart clinical information in unstructured and inconsistent ways. Customizing EMR designs to the end user's needs and clinical contexts and educating clinicians on the specific information required for coding would, in part, address these issues. Some participants also believed that clinicians were often asked to document unnecessary information. This made processing and analyzing data difficult and limited time spent with patients.

> *The downside and the danger is that you think, 'We can collect A, so why don't we also collect B, and while we are at it lets collect C' So instead of focusing on what is really important and what is fine to make a difference, you start to collect a gazillion things. I think that is the wrong approach. If you think about the user interface, that will make a huge difference.* (Participant 10, Doctor)

5.3.4.2 Subcategory 2: Highlighting pain as a priority

Participants shared how EMRs were a catalyst for raising awareness of pain and improving pain care practice. Intuitive EMR interfaces helped draw clinicians' attention to pertinent pain information, including sources of pain and treatment to prevent and minimize pain. One expert shared their experience of how an intravenous order-set which included sucrose and topical anesthetic, helped raise awareness about needle pain in their setting:

> *It is amazing that somebody can think that putting in an IV cannula doesn't need pain relief! So, our IV order-set has improved the awareness about pain, about asking about pain, and thinking of doing something about it.* (Participant 1, Doctor)

Iterative review and customization of EMR pain fields, workflows, and interfaces also helped increase clinicians' pain awareness.

> *Each time we have made changes, the nurses' documentation has improved, which then improves their attention to pain and willingness to engage in those assessments.* (Participant 4, Nurse)

5.4 Discussion

Findings from this study emphasize the need for a greater focus on optimizing EMR designs to drive clinicians toward evidence-based pain care for hospitalised children and their families. Key priorities include EMR designs that support biopsychosocial conceptualizations of acute pain assessment and treatment, ensuring EMRs are tailored to all end-users' needs and contexts, and for CDS to safeguard high-risk practices without overwhelming clinicians. Having patients and families enter real-time pain data using EMR-integrated technology is integral to optimizing engagement and outcomes.

Previous research has demonstrated that compliance with and accuracy of pain assessment documentation are important problems in children's hospitals worldwide, including settings using paper and electronic-based systems for documentation (Andersen et al., 2021; Vejzovic et al., 2020; Velazquez Cardona et al., 2019; Wilding et al., 2021). Some EMRs already include pain measurement tools, yet participants emphasized that EMR pain tools should be incorporated in ways that facilitate efficient and consistent pain measurement tailored to individual clinical contexts. Notably, participants felt that EMR designs drove clinicians to search for quantitative measures of acute pain and this only captured part of a child's pain experience. Representing pain as only a sensory phenomenon through pain intensity scores ignores other aspects of the experience and broader consequences of acute pain (Friedrichsdorf & Goubert, 2020; Hadjistavropoulos et al., 2011). A key recommendation in this study was for EMR designs to include functionality that directs clinicians to enquire about and record broader biopsychosocial dimensions of pain and capture pain patterns over time. Designing EMRs with features and content to guide clinicians to consider psychological and social ramifications of acute pain and contextual and developmental factors may impact how pain is understood and treated. This finding aligns with the Lancet Commission's recommendations that broad

biopsychosocial pain assessments foster holistic understandings of pain, reminding clinicians that pain is more than just a physical experience (Eccleston et al., 2021). Another critical recommendation was for interfaces that visually represent trends of pain over time. These outputs would draw clinicians' attention to pertinent data and serve as a visual reminder for clinicians to think about and prioritize pain.

Capturing broader psychosocial and functional consequences and tracking pain trends are features of many digital health initiatives for the self-management of persistent pain conditions. For example, the smartphone application iCanCope with pain (iCanCope) developed by Stinson et al. (2014) and Palmero et al.'s WebMAP Mobile (Palermo et al., 2020) supports youths' self-management of chronic pain and includes features to report and track pain and pain interference. Notably, while pain experts are pioneering research programs to develop and mobilize remotely delivered interventions for chronic pain, there are fewer reports of similar digital interventions for acute pain, and none intentionally designed for EMR integration targeting acute pain in hospital settings. Recently Stinson's team developed iCanCope Post-Op to address context-specific problems for acute postoperative pain (Birnie et al., 2019). However, neither iCanCope applications integrate with the EMR, and both primarily target youth. Participants in this study recommended EMR-integrated, patient-controlled bedside technology to address this critical gap.

In keeping with recommendations from work focused on chronic pain (Dressler et al., 2019), findings from this study suggest that having children and families view and enter real-time pain data through EMR-integrated technology as integral to shared decision-making and optimizing pain outcomes. Wireless transfer of patient-entered pain data to the EMR may also address the under-documented reassessments of acute pain and prompt clinicians to think about the need for interventions. In a pilot study conducted in a US pediatric hospital a pain management workflow was implemented that integrated the patient television, the EMR, nursing call bell, and pharmacy system to enable children and parents' self-reports of pain and support their engagement in pain care (Aldekhyyel, Melton, Hultman, et al., 2018; Aldekhyyel, Melton, Lindgren, et al., 2018). Pharmacological interventions triggered a timer, which, once elapsed, generated a pop-up window on the patient's television asking them to self-report their pain. Self-report data was wirelessly transferred to the EMR and alerted the nurse via a phone paging system. This intervention saw statistically significant improvement in pain reassessment documentation. Changes in pain interventions were, however, not reported. Therefore, whether these mechanisms improved pain outcomes or changed pain care practice is unknown.

In the present study, participants suggested inpatient portals as a way to enable timely self-reports of pain. These findings align with emerging evidence that patient-controlled digital bedside technology can improve patient engagement and help families better understand and monitor their care (Dendere et al., 2019). To date, inpatient portals in pediatric hospitals have given families real-time access to view their EMR clinical information, such as medications and test results (Kelly, et al., 2017; Kelly & Hoonakker, et al., 2019; Kelly & Thurber, et al., 2019), but no studies have focused on sharing pain-related data nor examined the potential for children and families to contribute pain data to the EMR via integrated patient portal systems.

In accordance with the findings of a recent systematic review (57 studies) examining the impact of inpatient portals in adult and pediatric hospitals (Dendere et al., 2019), some participants in this current study were concerned about workflow disruptions. Others challenged these assumptions, arguing that shared access to pain data may facilitate timely pain assessment, more informed treatments, and efficient pain care. These findings complement Kelly et al.'s work, where nurses, physicians, and ancillary staff were surveyed before (n= 94) and after (n=70) implementing an inpatient portal in a pediatric hospital and reported fewer challenges than anticipated (Kelly, et al., 2017). Findings also highlight that implementation processes of digital technologies must incorporate end-user needs and context and address potential issues.

Robust evidence demonstrates that the most effective pain treatment employs a combination of developmentally appropriate pharmacological, physical, and psychological interventions (Friedrichsdorf & Goubert, 2020). While EMRs have been well developed to support safe and efficient pharmacological practices through features such as order-sets and wireless real-time data capture from devices such as infusions, participants felt EMR designs were limited in their ability to drive clinicians to consider and record physical and psychological treatments for pain. This highlights how inadequate EMR designs may contribute to the underuse of physical and psychological therapies for acute pain. Further research should study mechanisms to integrate physical and psychological interventions as discrete treatments into the EMR and approaches to guide clinicians in their routine use and streamlined documentation.

Traditionally EMR alerts, such as prompts and reminders, were seen as measures to promote safety, improve clinical practice and outcomes. While studies have shown that CDS can improve care processes, EMR alert fatigue has emerged as a widely recognized concern impacting clinician wellness and responsiveness (Van Dort et al., 2021). In this

study, participants described how clinicians experienced notification fatigue because of poorly designed CDS. Alerts made it hard for clinicians to focus on pain care and contributed to stress and burnout. Participants recommended CDS alerts be limited to high-risk practices, such as pharmacological prescription. These findings support recommendations for additional guidance on when and how to use EMR prompts, and guidelines in their implementation (McGreevey et al., 2020).

5.4.1 Strengths and Limitations

To our knowledge, this was the first study to explore pediatric clinical pain experts' perspectives on EMR designs that support optimal pain care for hospitalized children. Insightful and well-developed categories were created from qualitative content analysis. However, limitations should be considered while interpreting findings. First, because the pediatric pain mailing list originated in Canada, there is potential that it over-represents North American clinicians. To address this, we successfully broadened participant representativeness through social media and snowball recruitment. Our study captured the views of nurse and physician experts. Further research is needed to represent other voices involved in interdisciplinary management of pediatric pain. Capturing perspectives of hospital administrators, informaticians, and human factor designers would also offer further composite insights into EMR designs to drive optimal pain care. Second, clinician-researchers analyzed the data, and all researchers possessed clinical and research expertise that undeniably influenced interpretations. The interviewer (NP) was from the nursing discipline and co-authors were nurses (n=3) and physicians (n=2). All but two authors (LC, DH) had experience using EMRs (1-6 years) in caring for hospitalized children. These factors may have influenced the interview design and questioning and data interpretation processes. Third, participants were recruited from various international hospitals, findings might not be generalized to outpatient settings or persistent pain conditions. Finally, interviews were a very effective method of understanding the needs of clinicians concerning EMR design for pain care. Field methodologies including observation and chart reviews can complement interviews to provide information about the context of pain assessment and documentation.

5.5 Conclusion

User-centered, evidence and theory-informed EMR designs are critical to improving pain care for hospitalized children. Participants with a range of EMR experience called for a greater focus on optimizing hospital EMRs to drive clinicians beyond searching for objective measures of pain and pharmacological interventions toward including psychological, social, and developmentally targeted assessments and treatments. Intuitive, customized EMR interfaces draw clinicians to the most pertinent data and safeguard high-risk practices without overwhelming them. Findings demonstrate that no single action will ensure that EMRs guide clinicians toward evidence-based practices. Pain education and institutional approaches that support quality improvement remain pillars of effective pain care. EMR use in children's pain management is an evolving practice. We must leverage their potential to highlight pain as a priority. Further research should study the use of patient-controlled interactive technology integrated with the EMR and their potential to support and promote shared decision-making.

Conflict of interest statement

All authors have completed the author disclosure form, and the authors have no conflicts of interest to declare.

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Chapter Conclusion

This chapter presented the findings from Study One of this Ph.D. thesis, exploring clinical pain expert recommendations on EMR designs to support optimal pain care practices for hospitalised children and their families. Important factors related to EMR design features to facilitate broad biopsychosocial pain assessments and multimodal treatments were identified. Recommendations also highlighted the need for customised functionality that safeguards high-risk practices without overwhelming clinicians. The comprehensive discussion contained within this manuscript positioned study findings in relation to existing literature and highlighted knowledge contributions resulting from this work. Future recommendations include exploring hospital-based patient-controlled interactive technology to support and promote family-child-clinician shared decision-making in pain care.

Chapter Six

6

Study Two Methods

This chapter describes the research methods used for the second qualitative study of this mixed methods project, including recruitment, data collection, and analysis procedures. Data management and ethical considerations, including privacy and confidentiality, are presented. Study methods are supplemented by detail in the peer-reviewed publication reporting findings, offered in Chapter 7.

6.1 Study Two Objective

Positioned within a constructivist worldview (Lincoln & Guba, 1985), this study employed a qualitative exploratory interview design to address the second objective; to examine the perspectives of primary caregivers' of hospitalised children (0-18 years) and of hospitalised youth (12-18 years) about their potential use of an inpatient portal to support their engagement in their/their child's pain care.

6.2 Study Two Setting

This study was undertaken at the Royal Children's Hospital, Melbourne (RCH), which uses an EMR but did not offer an inpatient portal for patients and their families at the time of the study. With an inpatient capacity of 340 beds, RCH is the largest tertiary paediatric hospital in Victoria, Australia. As of March 31, 2023, Australia had a resident population of 6.6 million people, approximately 12% of which were aged 0-19 years (Australian Bureau of Statistics, 2023). In addition, RCH is the designated state-wide major trauma centre for children and a nationally- funded cardiac and liver transplantation centre. Between 2019 and 2020, RCH provided specialist paediatric care for over 46,000 inpatient admissions, 92,000 emergency department presentations, and 300,000 ambulatory care visits (The Royal Children's Hospital and Controlled Entities, 2020). Its campus partners are the Murdoch Children's Research Institute (MCRI), The University of Melbourne, and the RCH Foundation, which support RCH to improve children's health outcomes through practice, education, training, and research.

In April 2016, RCH introduced an EMR using a commercially available platform customised to local needs (Epic Solutions) (Verona, WI, USA) and became the first Australian paediatric hospital to replace paper-based medical records. The EMR system went live after an 18-month project using a 'big bang' methodology (Owens, 2008). This involved the single-day transfer from predominantly paper-based records to EMR across every department, including inpatient areas, the emergency department, theatres, intensive care units, and regional outreach and ambulatory settings (South et al., 2021). The EMR system includes electronic documentation, eMAR (closed-loop barcode scanning), recording of blood products, referrals, and scheduling, and possesses mature software and clinical decision support (CDS) tools that can guide best practices at the point of care to streamline clinical interactions and eliminate variability and errors.

The RCH EMR system integrates with a patient and family online outpatient portal called MyRCH, which went live in May 2016. Since its introduction, the portal has been used by more than 11,000 patients and families, giving them access to medical notes, care plans, pathology results, and the capacity to add and update health issues, medications, and allergies (Glogolia et al., 2019). Families can also manage and view specialists' appointments and request repeat prescriptions via the MyRCH. In September 2022, following the completion of this study, RCH rolled out an inpatient portal in two hospital departments as part of a pilot implementation process preceding a hospital-wide project. Youth 12 to 16 years have shared, rather than independent, access to the inpatient and outpatient portals. From 16 years old, youth have independent access to their portal information, and must provide their permission for their parents to access their portal information.

6.3 Study Two Participants

The interview sample comprised two groups;

1. PCGs of hospitalised children (0-18 years) admitted to RCH as an inpatient with an acutely painful condition, injury, or illness requiring pain management (pharmacological and/or non-pharmacological) or with a condition likely to result in procedural or dynamic pain and
2. Adolescents (12-18 years old) admitted to RCH as an inpatient with an acutely painful condition, injury, or illness requiring pain management (pharmacological and/or non-pharmacological) or a condition likely to result in procedural or dynamic pain.

In addition, participants also met the following inclusion criteria;

3. PCG and adolescents who were able to speak and understand English
4. PCGs and adolescents who were willing to participate in the study
5. Written informed consent was provided by the PCG (parent/legal guardian) and adolescent (where the researcher deemed them competent to provide consent).

The minimum age for adolescent participants was 12 years, corresponding with the youngest age at which youth are given access to their RCH patient portal. Adolescents of this age also typically develop abstract thinking capacities and can provide meaningful interview responses (Stinson et al., 2013). If the adolescent was eligible for the study, but their PCG did not consent to participate or provide consent on behalf of their adolescent, their adolescent was not included in the study. If the PCG wished to participate, but the adolescent did not, only the PCG participated.

Adolescents and PCGs in the ED were excluded since patient portals in these clinical areas warrant separate examinations given the care context. Finally, adolescents and children with clinical or psychosocial circumstances considered by the clinical team to make participation inappropriate (e.g., acute mental health disturbance, clinical deterioration) were excluded.

6.4 Study Two Sampling and Recruitment

Theoretical purposive sampling was applied to identify adolescents and PCGs of varying demographics and painful conditions and injuries who were likely to meet the eligibility criteria. Unlike stratified purposive sampling, where the researcher establishes homogenous subpopulations *before* sampling, theoretical sampling is applied *during* the data collection and analysis to help build heterogeneity into the sample (Robinson, 2014). As a result, the sample comprised a diverse group of adolescents and PCGs regarding pain experiences (e.g., postoperative pain, pain related to injury or illness, procedures), previous hospitalisations, youth age, and PCG and youth sex.

It was understood that in using a theoretical purposive sampling approach, some adolescents and PCGs would be excluded from participating because of their circumstances or, in some cases, their demographic characteristics (Robinson, 2014). For instance, this study used a non-intrusive approach, which meant that adolescents and PCGs of children experiencing extreme pain and distress at the time of recruitment might not have been invited to participate. Finally, those who could not speak or understand English were not approached to participate to avoid unnecessary misunderstanding or confusion.

The study was publicly promoted throughout the hospital with advertising flyers and posters (Appendix V). The recruitment process involved in-person methods where the researcher (NP) screened for eligible adolescents and PCGs by reviewing EMR bed census data. A clinical team member advised potential participants about the study, and those interested in knowing more were then referred to the researcher. With permission from the clinical team, the researcher, who was not involved in direct patient care, approached potential participants, briefly explained the project's purpose, and provided the information sheet and consent form (Appendix W). These documents addressed what participation entailed, its voluntary and anonymous nature, and that their decision to participate would not impact clinical care. The researcher also met with interested participants to answer any further questions. This supported participants in reaching an informed, consensual decision to participate. Following informed consent, an interview was scheduled. The researcher ensured that recruitment processes did not delay or interrupt clinical care.

6.5 Study Two Data Collection

6.5.1 Demographic Data

A 9-item demographic REDCap® (Harris et al., 2009) survey captured information about PCG and child/adolescent age, sex, ethnicity, and computer literacy level. Survey questions were developed with input from the stakeholder committee and pre-tested for relevance and clarity before use. The final questionnaire is included in Appendix X. Questions were formatted as multiple choice and tick boxes. No identifiable information was collected. For analysis, demographic data were reported using means and standard deviations for continuous factors (i.e., mean for age) and frequencies and percentages for categorical factors (i.e., sex)

6.5.2 Interview Guide

Interview guides contained semi-structured interview questions developed in consultation with the stakeholder committee and extensively pre-tested with a 12-year-old youth with a recent hospitalisation and their PCG (mother). The pre-test considered the content and clarity of questions, to what degree they could capture adolescent and PCG's pain-related perspectives about their potential use of an inpatient portal for pain care, and the time to complete the interview. The interview guide was modified based on pre-test feedback to enhance comprehension and clarity. The pre-test youth and PCG did not participate in the final interviews, nor were their data used.

The interview questions invited participants to draw on hospital experiences and consider how they would like to use an inpatient portal to report pain symptoms and report and request pain treatments. Questions also focused on how the portal could be used to communicate with staff and to access information about pain. A final question captured participants' views about what might motivate or prevent them from using a portal for pain care during hospitalisation. The interview guide is presented in Appendix Y.

6.5.3 In-depth, Semi-structured Interviews

In-depth, semi-structured interviews were conducted by NP who had previous experience undertaking qualitative interviews and no prior relationship with participants. To maximise emotional and physical comfort, interviews took place at an RCH location chosen by the participant (at the bedside) and at a time convenient to them that did not interfere with clinical care. All interviews were undertaken during their admission, while

their hospital experience remained current, were audio recorded and transcribed verbatim by NP. This helped to maximise her immersion in the data (Creswell et al., 2011). Any identifying information or unique traits that could lead to identification were removed during transcription. No names were used when reporting findings. Transcripts were not returned to participants to check for validity. This avoided unnecessarily prolonging their research engagement.

NP recorded reflexive notes in a journal throughout and immediately following each interview (See Chapter 10, Section 10.4). This journalling was used to document non-verbal data, observations, and reflections on the potential influence of the environment. These notes helped NP be thoroughly absorbed in the data and the study context, which helped establish the credibility of qualitative findings (Golafshani, 2003). Journalling also allowed NP to reflect on and clarify biases that may have influenced the interview process (Holloway & Wheeler, 2010). Given her professional work, her interest in digital technology, and her experience using an EMR, the PI needed to be cognisant of how her assumptions, values, and experiences may have influenced data production and interpretation (Braun & Clarke, 2021; Trainor & Bundon, 2021). Reflexivity was also enhanced through collaborative discussions with the research team at regular meetings to help NP increase her awareness of her subjectivity (e.g., opinions, values, biases). All transcribed data were indexed in NVivo 10© software (QRS International, 2014). See Chapter 10, Section 10.4 for a detailed account of reflexivity.

6.6 Study Two Data Analysis

Study Two data analysis methods are described in Chapter 7, presented as a published manuscript in *PAIN*. This manuscript includes a comprehensive account of the reflective content analysis processes undertaken in parallel with ongoing recruitment to evaluate sample size requirements according to the principles of information power (Malterud et al., 2016). A detailed account of data analysis methods will not be repeated in this chapter; however, a summary of key information is provided in the following section.

Two authors (NP and SJ) first familiarised themselves with the data by multiple readings of the transcripts and making notes. They met regularly to discuss data collection and patterns of early analysis. This study's analysis unit was the interview text, and the analysis focused on manifest content. Relevant passages in the transcripts from participants were divided into meaning units containing related aspects. These were subsequently condensed, abstracted, and labelled with a code. Youth and PCG interview

data were reviewed individually and collectively. Common and differing patterns were identified and noted. NP and SJ coded each transcript independently. Differences between coders were resolved in consensus discussions (NP, SJ, DH). Codes were aggregated and organised into exhaustive and mutually exclusive candidate categories, which were further refined into final broad categories with input from the full co-author team (NP, SJ, DH, DC, GP, MS). Participant narratives were incorporated in results writing to represent diverse perspectives across each category. The research team jointly agreed that the final sample of 20 participant interviews provided adequate information power to support the research question. Further information on sample size evaluation is offered in the published manuscript in Chapter 7.

6.7 Ethical Considerations

Human Research Committee Ethics (HREC) approval was obtained through the Royal Children's Hospital, Melbourne (Ref: 83902/RCHM-2022) and the University of Melbourne (Ref. 2022-24382-29523-2). Ethics approval documents are included in Appendix Z. This study was conducted following the University of Melbourne HREC guidelines and the Declaration of Helsinki (International Association for the Study of Pain (IASP), 2015).

6.7.1 Consent and Data Management

Face-to-face interviews were undertaken at a time convenient to the participants. In addition to obtaining written consent, consent was recorded within the interview before data collection commenced.

6.7.1.1 Informed Consent

Written informed consent was obtained for each participant before data collection. A parent, legal guardian (PCG), or person with power of attorney signed the consent form for adolescent participants. The National Statement on Ethical Conduct in Human Research advises that all competent participants who can make their own decisions regarding treatment, management, and study enrolment should be involved in the consent process (National Health and Medical Research Council, 2018). Therefore, *in addition to* obtaining parent/legal guardian consent, youth were offered the opportunity to consent if they were deemed competent and mature enough to do so. Adolescents and children provided their written informed consent to participate by counter-signing their PCGs' consent forms.

The parent/guardian and participant information statements and consent forms (Appendix W) described the purpose of the study, the procedures, and the risks and benefits of participation. The researcher (NP) conducted the informed consent discussion with the potential participant(s) and:

1. Ensured the parent/guardian/participant had sufficient time to review the study information.
2. Ensured that any questions raised by the parent/guardian/participant about the study were addressed to the satisfaction of the parent/guardian/participant.
3. Checked that the parent/guardian and the participant (where deemed competent) fully understood the information provided.
4. Reiterated the voluntary nature of the study and that participants could withdraw from the study at any time without explanation or consequence and with the assurance that any unprocessed data would be withdrawn.
5. Signed the informed consent form following the consent of the parent/guardian/participant.
6. Ensured all adolescents, regardless of their capacity to consent, were involved in discussions about the project.
7. Provided a copy of the signed information statement and consent form to the parent/guardian and the participant.

6.7.1.2 Data Management

Data were managed in accordance with University of Melbourne procedures and the Australian Code for the responsible conduct of research (National Health and Medical Research Council- Australian Research Council, 2018). Hard copy data (participant consent forms) were stored in a filing locked cabinet in a secure storage facility at the University of Melbourne, only accessible to the researcher and associated investigators. Paper reflexive notes were destroyed once they were transcribed into electronic format. Electronic data were securely stored in the University of Melbourne's REDCap® database system (demographic survey data) and in password-protected files (interview transcripts, audio-recorded interviews, and reflexive notes) in network file servers, backed up nightly. Interview audio recordings on the digital recording device were transferred to these password-protected files and immediately deleted from the digital audio recording device. All data were de-identified. These data will be kept for seven years after the youngest participant turns 18. After this period, all electronic and paper-based data will be securely destroyed.

Data and all other information generated in this study are held strictly confidential. No report, publication, or presentation will contain any reference to individuals. Any identifying information or unique traits that could lead to identification have been removed. Pseudonyms chosen by the participants have been used when reporting findings. Results will not be reported in a way that identifies any individual. All demographic data were pooled, with summary statistics presented for potentially identifiable variables such as age and sex.

Chapter Conclusion

This chapter describes the design of the second study of this mixed methods project. The research procedures were presented, including data collection, analysis, and ethical considerations. The results of this study are presented in the following Chapter (Seven) as the accepted version of the publication of this study. Methods for study three are described in Chapter Eight.

Chapter Seven

7

Study Two Findings

This chapter presents the results of the second study of this thesis, addressing the second objective to examine the perspectives of primary caregivers of hospitalised children (0-18 years) and of hospitalised youth (12-18 years) about their potential use of an inpatient portal to support their engagement in their/their child's pain care.

PUBLICATION 2 – SEEING THE LIGHT IN THE SHADE OF IT: PRIMARY CAREGIVER AND YOUTH PERSPECTIVES ON USING AN INPATIENT PORTAL FOR PAIN CARE DURING HOSPITALIZATION.

Manuscript Details


PAIN®
The Journal of the International Association for the Study of Pain
RESEARCH PAPER
"Seeing the light in the shade of it": primary caregiver and youth perspectives on using an inpatient portal for pain care during hospitalization
Pope, Nicole[a,b,c,*]; Jones, Sophie[a,b,c]; Crellin, Dianne[a,b,c]; Palmer, Greta[a,c,d]; South, Mike[a,c,d]; Harrison, Denise[a,b,d,e];

This chapter contains the manuscript reporting results published in an international peer-reviewed journal, *PAIN*. All authors read and approved the final manuscript. Reference formatting is modified to align with the thesis style, and references are provided in the thesis reference list. Supplementary materials are included in Appendix V – Appendix Z. There are no changes to the manuscript text as it appears in the journal before typesetting. The bibliographic details for the following manuscript accepted in *PAIN* are:

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Author Contribution: My contribution was to all aspects of this study. This included my involvement in conceptualising and planning the project, preparation, ethics submission, and study coordination. I undertook all in-person interviews and transcribed audio-recorded interviews verbatim. I worked with co-investigator SJ in applying qualitative content analysis to interpret the data. I was the first and corresponding author and drafted and prepared the manuscript for publication, addressed manuscript revisions, including responses to reviewers, and approved the final manuscript for submission.

Preface

Results of Study One of this Ph.D. project highlighted that paediatric clinical pain experts advocated for hospital-based patient portals linked to EMRs to support child and family engagement in pain care, enhance shared-decision making, and optimise pain care and outcomes. In 2016, The Royal Children's Hospital, Melbourne, was the first in Australia to implement a comprehensive commercial (EPIC®, Verona, WI, USA) EMR and associated outpatient portal (Epic MyChart) system (Glogolia et al., 2019). It was also the first hospital to implement an inpatient portal system (Epic, Bedside), providing families online access to physician-selected hospital medical records (i.e., medications and laboratory results) and enhancing in-hospital patient-clinician communication through secure messaging. In September 2022, the inpatient portal was rolled out across two hospital departments as part of a pilot implementation process preceding a hospital-wide project. This provided a unique and timely opportunity to explore the potential use of inpatient portals in hospitalised children's pain care, an area that has not been previously explored.

Abstract

Studies from multiple countries report that most hospitalized children, especially the youngest and sickest, experience pain that is often severe yet inadequately treated. Evidence suggests this can lead to immediate and lifelong consequences impacting children, families, and communities. Partnership and shared decision-making by children, families and clinicians is the ideal pediatric healthcare model and can improve care quality and safety, including pain care. A growing evidence base demonstrates that inpatient portals (electronic personal health record applications linked to hospital electronic medical/health records) can improve child and family engagement, outcomes, and satisfaction during hospitalization. This study examined the perspectives of caregivers of hospitalized children and of hospitalized youth about using an inpatient portal to support their engagement in pain care while in hospital. A qualitative descriptive study design was used and 20 participants (15 caregivers; 5 youth) with various painful conditions in one pediatric hospital participated in semi-structured interviews. The authors applied a reflexive content analysis to the data and developed 3 broad categories: (1) Connecting and sharing knowledge about pain, (2) User-centred designs, and (3) Preserving roles. These findings outlined caregiver and youth recommendations for portal configurations that deeply engage and empower children and families in pain care through multidirectional knowledge sharing, supporting caregiver and clinicians' roles without burdening or replacing human interaction implicit in family-centered pain care. Further research should measure the impact of portals on pain-related outcomes and explore the perspectives of clinicians.

Keywords

patient portals, pediatric pain, qualitative, pain management

7.1 Introduction

Pain control is a fundamental human right, yet publications over the years show that hospitalized children face inadequately assessed and undertreated pain (Cruz et al., 2016; Senger et al., 2021; Vejzovic et al., 2020; Velazquez Cardona et al., 2019). Painful procedures, including needles, medical and surgical conditions, such as trauma, are common. Up to three-quarters of pediatric patients worldwide suffer moderate to severe pain, most commonly from needle procedures performed with no or inadequate analgesia (Cruz et al., 2016; Senger et al., 2021; Vejzovic et al., 2020; Velazquez Cardona et al., 2019; Wilding et al., 2021). Younger and sicker children are less likely to receive adequate analgesia. For example, infants in neonatal intensive care experience up to 17 painful procedures daily, most performed without analgesia (Cruz et al., 2016). Children with chronic and serious medical conditions also experience under-treated disease-related pain and pain from invasive and repetitive procedures (Fortier et al., 2020; Plummer et al., 2021).

Research has revealed that undertreated childhood pain is associated with adverse outcomes and detrimental repercussions impacting children, families, health services, and communities. Repeated pain exposure in premature infants is linked to poorer cognition and motor function (Grunau et al., 2021; Walker, 2019a), and subsequent needle phobia, vaccination non-compliance (McMurtry et al., 2015; McMurtry et al., 2016; Taddio et al., 2015) hyperalgesia (Grunau et al., 2021), and avoidance of medical care (McMurtry et al., 2016).

Evidence-supported clinical practice guidelines (CPG) have been developed to address pain in hospitalized children and include pharmacological, psychological, and physical interventions (Fisher et al., 2022; Friedrichsdorf & Goubert, 2020). Family-centered care, including partnership and shared decision-making by children, families, and clinicians, is the ideal pediatric healthcare model and can improve care quality and safety (Uniacke et al., 2018), including pain care (Rao-Gupta et al., 2018; Vasey et al., 2019). Finding effective ways to engage children and families in pain care is critical to capturing holistic understandings of pain and tailoring individual pain care treatment.

Use of digital health initiatives to promote patient and family engagement is an emerging area of interest in healthcare. Digital intervention development and dissemination have already influenced pediatric pain in ambulatory contexts. For example, the *iCanCope with pain* smartphone intervention suite supports youth to self-manage persistent pain (Stinson et al., 2014) and includes the *iCanCope PostOp* application addressing context-specific problems for acute postoperative pain (Birnie et al., 2019).

The *Pain Squad+* self-management application supports adolescents with cancer (Jibb et al., 2017). In hospitals, a growing evidence base demonstrates that inpatient portals (electronic personal health record applications linked to hospital electronic medical/health records [EMRs/EHRs]) can improve child and family engagement (Kelly et al., 2019; Kelly & Hoonakker, et al., 2019) outcomes, and satisfaction (Dendere et al., 2019) during hospitalization. However, prior studies have not focused on hospital-based portal use in pediatric pain care.

Our team recently examined the perspectives of pediatric pain experts regarding hospital EMR designs that support optimal pain care practices (Pope et al., 2023). Experts advocated for patient-facing digital health technologies, particularly inpatient portals, to support patient engagement in pain care, enhance shared-decision making and optimize pain outcomes (Pope et al., 2023). The present study builds on that research through interviews generating qualitative insights into the perspectives of primary caregivers (PCGs) of hospitalized children and of hospitalized youth. The aim was to explore consumers' perspectives on the establishment and role of using an inpatient portal in supporting patient and family engagement in pain care during hospitalization.

7.2 Methods

7.2.1 Design and Participants

Guided by the general principles of naturalistic inquiry situated within a constructivist worldview (Lincoln & Guba, 1985), this study employed a qualitative exploratory interview design to describe the perspectives of PCGs of hospitalized children (0-18 years) and of hospitalized youth (12-18 years) about using an inpatient portal to support their engagement in pain care. This design was considered suitable to explore the potential use of an inpatient portal for pain care as perceived by hospitalized youth and PCGs.

The single study site hospital has used an EMR (Epic Systems) and an outpatient portal (MyChart Bedside) since 2016. This study was conducted before the introduction of an inpatient portal. Clinicians record all pain care in EMR flowsheets, progress notes, and the electronic medication record (eMAR). Hospital guidelines require documented assessments for all children at least once per shift and more frequently for children reporting pain or receiving pain interventions. Data access via the EMR is restricted to authorized hospital staff. Patients and families do not have inpatient portal access to their hospital EMR data, including pain care data. Children and families are engaged in pain care through verbal conversations with clinicians and can maintain pain diaries at their discretion.

The study was publicly promoted in print through flyers and posters in hospital wards. The first author (NP) screened for eligible participants by reviewing EMR bed census data of all inpatient wards on weekdays. English-speaking PCGs of hospitalized children (aged 0-18 years) and English-speaking hospitalized youth (aged 12-18 years) were eligible and approached if their child/they were admitted with an acutely painful condition, injury, or illness requiring pain intervention (pharmacological and/or non-pharmacological) or with a condition likely to result in procedural pain. Youth and PCGs in the emergency department and those with clinical or psychosocial circumstances considered inappropriate for participation (i.e., acute mental health disturbance, clinical deterioration) were excluded and, therefore, not approached. Children under 12 years old were excluded because of legal limitations excluding them from shared access to the patient portal. Youth over 12 years will have shared, rather than independent, access to the portal once it is rolled out across the hospital. Purposive sampling was used to identify a diverse sample of participants in terms of pain experiences (e.g., postoperative pain, pain due to injury or illness, procedural pain), previous hospitalization, youth age, and PCG and youth sex.

7.2.2 Procedure

The study was conducted in accordance with the Declaration of Helsinki and approved by the institutional review boards (approval ID: HREC/83902/RCHM-2022; 09th June 2022). Reporting is per the Consolidated Criteria for Reporting Qualitative Research checklist (Tong et al., 2007). Signed written parental informed consent was obtained prior to interviews. Youth participants countersigned their PCGs' consent forms.

7.2.3 Interview Guides

Interview guides containing semi-structured interview questions were developed in consultation with stakeholders comprising academics, clinicians, and consumers (Supplementary material). Questions had been pre-tested with a 12-year-old youth with a recent hospitalization and their PCG, which led to adjustments for clarity and removal of a question perceived as redundant. Neither were study participants. Interview questions related to how they envisaged using an inpatient portal to report and review pain-related data during hospitalization and how this might impact pain care and outcomes. Interview questions were iteratively modified based on an analysis of preliminary interviews to address the adult and youth needs, enhance clarity and comprehension of questions, and explore new concepts as they unfolded, such as remote access to the portal outside the hospital and perceived burdens related to portal use.

7.2.4 Face to Face interviews

In-person interviews were undertaken in English between July and September 2022 by the first author (NP), a woman, a registered nurse, and a Ph.D. candidate with training and experience in qualitative research. Her professional work as a registered children's nurse in a pediatric hospital with an EMR, a commitment to improving pain management in hospitalized children, and being a mother of young children motivated NP to undertake this work. The study was conducted in the hospital where NP was employed as a clinical nurse but not in the clinical area where NP worked. NP had no previous relationship with participants, which helped to safeguard against PCGs and youth feeling coerced into participating in the study (Dodgson, 2019).

Congruent with a semi-structured interview approach (Creswell & Clark, 2011) and the exploratory design, NP used prompts to elicit detail (e.g., 'Can you tell me more about that'), paraphrasing and checking to clarify participant responses (e.g., 'Am I getting the right idea here, or not really?') and flexibility to probe and navigate the interviews to ensure naturally flowing conversations. As a skilled clinician-researcher, NP carefully tailored communication strategies to the context of each interview to resonate with the diverse audience. For example, language such as 'sore' or 'hurt' rather than 'pain' was used during some youth interviews where appropriate. NP acknowledged that her professional credentials may have made PCGs and youth inclined and comfortable to openly share their perspectives. This supported an interactive interview approach, facilitated rapport, and helped capture insights into how PCGs and youth wanted to use a portal in their pain care.

To maximize emotional and physical comfort, interviews took place in a location chosen by the participant(s) (at the bedside or in a meeting room on the ward) and at a convenient time that did not interfere with clinical care. All interviews were audio-recorded and undertaken during the participant's hospital admission while their hospital experience was current. No non-participants (e.g., clinical staff) were present during the interviews. All youth participants requested to be interviewed in pairs with their PCG. Joint interviews facilitated a synergistic understanding of PCG and youth's perceptions regarding their potential role using a portal. At times during the interviews PCGs and youth worked together to spontaneously probe and develop meaning that further enhanced their individual perspectives. To facilitate reaching the youth during the interviews and ensure their distinct perceptions were also captured, NP directed interview questions specific to the youth using developmentally appropriate language. To maximize data immersion (Lincoln & Guba, 1985), all audio-recorded interviews were transcribed

verbatim by NP and proofread alongside the original recordings to ensure accuracy. Interview transcripts were uploaded and managed in NVivo (QRS International, 2014).

7.2.5 Data Analysis

Qualitative content analysis (QCA) was applied (Elo & Kyngas, 2008) to the interview data and involved a systematic, iterative process of inductive and deductive coding, categorizing, and conceptualization. This study's analysis unit was the interview text, and the analysis focused on manifest content (Elo & Kyngas, 2008). Two authors (NP and SJ) familiarised themselves with the data by conducting multiple readings of the interview transcripts to get a sense of the whole and making preliminary coding notes about the content (Elo & Kyngas, 2008). They met weekly to reflexively discuss emergent patterns of early analysis. SJ is a woman and clinician researcher with expertise in qualitative research and an interest in patient portals to support children and families in disease self-management. As users of this EMR system and health researchers, NP and SJ inherently influenced data analysis. They each brought the emic perspective to examine patient portals in hospitalized children's pain care (Dodgson, 2019. However, they consciously mediated their own pre-existing expectations about patients' using portals to allow them to uncover participants' perceptions. Relevant passages in the transcripts from youth and PCG participants were divided into meaning units containing related aspects (Graneheim & Lundman, 2004) that were then condensed, abstracted, and labelled with a code. To provide a collective understanding of the role of patient portals in pain care, PCG and youth interview data were reviewed individually and collectively, and patterns that were common and different were identified. NP and SJ coded each transcript independently, with the second coder verifying each transcript coding for correctness to ensure the whole context was considered when coding. What differed between coders was their judgment about what comprised sharing knowledge and connecting for pain care. A process of reflection and consensus discussions (NP, SJ, DH) resulted in an agreement about how to sort the codes. Codes were aggregated and organized into exhaustive and mutually exclusive candidate categories. These were subsequently reviewed and refined into final broad categories which were conceptualized deductively, based on the researchers' prior theoretical knowledge of pain and pain care (theory-driven), and inductively from the participant's reported experiences and perspectives (data-driven). During the process, the reflexive researchers remained close to the data yet cognisant that some degree of interpretation was involved (Elo & Kyngas, 2008). Representative quotations from the transcripts were incorporated for each category. To further enhance trustworthiness, debriefing sessions with the entire authorship team (NP, SJ, DH, DC, GP,

MS) were held throughout the analysis to improve the interpretation and content of the codes, candidate categories, and final broad categories. Working through data analysis reflexively with this experienced team of clinician researchers and constantly returning directly to the data assured the rigor of the study. Participants were not asked to review transcripts or provide feedback on the findings. An audit trail was constructed throughout the study, including information about interview guide development and methodological, analysis, and synthesis processes.

The dual approach of exploring PCG and youth perspectives allowed for a collective understanding of the role of portals in pain care, which was congruent with the intention for PCG-youth shared portal access. As stated above, once the inpatient portal access is rolled out in the study hospital, youth over 12 years will have shared, rather than independent, access to the portal.

Sample size requirements were guided by the principles of information power (Malterud et al., 2016), in which five items (study aim, sample, theory, dialogue quality, and analysis strategy) were iteratively assessed throughout the research processes. The research team jointly agreed that the final sample of 20 participant interviews provided adequate information power to support the research question. The richness of information was based on the combination of purposive sampling, the narrow study aim, the dense sample of PCG and youth participants with diverse pain experiences, and the underpinning of biopsychosocial and family-centered pain care theories that explained important aspects of pediatric pain care. The dialogue was strong (i.e., rapport was established, participants were engaged, and conversations flowed naturally) and focused. The data was suitably rich in terms of depth and breadth to address the research aim and provide a shared understanding of the role of portals in pain care.

7.3 Results

A total of twenty participants (16 caregivers total: 12 alone and four caregiver and youth pairs) were interviewed. Table 7.1 summarizes the participants' demographic characteristics. The mean interview duration was 18 (range 13 – 26) minutes. The research team organized qualitative results into three broad categories (Table 7.2) labelled: (1) Connecting and sharing knowledge about pain, (2) User-centred designs, and (3) Preserving roles. These categories and their corresponding sub-categories are presented below with supporting participant narratives. All potential participant identifying information has been removed.

Table 7.1
Participant characteristics (n=14)

Characteristic	Value n (%)
Role, n (%)	
Mother (Child sex; 4 female, 5 male)	9 (45%)
Father (Child sex; 1 female, 4 male)	5 (25%)
Other: Grandmother 1, Aunty 1(Child sex 2 female)	2 (10%)
Youth (2 female, 2 male)	4 (20%)
Age, (y)	
Primary Caregiver (38-68)	Mean 46.4
Primary Caregiver Children (non-paired) (10months-13)	Mean 9.6
Youth (13-16)	Mean 14.5
Primary Language, n (%)	
English	17 (85%)
Other	3 (15%)
Reason for Hospital Visit, n (%)	
Surgery/Trauma	11(55%)
Acute Illness	4 (20%)
Known disease	5 (25%)
Current use of Outpatient Portal, n (%)	
Yes	3 (15%)
No	17 (85%)
Level of Computer experience*, n (%)	
Less experienced (browsing web, checking email, or less)	14 (70%)
Somewhat experienced (editing photos, using spreadsheets)	6 (30%)
Highly experienced (creating web pages, writing computer programs)	0 (0%)

NOTE: Computer experience question based on previously used survey item. From: Aldekhyyel RN, Melton GB, Hultman G, Pitt MB. Using a bedside interactive technology to solicit and record pediatric pain reassessments: Parent and nursing perspectives on a novel workflow. *AMIA Jt Summits Transl Sci Proc*. 2018;2017:300-9.

Table 7.2

Qualitative Results

	Category		Sub-Category	Example Narratives
1	Connecting and sharing knowledge about pain	1.1	Deep insights into pain experiences	*I want to be able to record both [score and describe pain]. Like when I have pain, I feel weak, like I can't stand up. I want to include that as well.* (Participant 20, Male youth) *There is a bigger picture. It is not just about pain. Like I am really focused on sleep at the moment because that is a big part of my child's pain. It is also important to be able to record the overall well-being.* (Participant 8, Mother) *The doctors come in in the morning and want to know how things went overnight; it's all a bit of a blur because you lose track of time. If there were some way for me to record that, like, at 4 am, my child's pain was this much better, that would be really good.* (Participant 8, Mother) *Seeing the progress, sometimes these places are about just one or two steps forward. We have our little board here where we have our goals for the day. Those ticks are good for us, and it is good for my child mentally. So, if you could have a device where you can see your child is getting off oxycodone, that's a great outcome to celebrate as well.* (Participant 4, Father)

	Category		Sub-Category	Example Narratives
1 (cont.)	Connecting and sharing knowledge about pain	1.2	Transparent information for empowerment	*As a patient, you get curious. Like it would be good if you could type [into a portal] what [medication] you are taking… I know some medications say you shouldn't do too much physical stuff. What to avoid to make sure my treatment has the best possible outcome for myself, without making myself worse or anything like that.* (Participant 12, Female youth)
				If you could access the child's [medication] schedule, you could see they had [pain medication] at this time; it's another six hours until the next dose. That would be helpful because then, if you see they have pain, they are starting to be a bit wiggly; you could look on your portal and see when they are due their next dose [of pain medication]. You kind of then feel a bit more in control. Sometimes when they are in pain, you don't know if that is normal or not because you can't see what their schedule of medication is. It may well be that the medicine is just wearing off. Whereas sometimes you might think, "Hang on a minute, if he has already had medication and is still in pain, is something going wrong?" (Participant 15, Mother)
				It is smart. It would help you see things that you might have forgotten. (Participant 5, Male youth)
				As a patient, you get curious. Like it would be good if you could type [into a portal] what [medication] you are taking… I know some medications say you shouldn't do too much physical stuff. What to avoid to make sure my treatment has the best possible outcome for myself, without making myself worse or anything like that. (Participant 12, Female youth)
2	User-centred designs			*As a parent you get busy, trying to entertain the child, you are trying to do your own thing and work with the nurses. So, a little app reminder that popped up would be good. But how frequently? You don't want it to constantly pop up. Like this (intravenous pump) machine drives us nuts because it is constantly making noise, like multiple times a night, it goes off and it is like gahh. It is actually quite a lot.* (Participant 9, Father)

	Category		Sub-Category	Example Narratives
3	Preserving roles	3.1	Complementing clinician roles	*I tend to like to have conversations. I wouldn't want [the portal] to be the only method of communication. In my view that the recording of information helps with efficiencies, helps with data storage, but doesn't take away that personal contact or questioning that I think is critical* (Participant 3, Father)
				We have a lot of nurses here that come and check on us every now and then. It would be nicer to be able to ask questions and answer directly also, rather than looking up information on your own. You need that human touch with pain also, right? (Participant 10, Mother)
				If you could communicate with nurses and doctors, that would be really helpful. But then again, how soon could they reply? Because they might put you in line and you can wait for so long. If they are in the middle of something, then it won't be so convenient also. (Participant 10, Mother)
				I don't think we should have direct contact with the nurses; they have enough stress. They have that many patients to deal with. They are going to be able to see the information on their system anyway - so, like, look, [child's name] is at pain score 6 - that is probably all they need. (Participant 7, Father)
		3.2	Protecting primary caregiver roles	*As a mum, the first priority is to look after your kids, and let the medicos do what they do best.* (Participant 11, Mother)

7.3.1 Broad Category 1: Connecting and sharing knowledge about pain

This category relates to participants' views on an inpatient portal serving as a platform for reciprocal information exchange between patients, families, and clinicians. Participants envisage that sharing real-time information about their pain experience and accessing pain-related health information via the portal would facilitate child-family-clinician partnerships and ultimately enhance pain care and outcomes. Two sub-categories were identified.

7.3.1.1 Deep insights into pain experiences

Participants suggested that a portal could provide opportunities for children and families to view and contribute to their pain-related data. This would support their engagement in pain care and offer clinicians deep insights into individualized pain experiences. Entering real-time pain reports in the portal was regarded as essential to capturing fluctuating pain symptoms, understanding the context in which pain is experienced, and *'seeing the light in the shade of it.'*

> *Nurses might see the child, and the child might say, 'I am fine at the moment; my pain is a 2'. Then my child might do a movement or eat, and their pain goes up to 6, but the nurses are busy, and it might not be as important to drag them in right now. But if I can let them know their pain went up when my child went to the toilet or was sick, that would be important.* (Participant 9, Father)

PCGs described how their continued bedside presence and intuitive connection with their child allowed them to quickly recognize and report detailed pain accounts. Access to a portal would help capture and communicate these unique pain insights, with the potential of portal use enhancing care.

> *With my child being non-verbal, I understand when they are in pain because they make different sounds, so it would be very beneficial for me to be able to write down, using a portal, when they are in pain. This would be a really good thing for me and my child.* (Participant 6, Grandmother)

Because the experience of pain is more than physical, both caregiver and youth participants advocated for portals to include functionality where they could report and monitor broader pain symptoms, including functional, social, and psychological dimensions of the pain experience.

Being able to write and check your mood with a portal that's important. Because sometimes, with pain, your mental health gets affected as well. (Participant 12, Female youth)

Participants shared how capturing the bigger picture of pain also included reporting the effects of pain interventions. They believed that a well-designed portal would help communicate these details efficiently and perceived this as essential to optimizing pain care outcomes, an expressed example being timely reporting of the side effects of pharmacological interventions.

The pain medication was creating nausea and vomiting and stopping my child from eating and drinking. If that information could have been communicated better, then I would use [the portal] to make a comment. (Participant 2, Mother)

Participants also felt that a portal could help them gauge and track pain, set and review treatment goals, and monitor recovery progress. Viewing and contributing pain information via the portal would provide opportunities for their engagement in pain care and enhance shared decision-making. For example, one PCG felt that recording pain via a portal would allow tracking of the pain, with a youth commenting on improved accuracy of self-report and better communication with clinicians.

[Recording pain via the portal] would help me. Because [clinicians] come in and ask, 'What is your pain?' and I forget what I said last time. So, if I could record it and see what I was feeling and what in my mind an eight was, I would be able to base it more on that. Because if it is still sore, and I said a nine last time, and I am saying a nine again, but it is actually better. (Participant 18, Female youth)

Further to the above, one of the most common participant perspectives identified was the portal's potential to allow children and families to track their recovery. Seeing progress helped set expectations and offered a sense of hope and confidence in their recovery from pain.

I would like to (use the portal) to see progress. Obviously, if my child is starting to come back from the medication, you kind of know then that they are mending and getting better quicker. So that has got to be the main thing for me (Participant 15, Mother)

As well as benefiting patients, participants envisaged that access to patient-entered pain data on a portal would help clinicians and their workload by providing insights into pain trends, facilitating efficient work practice, and informing care planning.

> [Patient entered pain data] *might allow the medical staff to see anecdotally what the pain looks like from the child's perspective. I imagine that might also be helpful if they reflect back; they have got the data there* (Participant 15, Mother)

The general consensus among participants was that patient-entered data would contribute valuable information toward the shared goal of improved pain care.

> *It is just an add-on, extra information for the nurses to help put the jigsaw puzzle together to get to the end result.* (Participant 1, Father)

While all participants advocated the potential benefits of self-recorded pain data, some had questions about what information they should record. Some questioned their ability to provide the *right* information and suggested guidance was required.

> *As long as you get some guidance about the types of things you should report, this is how you might report it.* (Participant 13, Mother)

Many participants foresaw the value of ubiquitous portal access for designated family caregivers from any location. This was particularly important for parents who could not remain at the bedside due to work or other commitments and especially where the COVID-19 restrictions limited caregiver numbers at the bedside.

> *Probably peace of mind for people at home, too, if their kids are in here. Especially because of COVID and how it is now, we are only allowed two parents in here during the day. Even if the other parent has to be away working or whatever, at least they could still see what is going on with their kid.* (Participant 7, Father)

7.3.1.2 Transparent information for empowerment

Participants foresaw the portal as more than a mechanism for unidirectional information sharing between patients and clinicians. They wanted transparency through real-time access to their health information and care plans via the portal. Participants also advocated for the portal to integrate reliable pain-related resources about pain and pain treatments, particularly medicines. This information was important to support understanding and participation in care.

Regarding care plans, most participants wanted access to information about their/their child's prescribed medications and dosing, helping them monitor and respond to their/their child's condition and feel a sense of control, remaining informed and involved in pain care.

> [Seeing treatment plans within a portal] *would be brilliant because you are so in the dark. You can't view anything, and* [clinicians] *come in with information and can go off and look on the system, and you* [feel], *'That is my child! I would like to be able to see that information as well.' I have got no visibility. If I could see* [pain treatment plans] *and if there were changes made, that would help my understanding.* (Participant 8, Mother)

According to participants, the portal should offer text supplements to verbal information about care plans, helping children and families better understand and retain pain care information. This is particularly important in the context of a stressful hospitalization.

> *There is just a lot going on emotionally and mentally right now; I think sometimes your ability to interpret, digest, and query information is just gone. You are just worried about your kid. A lot has happened to get you to that stage in hospital… I think having that information* [via a portal] *would really help us.* (Participant 4, Father)

Participants spoke about how empowering patients and families with knowledge through shared access to care plans could also help to reduce anxiety, fear, and stress and permit PCGs and patients to navigate changes in their child's/their condition and keep up to date with care plans.

> *I reckon* [seeing your care plans] *would be good. I reckon it would be a bit less scary because you know what is actually happening. Like now, someone just walks in, gives you something, and you have no idea what is going on.* (Participant 18, Female youth)

In addition to care plan access, participants wanted trusted, evidenced-based information delivered via the portal. This timely, efficient provision of reliable information would help children and families be informed and involved in pain care, assisting PCGs in monitoring and responding to their child's condition. Medication-specific information was mentioned as particularly crucial.

> *Steering us to valid, authorized information would be better than people running off the Google highway. If I know there are certain signs and symptoms to watch out for and certain side effects. It would be great to know what the drug is, what it does, and the side effects.* (Participant 4, Father)

Directing patients and families to trusted resources was also envisaged as essential to address potential misconceptions and fears about pain and treatment.

> *You just put your trust in* [clinicians] *and go ok, so they are giving my child opioids. And you have this knowledge, this incorrect knowledge about what that means. So, drug education would be amazing, and then people can decide on how much they want to read* (Participant 8, Mother)

7.3.2 Broad Category 2: User-centred designs

This category captures participants' perspectives about how inpatient portals should be designed to be easy to use, helpful, and accessible to all hospitalized patients and families. In addition to the care plan and medication information, participants wanted the portal to include functionality allowing for personalized features tailored to their clinical situation and preferences and remote (out of hospital) access for family caregivers. Concerns regarding information security in patient portals were common across PCG participants, specifically regarding the security risks of providing portal access via personal devices.

All participants advocated for portal designs that supported convenient and efficient entry of pain data, especially as they tried to manage stressful situations.

> *From a user experience, you want to keep it relatively simple. If I can go, ok, my child looks like they are in pain, I am just going to quickly log in and [record] they are wriggling a bit, and they are saying they are a little bit sore. If you are able to do that quickly and easily, that would be good.* (Participant 13, Mother)

Regarding portal design features, participants advocated for simple, intuitive functionality that enabled tailoring content and displays based on the end-user's age, developmental stage, clinical situation, and health literacy. Voice-to-text technology and drop-down options were suggested as interactive and innovative ways to enhance end-user engagement.

> *For the kids that have learning difficulties and* [similar], *you need to cater to them. Even a voice so they can hear things, and pictures and stuff like that. Making it as simple as possible with the drop-down menus.* (Participant 14, Aunty)

Aligned with intuitive and interactive functionality, participants identified the need for personalized features to humanize the patient experience, increase their engagement in pain care and enhance child-family connection with clinical teams.

> *A problem would be it not being appealing to the patient. Because a lot of the time, you don't want to fill out another survey; if it is generic, it could come across as unappealing and force you into doing it. It needs to be more of a conversation than, like, questions, more interactive.* (Participant 12, Female youth)

Participants contemplated accessing the portal via hospital-supplied or their own devices. They emphasized the critical need to address disparities in families who have, and do not have, smart device access and those with high versus low digital literacy skills;

> *I am very IT savvy, so we have an iPhone, iPad, laptops, and so forth. But there are other patients that will not be as fortunate, and many people my age or younger have no interest in* [smart devices]. *So, it needs to be made as simple as possible, and you need to think about how to make that resource available to people who don't have sufficient funds privately to interact with them every day or just have no interest* (Participant 9, Father)

There was a unanimous agreement for children and families to access hospital-supplied devices, if needed, to support broad access to the portal.

> *If the hospital can give you a tablet and then it's just like a log-in box, and you sign in. So, it's not like parents have to download the app and go out of their way. It is just there in the room. Some people's own devices' batteries die, or you can't use them because the signal is gone or whatnot.* (Participant 12, Female youth)

As well as being convenient, accessing the portal via hospital-supplied devices was foreseen as a useful way for PCGs to disconnect if needed and balance other responsibilities.

> [The device] *should be part of the bed space. Because if people know it is not a part of them, it helps separate things. If I had my quiet moment, knowing that the system is here, then I can just tap it. Also, say one of the other kids is facetiming you, and you are then thinking, 'oh, I really want to just do something quickly on my phone for my sick child' you can still be Face-timing then tapping information in the notes.* (Participant 2, Mother)

On the other hand, accessing the portal using personal devices was also considered a convenient way to optimize family opportunities for portal access, particularly for family caregivers who could not be at the bedside. Yet, participants acknowledged that remote portal access would require more advanced health data security.

> *When I go home in the evenings, I would want it* [on my phone], *so I can access it from outside the hospital. That would be really important.* (Participant 16, Father)

Participants had mixed feelings about portal push notification functions to remind them to record pain information. Some saw the benefit of having pop-up prompts directing them to enter pain information. Others worried that too many prompts might be overwhelming, particularly as other hospital devices are already a source of stress for parents and children.

> *As a parent, you get busy trying to entertain the child. You are trying to do your own thing and work with the nurses. So, a little app reminder that popped up would be good. But how frequently? You don't want it to pop up constantly. Like this (intravenous pump) machine drives us nuts because it constantly makes noise, like multiple times a night, it goes off and is like, gah. It is actually quite a lot.* (Participant 9, Father)

Having control over personalized push notifications, with the option of a snooze or reminder function, was important to address burdening parents and children.

> *At the very beginning, there is going to be a lot going on; you don't want to be bombarded with all this information and then prompts. I think if the prompts can be controlled by the user: I could say, 'I don't want prompts now, and I will tick it in about 3 hours, one day, two days later', or 'remind me in 3 days to turn it on', something like that I wouldn't mind.* (Participant 11, Mother)

Among the most common perspectives identified among participants was addressing health data security, privacy risks, and environmental constraints, such as network reliability, account setup, and access.

> *I think there would be fears around breaches and data security. A long as it looked and felt like a genuine app to support my child as opposed to an app to collect data and then sell stuff to you. As parents who have had experiences with some of the remote learning applications, they were very much [advertisement]-driven.* (Participant 4, Father)

7.3.3 Broad Category 3: Preserving roles

The final category reflects participants' views about how a portal should augment and complement care and support child-caregiver-clinician partnerships but not replace inherent roles and genuine care nor burden patients or clinicians. Two sub-categories were identified.

7.3.3.1 Complementing clinician roles

Participants envisaged that introducing a patient portal would complement clinician roles and support efficient care and decision-making through timely pain reports and enhanced communication. The portal was viewed as a potential adjunct to effective pain care, but participants warned that it should not replace the face-to-face human interaction integral to pain care.

> *I tend to like to have conversations. I wouldn't want* [the portal] *to be the only method of communication. In my view that the recording of information helps with efficiencies, helps with data storage, but doesn't take away that personal contact or questioning that I think is critical*. (Participant 3, Father)

Participants also worried about how a portal would impact clinicians' work. Some were concerned that clinicians would be too busy to incorporate a portal into their work and that the portal would increase clinician workloads. They highlighted the need to balance the expected benefits of the portal with an increased clinician workload. This was emphasized in discussions about secure messaging functionality. Some participants felt that secure messaging would add value by facilitating efficient clinician-family communication.

> *If mum had questions, it would be good if there could be a way mum could message or even call* [clinicians] *and* [ask], *'Hey, you wrote this in your notes; I am just wondering what you meant by it?'* (Participant 12, Female youth)

Others acknowledged that while secure messaging seemed useful, it might not necessarily be the most convenient communication method. They worried patients could overuse it and about how it could adversely affect verbal communication, with one PCG stating it would negatively impact clinician workload and was unnecessary.

> *I think it could go two ways, though; if you were a kind of anxious mother and you have got something going on like something is beeping, and that is really worrying you, but there is nothing majorly wrong, the poor nurses could really be busy. That is the only downside.* (Participant 17, Mother)

7.3.3.2 Protecting primary caregiver roles

While all participants perceived they had a role in using an inpatient portal for pain care, many PCGs spoke about balancing its use while preserving and protecting their inherent caring roles. When a child is in hospital, PCGs felt their intrinsic role in nurturing, comforting, and attending to their child's pain care needs is the priority. Because hospitalized children tend to be significantly unwell and family caregivers are in a state of

crisis, PCG participants suggested that patients and families need time to come to terms with the clinical situation and settle in before accessing and using the patient portal.

> *Being in here sometimes is challenging. Whenever my child is in pain, there would be pressure on us as parents. Most of the time, my child requires a lot of attention, and for us to record everything on an app would be challenging. We would attend to his needs most of the time, and then we can only get to do* [the portal] *whenever we are free, if we remember*. (Participant 10, Mother)

Similarly, while PCGs and youth felt that the portal would be an important way to communicate information about care plans, they wanted some control over the release of content concerning timing and detail of information. For PCGs, this was important to balance their role as caregivers, their priority to respond to their child's needs, and avoid information overload.

> *I definitely would not want all the information upfront. I would not have been able to cope with knowing what* [clinicians] *are doing. I probably would appreciate that information a few days into a stay. Once you can actually clear your thoughts, look at where we are at, and 'Do we move forward?' and 'What do we need to do to move forward?.' So, transparency. How much transparency, I am not sure*. (Participant 11, Mother)

7.4 Discussion

This study details the perspectives of a group of PCGs and youth through face-to-face interviews during an inpatient admission regarding how patient portal use during hospitalization could support communication and shared decision-making in pain care. Findings demonstrate participants' beliefs about harnessing a portal as a powerful tool to foster documentation, report, and shared understandings about pain experiences, optimize patient engagement and timely interventions, and support recovery during hospitalization. PCGs and youth desire a seamless experience accessing real-time clinical information about pain care during hospitalization. They suggested access to pain care plans, medication charts, and physician notes through a portal as valuable to improve insight into and understanding of pain care and support more effective patient-family engagement and empowerment. These consumers perceive mitigating potential risks and preserving and protecting end-user roles as critical when considering portal use.

A fundamental right has been proposed for hospitalized children and families to access complete and unbiased information about their care in affirming and useful ways

(Uniacke et al., 2018). This is important given that hospitals are unfamiliar and isolating places for children and families who feel disempowered by the pain experience (Page, Stinson, et al., 2012) and more so when access to information is limited (Jepsen et al., 2019. Despite this, previous work evaluating the potential impact of portals in pediatric settings demonstrates that clinicians worry that sharing medical information could lead to patient and family anxiety and confusion (Collins et al., 2017; Kelly et al., 2017; Pope et al., 2023). In our prior work, clinical pain experts advocated for patients to have portal access to pain-related information but were concerned that too much information could overwhelm families (Pope et al., 2023).

Although parental and child anxiety and distress are understandable in the context of hospitalization, they are important contributors to pediatric pain severity and pain-related disability (Lund et al., 2021; Raja et al., 2020) and prolonged high levels of distress are associated with chronic pain trajectories (Birnie et al., 2018; Khadij et al., 2021; Rabbitts et al. 2015). Contrary to clinicians' predictions (Pope et al., 2023), youth and PCG participants in the present study believed access to clinical information would help alleviate uncertainty and anxiety because they would be better able to understand, monitor and make decisions about pain care. These findings are similar to those of a youth group (n= 23, aged 13-17 years with cancer and blood disorders) who reviewed the accuracy of their medical information in the inpatient portal (Hong et al. 2016). They described anxiety reduction and increased knowledge about their illness (Hong et al. 2019). In the present study, participants also believed that family caregivers' access to portal data at home would help keep them informed, reducing anxiety about being absent. Reporting and tracking pain via the portal was perceived as a promising way to goal set, instilling a sense of hopefulness in recovery. Similarly, youth and parents using the *iCanCope Post-op* app regard tracking pain trends and goal setting as essential features to support realistic, individualized postoperative recovery (Birnie et al., 2019). Finally, in line with clinician concerns (Dendere et al., 2019; Pope et al., 2023), participants acknowledged the potential burden of too much information, raising questions about how portal designs could ensure that families can control the timing and content of the information they access. Future investigations should explore best practices regarding patient-family access to pain-related portal data and the repercussions of portal information sharing on pediatric and parental pain-related outcomes.

Pain science and medicine have battled a long and worrying history of misconceptions about pain and pain sensitivity. Unfortunately, myths regarding pain persist, where studies

suggest that patients and families believe myths and hold misconceptions about pain and pain interventions (medicine and non-medicine), exacerbating the undertreatment of hospitalized children's pain (Chng et al., 2015; Kaminsky et al., 2019; Khin Hla et al., 2014). Misconceptions and mismanagement of pediatric pain have provided the impetus for consumer-targeted educational interventions to support pain understanding and the use of safe and effective multimodal treatments (Chambers et al., 2020; Harrison, Larocque, Reszel, et al., 2017). Participants in this study suggested the portal could provide convenient access to trusted, evidence-based resources about pain, most notably medication information. Ideally, the content should extend beyond patient or caregiver Google searching and be tailored to portal users' developmental and literacy needs. This would steer patients and families away from misinformation and address misunderstandings about pain and its treatment. Going forward, stakeholders involved in portal implementation, including interdisciplinary pain teams, should focus on transferring pre-existing educational resources to portal platforms and collaborate with families to innovate novel portal-delivered evidence-based pain education for hospitalized children and families.

Previous qualitative work demonstrates that hospitalized children and adolescents are willing and capable of providing detailed accounts of their pain when given the means and opportunity (Pope et al., 2018; Pope et al., 2023; Sng et al. 2017). In this study, participants perceived the portal as a tool they could use to contribute to their pain data by sharing detailed accounts of their pain experience, including intensity, quality, interference, and meaning of pain. Reporting pain in real-time via a portal was particularly valued because participants felt that often pain experiences were not fully captured during hospitalization. Increasing the visibility of pain through patient-generated data is critical to understanding total pain and providing timely and appropriate interventions (Pope et al. 2023). Harnessing portals to optimize how children and PCGs self-report pain reasserts that they are experts in their (inherently personal) pain experience (Raja et al. 2020) and re-affirms their role as partners in pain care (Vasey et al. 2019). This can contribute to patient empowerment and validate their pain experiences. It can also offer clinicians insights into the complexity of pain, its multifactorial consequences, and the necessity for multimodal interventions. Finally, patient-generated pain data serves as a rich data source that can be leveraged to further understand pain in hospitalized children, inform innovative research and analytic endeavors, and shape the future of pediatric pain care.

An ever-growing evidence base boasts the potential benefits of EMR alerts and care reminders to guide clinicians' compliance with evidence-based practices (Algaze et al.

2016; Bauer et al., 2013; Hogan et al., 2020). Thatt said, there is also increasing evidence regarding EMR notification fatigue and how it impacts clinician wellness (Van Dort et al., 2021) and pain care practices (Pope et al., 2023). Similarly, in the present study, participants were concerned that portal alerts, like prompts reminding patients to enter pain information, could be burdensome. They also worried about the potential repercussions of portals on clinician workloads, mirroring clinicians' (n=94) pre-implementation concerns about a portal disrupting their workflows in one pediatric setting, which did not materialize (Kelly et al., 2017). Most notably, PCG participants were concerned about protecting their inherent roles as carers for their hospitalized child and ensuring that portals augment (not replace) the human interaction that underpins family-centered pain care. These findings call for stakeholders to partner with patient-family advisors to develop portal functionality and protocols that mitigate potential negative consequences before wide-scale implementation of an inpatient portal.

7.4.1 Strengths and Limitations

This was the first study to explore the perspectives of PCGs and youth about the potential role of using a portal to support their engagement in pain care during hospitalization. Rigorous application of QCA ensured insightful and well-developed categories were created, strengthening the quality of results. However, study limitations, pointing to directions for future research, are acknowledged. First, while our sampling strategy ensured that various pain conditions were represented, interviews were undertaken with a convenience sample from one tertiary pediatric setting with more PCG participants than youths. The latter may lead to an over-representation of PCG over youth perspectives, and both voices have equal merit. Detailed description of the research context allows readers to assess the transferability of findings. Second, we excluded non-English speakers, as we did not have the resources for interpreters. All participants were cognitively intact with no communication impairments. Future research is needed to represent the voices of these populations. The interviews were brief. This can be explained by the specific nature of the topic. All youth participants chose to be with their PCGs during the interviews. As this research did not explore a sensitive topic, it was considered unlikely that youth censored their responses in front of their parents. However, it is possible that individual youth interviews may have gained more information about their perspective, and this would be valuable if youth were granted independent portal access. Finally, in keeping with the epistemological foundations of naturalistic inquiry (Lincoln & Guba, 1985), transcripts were not returned to participants to review, nor were participants involved in interpreting

results. This avoided unnecessarily prolonging their research engagement and ensured participants' initial views were captured (Varpio et al., 2017).

7.5 Conclusion

This study's results can assist stakeholders in implementing portal systems in acute care settings. It has successfully delineated considerations for future design, development, and research on portals for pain care in hospitalized children. Inpatient portals are still in their infancy, but our findings from a sample of hospitalized youth and PCGs highlight recommendations to inform the design and configuration of portals for pain care and support patient-family-engagement. A well-designed portal has the potential to deeply engage and empower children and families in pain care through multidirectional knowledge sharing about pain experiences and treatments, improving upon traditional unidirectional transfer. Portal designs should augment and complement pain care and support caregiver and clinician roles and partnerships without burdening or replacing human interaction implicit in family-centered pain care. Understandably, conclusions leading to recommendations will evolve as portals in pediatric hospitals mature. Further research should build on these findings and measure the impact of portals on pain-related outcomes.

Conflict of interest statement

All authors have completed the author disclosure form and have no conflicts of interest to declare.

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Chapter Conclusion

This published qualitative study presented in this chapter utilised in-person interviews to explore the perspectives of PCGs and youth about their potential to use an inpatient portal during hospitalisation. Findings provide a unique contribution to the literature by providing insight into the hopes and needs of a heterogenous sample of PCGs and hospitalised youth regarding portal designs and functionality to optimise their engagement in pain care during hospitalisation. The critical discussion offered within this manuscript positioned the study within the existing literature. It demonstrated how this work contributed novel insights into the potential of a patient portal for pain care and provided a resource for stakeholders making decisions about implementing a patient portal system in acute settings and those providing pain care to hospitalised paediatric patients.

Supplementary materials are provided in Appendix V – Appendix Z.

Chapter Eight

8

Study Three Methods

This chapter describes the research methods used for the third study, a cross-sectional online national Australian survey of clinicians. Survey development and distribution are described, and data analysis and management, and ethical considerations are presented. Study methods are supplemented by details in the peer-review publication reporting findings, offered in Chapter 9.

8.1 Study Three Objective

This descriptive, cross-sectional survey addressed the final objective, which examined how paediatric clinicians use EMR systems in pain care for children hospitalised in an Australian tertiary paediatric hospital.

8.2 Study Three Data Collection

8.2.1 Instrument Development and Pre-testing

A novel online survey tool was created, as no appropriate tool existed in the literature. Survey content was informed by current literature and published guidelines regarding evidenced-informed pain care practices. The multi-stakeholder committee comprising clinician-researchers, pain experts, and informaticians also informed the survey development.

The anonymous survey was designed and hosted on an online survey software program (Qualtrics TM; Qualtrics, Provo, UT, USA) and piloted before distribution to a convenience sample of four clinician experts for feasibility, acceptability, readability, validity, and technical quality. The experts were asked to provide feedback on the appropriateness and relevance of survey items. They recommended some modifications to the wording of response options to enhance clarity and comprehension. Survey feasibility and acceptability were established, with the experts reporting it took 10-15 minutes to complete the survey. No technical difficulties were reported during the pilot test.

8.2.2 Final Instrument

The informed consent page included study information (purpose, length of time of the survey, data management, investigator details) and a checkbox to agree/refuse to participate. This was followed by the 14-item survey comprising three domains: (a) current pain assessment and treatment practices using EMRs, (c) perceptions about how EMRs influenced family-centred pain care, and (c) participant demographic characteristics. Respondents' perceptions about EMR use in pain care were captured using multiple choice and fixed questions formatted as either 5-item (always/often/sometimes/rarely/never) or 7-item Likert scales (i.e., strongly agree, agree, somewhat agree, neither agree nor disagree, disagree, somewhat disagree, strongly disagree and extremely useful, moderately useful, slightly useful, neither useful/useless, slightly useless, moderately useless, and extremely useless). Adaptive questioning, where items were conditionally displayed based

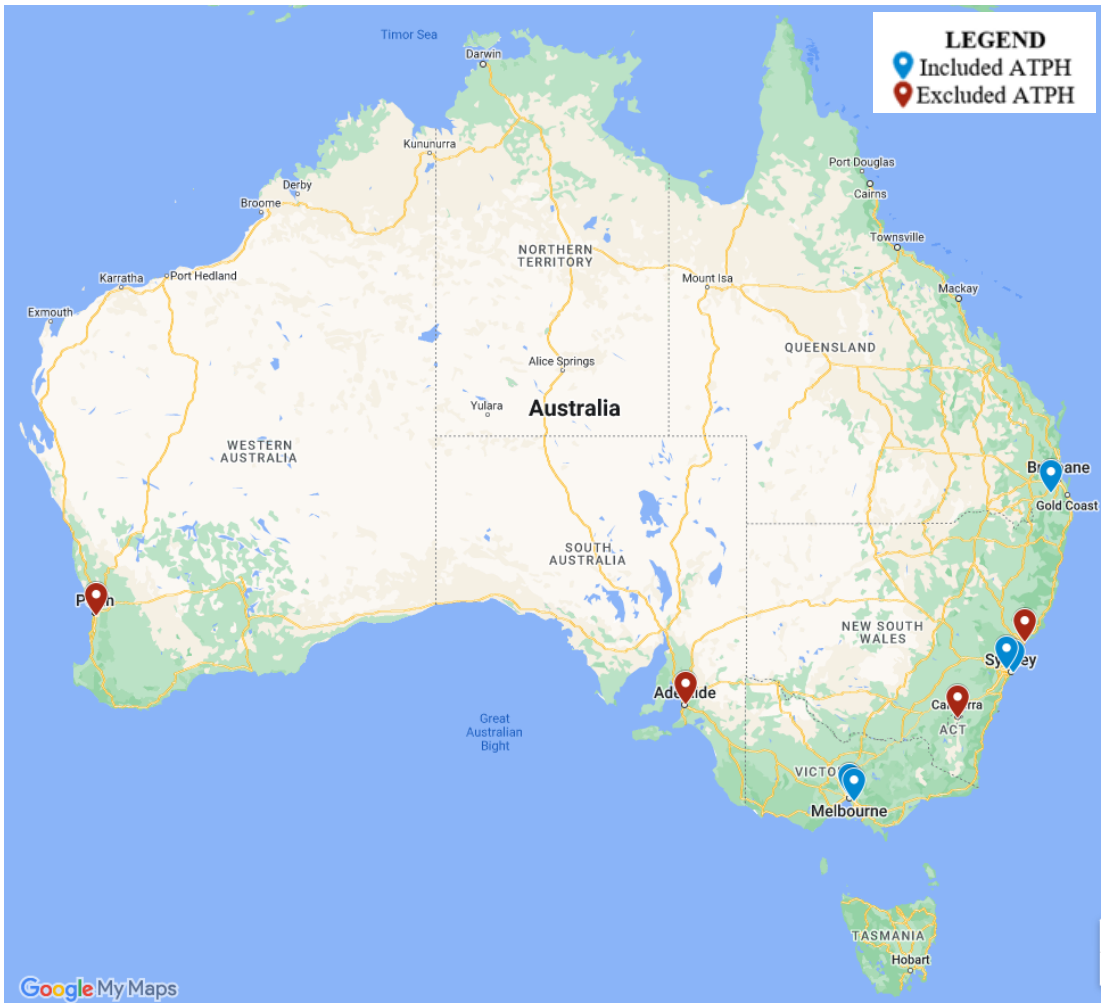
on responses to other questions, was used to reduce the number and complexity of the questions. Open-ended questions allowed respondents to elaborate on their responses and suggest any changes to the EMR that might improve pain care. No survey items were enforced as mandatory. Respondents could review and change entries before submission using a back button. They could exit the survey anytime, and responses to each item were automatically saved. No identifiable information was collected. The full survey is provided in Appendix BB.

8.3 Study Three Setting, Sampling and Participants

A purposive sample of English-speaking registered nurses and medical doctors (aggregated as 'clinicians') working in various clinical areas at one of the five Australian tertiary paediatric hospitals with a comprehensive EMR were targeted. A comprehensive EMR was defined as a system comprising the essential functions to support pain care: electronic documentation of vital signs, pain assessment and documentation of pain care-related interventions, and order entry for actionable items. Five of the nine tertiary paediatric hospitals in Australia have this level of EMR. They are in major Australian cities in the eastern states (Figure 8.1). Two hospitals were in Victoria, two in New South Wales (NSW), and one in Queensland. As of August 2022, these three States comprised a total population of 20.1 million, representing 78% of Australia's population. (Australian Bureau of Statistics, 2021). The Victorian hospitals were RCH and The Monash Children's Hospital, Melbourne (MCH). The NSW hospitals were Sydney Children's Hospital and The Children's Hospital at Westmead (CHW). The Queensland Children's Hospital (QCH) was the only tertiary paediatric hospital in Queensland. One of the hospitals had been using its EMR for six years, and the remaining hospitals introduced their EMR less than five years before the study. Eligible participants were (1) registered clinicians, (2) full-time, part-time, or casually employed, (3) working in acute care areas at one of the study sites (4) primarily involved in direct patient care. Most respondents were anticipated to be nurses, as nurses constitute the largest group of hospital clinicians (Australian Institute of Health and Welfare, 2021). An estimated total of 750 eligible clinicians were available to participate. With an expected modest response rate of 20 – 30%, typical for online surveys (Eysenbach, 2004), a respondent sample size of 150-225 was anticipated.

Figure 8.1

Map of Australia representing Australian Tertiary Paediatric Hospitals (ATPH)



NOTE: Created using Google MyMaps.
https://www.google.com/maps/d/edit?mid=1oZsgIYibOAjX6xXDrLHMju6bFnPBqSYA&usp=sharing

8.4 Study Three Survey Administration

The researcher liaised with clinical heads of departments (HoD) representing nursing and medical clinicians in the participating hospitals to discuss the study aims, significance, and recruitment and answer questions. All HoD gave their permission to proceed with the study. The survey was emailed to clinicians by representatives of HoD at the five identified hospitals. The email included a weblink to the online survey, which comprised the study information sheet (Appendix BB), electronic consent (Appendix CC), and the questionnaire. This non-probability, purposive sampling provided the opportunity to target clinicians who provide direct clinical care and have knowledge and experience using EMRs. Targeting all clinicians working in various clinical areas within each hospital was necessary to build a heterogeneous sample. While a random sample is ideal, it was not

feasible in this study. The survey was launched in October 2022 and remained open for ten weeks. Reminder emails were sent three and six weeks after the initial launch to increase response rates. The survey was also advertised via online bulletins and posters displayed in staff tea rooms at each participating hospital, and snowball sampling was used whereby respondents were encouraged to share the study with their networks via email. No incentives were offered.

8.5 Study Three Data Analysis

Data analysis was led by NP with statistical consultant guidance. The survey response rate was calculated as the number of participants completing the electronic consent and commencing the survey divided by the estimated potential respondents (n=~750) who comprised the total sample group. Some respondents did not answer every question. It is unknown whether the respondents overlooked the items, did not have the time or capacity to complete all items, or perceived some items as irrelevant to them. We acknowledge the challenges of the COVID-19 pandemic, leading to survey fatigue and potentially reduced response rates (de Koning et al., 2021). As this was a descriptive study, with no comparisons or relationships examination planned, responses to all items were included and individually reported, including from incomplete questionnaires.

8.5.1 Quantitative analysis

Quantitative data were automatically captured within Qualtrics and exported to the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) for Windows (Version 22, 2013) for analysis. Distribution and frequencies of characteristics for respondent samples and the Likert scale responses were calculated and tabulated or displayed graphically using bar charts. Due to very few responses in strongly and somewhat categories, the response for the 7-Likert scales for rating agreement or usefulness were consolidated into three categories: (1) ‘agreed’ (combining strongly agree, agree, and somewhat agree) or ‘useful’ (combining extremely useful, moderately useful, and slightly useful) (2) ‘neutral’ (neither agree nor disagree or neither useful/useless) and (3) disagree (combining the remaining categories).

8.5.2 Qualitative analysis

Very few respondents provided open-ended responses to elaborate on survey item responses. Therefore, content analysis of text responses was not undertaken. All text responses are integrated in the results as illustrative quotes.

8.6 Ethical Considerations

Human Research Committee Ethics (HREC) approval was obtained through the University of Melbourne (Ref. 2022-23409-30913-3). Ethics approval documents are included in Appendix DD. This study was conducted following the University of Melbourne HREC guidelines and the Declaration of Helsinki (International Association for the Study of Pain (IASP), 2015).

8.6.1 Consent and Data Management

The consent form was embedded within the online survey, following the instructions and the study information sheet. Respondents could download a copy of the consent form and study information sheet via an embedded link. The consent form outlined:

1. The possible effects of participation.
2. The voluntary nature of participation and that participants could freely withdraw from the survey at any time without explanation, with the assurance that any unprocessed data would be withdrawn.
3. Data would be stored at the University of Melbourne for five years and subsequently destroyed.
4. Confidentiality of provided information was safeguarded subject to legal requirements and only accessible to named researchers.
5. Responding to the survey implied their consent to participate in the study.

Data were managed following University of Melbourne procedures and the Australian Code for the responsible conduct of research (National Health and Medical Research Council- Australian Research Council, 2018). All anonymous survey data collected were automatically entered into a password protected Qualtrics database securely hosted at the University of Melbourne. Exported SPSS data were securely stored in password-protected files in network file servers, backed up nightly, and only accessible to the research team. The data was backed up on a password-protected external hard drive stored in a locked cabinet in a secure storage facility at the University of Melbourne, only accessible to the researcher and associated investigators. These data will be safely and confidentially destroyed five years after the last publication.

Chapter Conclusion

This chapter outlined the quantitative methods used for the final study of this mixed methods project. The sampling strategy, target respondents, and setting were described. Development and administration of the cross-sectional survey was outlined, data analysis was discussed, and ethical issues were addressed. The detail presented here is supplemented in the published manuscript reporting findings, which is presented in the following chapter.

Chapter Nine

9

Study Three Findings

This chapter presents the results of the final study of this thesis, addressing the third objective to examine how paediatric clinicians use EMR systems in pain care for children hospitalised in an Australian tertiary paediatric hospital.

PUBLICATION 3 – USING ELECTRONIC MEDICAL RECORDS TO CARE FOR HOSPITALISED CHILDREN IN PAIN: AUSTRALIAN NATIONAL SURVEY OF CLINICIANS.

Manuscript Details

This chapter contains the manuscript reporting results submitted to an international peer-reviewed journal, *The Journal of Child Health Care*. All authors read and approved the final manuscript. All authors read and approved the submitted manuscript. Reference formatting is modified to align with the thesis style, and references are provided in the thesis reference list. Supplementary materials are provided in Appendix AA – Appendix DD. No changes were made to the manuscript content. The bibliographic details for the following manuscript accepted in *The Journal of Child Health Care* are:

Pope N, Keyser J, Crellin D, Palmer G, South M, Harrison D. (2023). Using Electronic Medical Records to Care for Hospitalised Children in Pain: Australian National Survey of Clinicians. *Journal of Child Health Care* [Under-Review]
Impact Factor: 2.3

Author Contribution: My contribution included all aspects of the study: I engaged and led coordination at five participating tertiary paediatric hospitals. I was also responsible for submission to the Human Research and Ethics Committee, Governance, and submission of annual reports. I engaged with expert statistical consultation for data analysis. I was the first and corresponding author and drafted and prepared the manuscript for publication and led manuscript revisions, including response to reviewers and final manuscript approval for submission.

Abstract

Pain in hospitalised children is common, yet inadequately treated. Electronic medical records (EMR) can improve care quality and outcomes during hospitalisation. Little is known about how clinicians use EMRs in the daily care of children with pain. This national cross-sectional survey examined perceptions of clinician EMR users about current and potential use of EMRs in children's pain care. Of the 194 clinicians who responded, the majority (74%) were nurses; most used EPIC (49%) or Cerner (38%). Most (74%) agreed the EMR supported them in initiating pharmacological pain interventions. Fewer agreed that the EMR supported initiation of physical (43%) or psychological interventions (37%). Forty-four percent reported their EMR had prompts reminding them about pain care, and 78% perceived prompts as useful. Most agreed the EMR supported pain care provision (85%) and documentation (89%). Only 39% agreed the EMR improved their pain treatment, and 31% agreed EMR improved how they involve children and families in pain care. Findings highlight important recommendations for EMR designs that support clinicians' understanding of the multidimensionality of children's pain and drive comprehensive pain assessment and treatments. This contribution will inform future translational research on harnessing technology to support children and families as partners engaged in pain care.

9.1 Introduction

Most hospitalised children, especially the youngest and sickest, commonly experience pain that is often severe and inadequately treated (Cruz et al., 2016; Plummer et al., 2021; Senger et al., 2021). Yet, their access to effective pain care is considered a fundamental human right (Olmstead et al., 2010). Painful procedures, such as injections, and medical and surgical conditions, such as abdominal pain and trauma, are common. Although paediatric pain care has dramatically improved in the last 30 years (Eccleston et al., 2021), pain remains a persistent problem for hospitalised children. A systematic review of 18 epidemiological studies representing 13 countries reported that critically unwell neonates undergo up to 17 painful procedures per day, most performed without analgesia (Cruz et al., 2016). Hospitalised children with severe and chronic medical conditions also suffer inadequately treated disease-related pain and pain from invasive procedures (Fortier et al., 2020; Plummer et al., 2021).

The undertreatment of children's pain is deeply disturbing, given that it increases the risk of short and lifelong health-related consequences impacting children, their families, and communities. Undertreated pain is linked to delayed recovery from illness and surgery (Williams et al., 2015), prolonged hospitalisation, and increased complications, such as infections (Rosenbloom et al., 2021). Repeated pain exposure in premature infants is associated with long-term trajectories of poor cognition, poor motor function, and hyperalgesia (Valeri et al., 2016; Williams & Lascelles, 2020), subsequent needle phobias, and avoidance of medical care (McMurtry et al., 2015; McMurtry et al., 2016).

Evidence-informed clinical practice guidelines outlining multimodal strategies to treat hospitalised children's pain have been developed, disseminated (Friedrichsdorf & Goubert, 2020; Health Standards Organization, 2023), and widely promoted in various knowledge translation initiatives (Chambers et al., 2020; Stevens et al., 2014; Stocki et al., 2018). Despite the long-standing guidance on effective pain management and commitment to their promotion, there is little evidence of sustained practice change and/or improved outcomes (Eccleston et al., 2021). Although calls for universal adoption of evidence-based pain interventions should be repeated, further actions are needed to address barriers to their sustained implementation.

The use of digital technology to support high-quality care, safe practices, and improved outcomes is an emerging area in healthcare. Digital solutions have already influenced children's pain in ambulatory settings. For example, in Canada, the *iCanCope*

with Pain platform supports youth to self-manage persistent pain conditions (Birnie et al., 2019). In Australia, the pain*HEALTH* website provides a digital resource supporting young people with musculoskeletal pain (Slater et al., 2020).

In paediatric hospitals, a growing evidence base demonstrates that electronic medical records (EMRs) and patient portals (electronic personal health record applications linked to EMRs) can improve adherence to best-practice guidelines (Horton et al., 2020), child and family engagement (Bush et al., 2016) and outcomes during hospitalisation (South et al., 2022). Paediatric pain experts (Pope et al., 2023), children, and families (Kelly et al., 2019; Kelly & Hoonakker, et al., 2019) have also previously advocated for hospital-based digital technologies co-designed with these stakeholders and tailored to their needs and clinical context to optimise pain care. But not much is known about how clinicians use EMRs in the daily care of children with pain. Building on prior studies in our research program, this national survey study measured perceptions of clinician EMR users in Australian tertiary paediatric hospitals to understand the current and potential use of EMRs in children's pain care.

9.2 Methods

This online, descriptive, cross-sectional survey study was approved by the University of Melbourne Ethics Committee (ID: 2022-23409-33735-4). Reporting follows the Checklist for Reporting Results of Internet E-Surveys (Eysenbach, 2004). English-speaking registered nurses and medical doctors (aggregated as 'clinicians') working in various clinical areas at one of the five Australian tertiary paediatric hospitals with a comprehensive EMR were targeted. A comprehensive EMR was defined as a system comprising the essential functions to support pain care; electronic documentation of vital signs, pain assessment and documentation of pain care-related interventions, and order entry for actionable items. Five of the nine Australian tertiary paediatric hospitals have this level of EMR. They are in major Australian cities in the eastern states. One of the six hospitals had used its EMR for six years, and the remaining hospitals introduced their EMR less than five years before the study.

The anonymous survey was designed and hosted on Qualtrics ™ (Qualtrics, Provo, UT, USA) and piloted by clinician experts. In brief, the 14-item survey comprised questions about pain assessment and treatments using EMRs, perceptions about how EMRs influenced pain care, and respondent demographic characteristics. Survey items were multiple choice and fixed questions formatted as 5- or 7-item Likert scales. Open-

ended questions allowed respondents to elaborate on their responses. No survey items were mandatory. Respondents could modify entries before submission and exit the survey anytime. Representative heads of clinical departments at the five hospitals emailed the survey to clinicians. The email included a weblink to the survey, comprising study information, electronic consent, and the questionnaire. The survey was open from October to December 2022. No incentives were offered.

Response rate was calculated as the number of participants completing consent and commencing the survey divided by the estimated potential respondents (n=~750) who comprised the total sample group. We used descriptive statistics and Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA) for Windows (Version 22, 2013) for analysis. Due to very few responses in strongly and somewhat categories, 7-Likert scale responses were consolidated into three categories: (1) 'agreed' (combining strongly agree, agree, and somewhat agree) or 'useful' (combining extremely useful, moderately useful, and slightly useful) (2) 'neutral' (neither agree nor disagree or neither useful/useless) and (3) disagree (combining the remaining categories). All survey item responses were included and individually reported, including partially completed questionnaires.

9.3 Results

9.3.1 Respondent characteristics

A total of 194 clinicians working in one of the five hospitals with comprehensive EMRs consented to participate (response rate ~26%). Very few respondents (n=6, 3.1%) provided open-ended text responses; these data are integrated as illustrative quotes in results reporting. Table 9.1 reports respondent characteristics. Most (74%) were nurses, and over half (58%) were from the two Melbourne centres. They were mostly experienced clinicians, with 69 (63%) having more than ten years of clinical experience and half overall having more than ten years of experience in paediatric healthcare. Most respondents had experience using EPIC[4] or Cerner[5] systems (see Table 3.1).

[4] https://www.epic.com/software

[5] https://www.cerner.com/solutions/health-systems

Table 9.1

Respondent characteristics of clinicians working at five Australian tertiary paediatric centers with comprehensive EMRs

Characteristic	Value n (%)
Profession, n (%)	**n=109**
Nursing	81 (74%)
Registered Nurse	75 (69%)
Nurse Practitioner	4 (4%)
Clinical Nurse Consultant/Educator	2 (2%)
Medical doctor	21 (19%)
Paediatrician	13 (12%)
Anaesthesiologist	4 (4%)
Neonatologist	2 (2%)
Registrar (trainee in residency program)	2 (2%)
Other (did not specify)	7 (6%)
City location of the tertiary paediatric hospital, n (%)	**n=110**
Melbourne (Royal Children's Hospital; Monash Children's Hospital)	64 (58%)
Brisbane (Queensland Children's Hospital)	32 (29%)
Sydney (Sydney Children's Hospitals: Westmead and Randwick)	14 (13%)
Years of experience as a registered health professional, n (%)	**n=110**
More than 20 years	28 (26%)
11 to 20 years	41 (37%)
5 to 10 years	22 (20%)
Less than 5 years	19 (17%)
Years of experience in paediatric health care, n (%)	**n=110**
More than 20 years	24 (22 %)
11 to 20 years	33 (30%)
5 to 10 years	28 (26%)
Less than 5 years	25 (23%)
MetaVision	4 (4%)
Reported use of EMR Type, n (%)	**n=109**
EPIC	53 (49%)
Cerner	42 (38%)
MetaVision	4 (4%)
Other	10 (9%)

9.3.2 EMRs in pain assessment

Respondents reported 14 pain assessment tools integrated into their EMRs (Table 9.2). The most common were the Face, Legs, Activity, Cry, Consolability scale, Numerical Rating Scale, and the Wong Faces Pain Scale–Revised. As seen in Figure 9.1, most respondents; i) (84%; n=101/119) agreed the EMR pain assessment tools were easy to access; ii) agreed (65% n=71/109) EMR pain assessment tools improved how often they undertook pain assessment compared to when they did not use an EMR and iii) used the pain assessment fields to record pain scores (66%; n=86/129), while one-quarter (25%; n=32/129) still recorded pain scores in free-text fields.

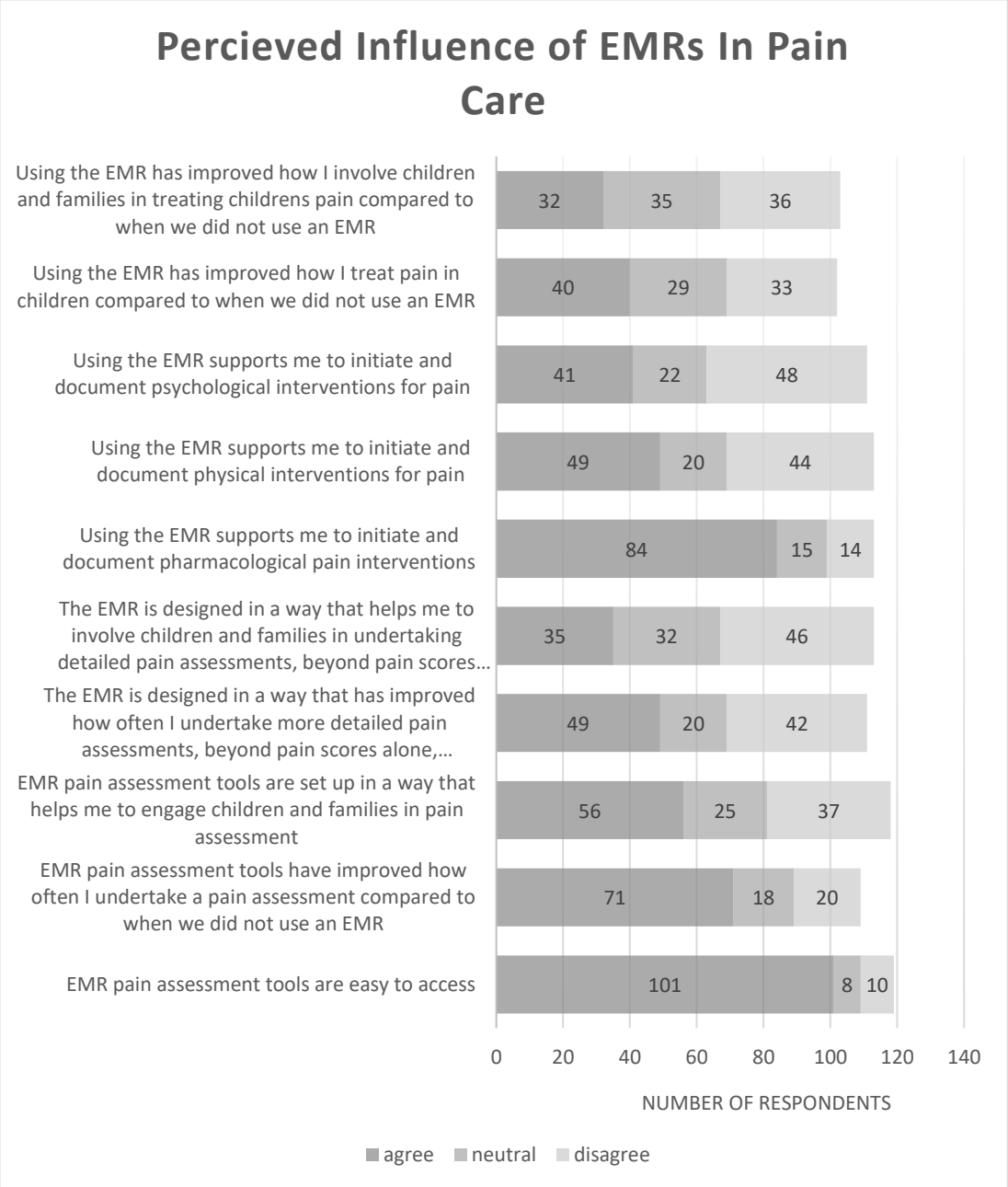
Table 9.2

Paediatric pain assessment scales used in comprehensive EMRs at five Australian tertiary paediatric centers (n=194)

Pain scale	Frequency n (%)
Face Leg Activity Cry Consolability Scale	90 (69.8)
Numerical Rating Scale	75 (58.1)
Wong-Baker Faces Pain Rating Scale	66 (51.2)
Modified Pain Assessment Tool	32 (24.8)
Neonatal Pain Assessment Tool	21 (16.3)
Faces Pain Scale- Revised	20 (15.5)
Functional Activity Score	20 (15.5)
Comfort B	18 (14)
Visual Analog Scale	10 (7.8)
Premature Infant Pain Profile	8 (6.2)
Neonatal Pain, Agitation, Sedation Scale	8 (6.2)
Face Legs Activity Cry Consolability- Revised Scale	8 (6.2)
Comfort Analog Scale	2 (1.6)
Premature Infant Pain Profile Revised	1 (0.8)

Figure 9.1

Distribution of ratings of perceived agreement with influence of EMR on components of pain care practice from clinicians using EMRs (n=103-119)



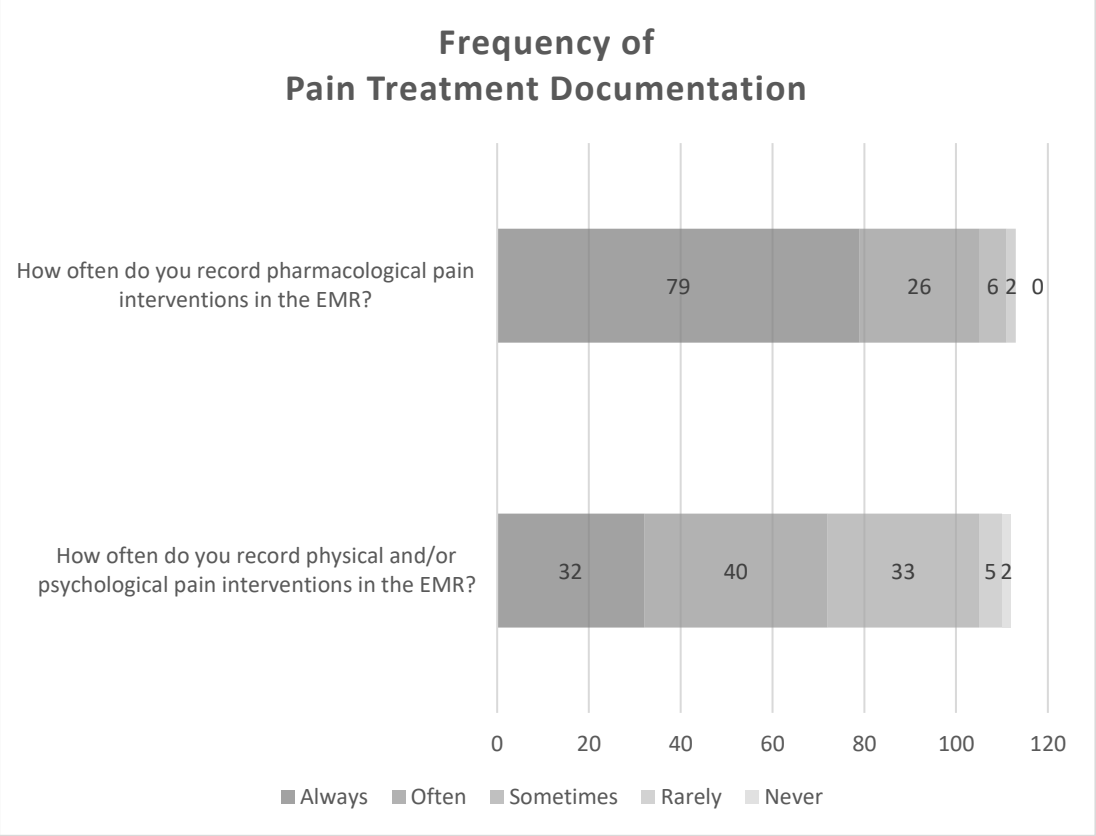
9.3.3 EMRs in pain treatment

9.3.3.1 Pharmacological treatments

Most (74%; n=84/113) agreed the EMR supported them in initiating and documenting pharmacological pain interventions (i.e., medications including sucrose) (Figure 9.1). Regarding documentation frequency, most (70%; n=79/113) reported always recording pharmacological interventions in the EMR (Figure 9.2). The majority (85%: n=96/113) recorded these in the electronic medication administration record (eMAR); most (73.5%: n=83/113) also recorded pharmacological interventions in their nursing or medical electronic progress notes (i.e., they duplicate recorded).

Figure 9.2

Distribution of ratings of frequency of pain treatment documentation from clinicians using EMRs (n=112-113)



9.3.3.2 Physical and psychological treatments

Less than half (43%; n=49/113) agreed that the EMR supported them in initiating and documenting **physical** interventions for pain (i.e., comfort positioning, breastfeeding, skin-to-skin, heat/ice packs, etc.) (Figure 9.1). Fewer (37%; n=41/111) agreed that the EMR supported them to initiate and document **psychological** interventions (i.e., distractions such as games, music, iPad, TV, reading). Regardless, the majority (79%: n=89/113) of respondents stated they still usually recorded physical interventions, and many recorded psychological interventions (67%; n=76/113) and interdisciplinary referrals (i.e., occupational therapist, music therapist, life specialist, pain team) (65%; n=73/113). The majority of respondents recorded non-medication interventions in progress notes (81%; n=91/113), almost a third (28%; 32/113) reported using the pain assessment fields, and fewer (18%; n=20/113) recorded this in vital signs fields. However, only 29% (n=32/112) reported they always recorded these interventions in the EMR (Figure 9.2).

9.3.4 Prompts

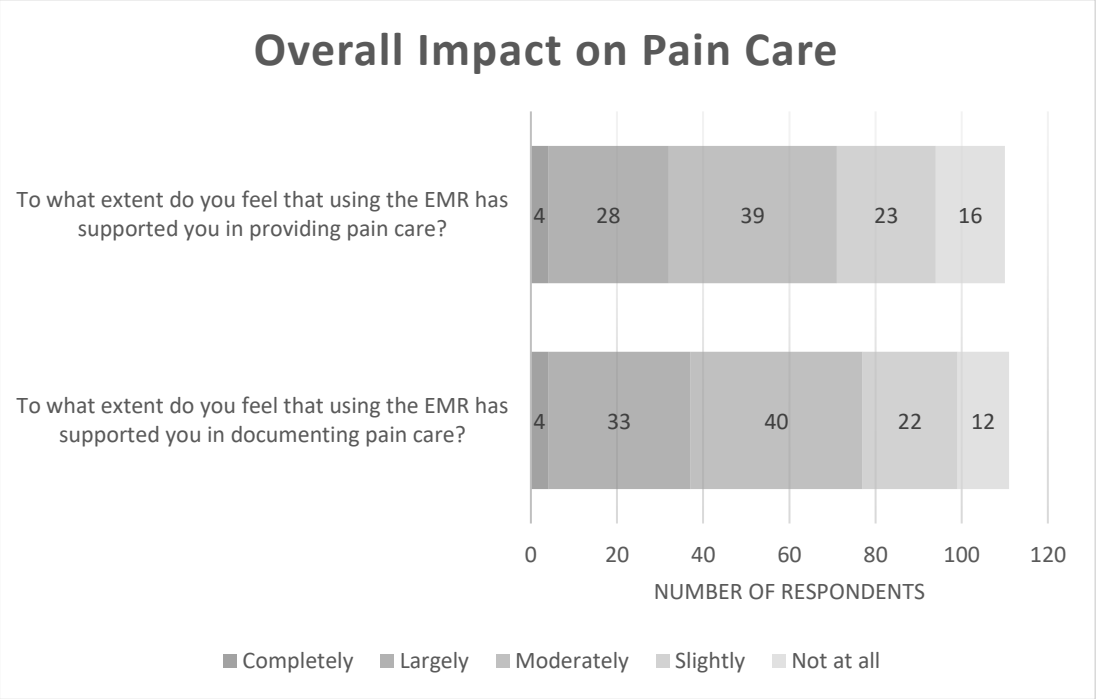
Less than half of respondents (44%: n=51/116) reported that their EMR had prompts or alerts to remind them to undertake a pain assessment or initiate medications. Only 8% (n=9/112) reported prompts for other pain interventions (physical and/or psychological). Of the 51 respondents whose EMR had capacity for prompts (78%; n=40/51), most agreed these were useful, although some suggested that active prompts were unnecessary, *'I just assess the pain regardless of if I'm prompted or not,'.* Task lists and checklists were prompts in themselves that '*improved the visibility of required actions.'* Some also suggested the need to balance prompts to prevent *'prompt/click fatigue.'*

9.3.5 Overall influence and suggestions for EMRs in pain care

The majority agreed that using the EMR supported them in pain care provision (85%; n=94/110) and documentation (89%; n=99/111) (Figure 9.3), yet fewer respondents (39%; n=40/102) agreed that the EMR improved how they treat children's pain compared to when they did not use an EMR (Figure 9.1). Even fewer (31%; 32/103) agreed that the EMR improved how they involve children and families in treating children's pain compared to when they did not use an EMR. There were suggestions about the potential for patient-facing portable devices and *'client/patient portal views'* to *'empower'* and '*give ownership'* to patients and families.

Figure 9.3

Distribution of perceived impact of EMR on pain care and documentation by clinicians using EMRs (n=110-111)



9.4 Discussion

Prior research describing clinicians' perceptions about current and potential use of EMR in hospitalised children's pain care is scarce. Thus, this survey uniquely contributes with its findings reflecting pertinent perspectives on using EMRs in paediatric pain care reported by a diverse sample of experienced nurses and medical clinicians. With the clinicians' years of experience, they were likely, before the EMR, to have used paper-based systems for children's pain care. A key finding from this work is that clinicians perceived that the EMR had little overall influence on the pain care they provided to hospitalised children compared to when they used paper-based systems. This aligns with other studies describing clinician skepticism regarding the effect of EMRs on their provision of care in adult settings (Crowley et al., 2019; Emani et al., 2017) and might reflect an expectation and experience gap between the benefits of an EMR to address workflow and clinical issues and clinician interactions with these systems.

Multiple standard-setting organisations require pain assessment documentation as a key quality indicator (Health Standards Organization, 2023; Schechter et al., 2009). Yet, issues with standardization and completeness of pain documentation are commonly

reported in paediatric hospitals worldwide across various clinical contexts using paper and electronic systems (Andersen et al., 2021; Senger et al., 2021; Vejzovic et al., 2020). Clinicians in this study reported that the EMR provided efficient access to various pain assessment tools that supported consistent pain assessments and contributed to an increase in the frequency of undertaking pain assessment compared to before EMR use. This finding aligns with previous studies in adult hospitals reporting improved frequency of pain assessment documentation among clinicians following the EMR introduction (Gilbertson-White & Shapiro, 2007; Samuels, 2012).

Pain intensity, identified using pain assessment tools, is only one facet of a child's pain experience and one aspect of the comprehensive pain assessment (Raja et al., 2020). Commensurate with the Lancet Commission's priority for increasing the visibility of paediatric pain (Eccleston et al., 2021), paediatric pain experts, children, and families have campaigned for EMR and patient portal designs that drive users beyond reporting quantitative pain measures toward capturing broader socio-psychobiological dimensions of pain (Pope et al., 2023). Yet a critical finding in this study was that EMR designs do not currently support clinicians to think, inquire about, or record broader dimensions of acute pain. Relying only on quantitative measures (i.e., pain scores) forsakes understanding pain's functional, social, and cognitive consequences and contributes to undermanaged pain (Raja et al., 2020) and unsatisfactory hospital experiences for children. To make pain visible, we must harness the potential of EMRs and patient-facing technologies to capture both clinician and patient-generated data on holistic pain experiences. Bringing such pain data to the point of care will offer deeper insights into the complexity of pain, its multifactorial consequences, and the necessity for multimodal interventions.

Electronic medical record-based medication interventions can facilitate safe and reproducible prescribing, mitigate variability, and improve prescription quality. For example, a post-tonsillectomy EMR order set that presented four medications (acetaminophen [paracetamol], ibuprofen, oxycodone, and dexamethasone) on postoperative recovery room discharge resulted in standardised and improved pain control regimens and consistency in opioid prescription for children (Horton et al., 2020). Findings from the present study indicate clinicians report that EMRs supported them in the safe administration and management of medications for pain. Still, clinicians reported EMRs had little influence in steering them toward non-medication interventions while reporting they routinely initiate non-medication interventions without documenting them. Our survey questions did not explore why clinicians did not document these interventions.

However, the lack of documentation could be partly explained by emerging evidence demonstrating that clinicians are overwhelmed with documentation and alert fatigue with the introduction of EMRs (Van Dort et al., 2021), which have been reported to negatively impact paediatric pain care practices and clinician well-being (Pope et al., 2023). Then again, our study findings also demonstrate that clinicians spend time double documenting, such as recording pharmacological interventions in free-text progress notes as well as the eMAR. These findings resonate with an adult US hospital EMR audit of 1500 records revealing duplicate documentation of similar pain care information in two or more places in the EMR in nearly one-third of records (Samuels & Kritter, 2011). Duplicate documentation entries in EMRs between clinician groups across other aspects of inpatient care have also been reported (Laitinen et al., 2014; Törnqvist et al., 2016). Although different sources of pain information may support care continuity, it can also contribute to wasted time and work overload (Gesner et al., 2019). Electronic medical record designs that make it possible to work in integrated ways and with a focus on interdisciplinary pain care are needed to address EMR-associated work overload and information redundancy. Future work could explore the effects of voice recognition and transcription systems on pain care documentation and documentation fatigue.

Research and policy call for the systematic inclusion of children and families as partners in hospitalisations to improve pain-related outcomes (Gatchel et al., 2018; Pope et al., 2023; Vasey et al., 2019). Active engagement and shared-decision making throughout the continuum of pain care has been associated with improved communication between the child and family and clinician interdisciplinary teams and improved pain care quality and outcomes (Rao-Gupta et al., 2018; Vasey et al., 2019). Furthermore, when included as partners in care decisions, children and families report feeling more informed, in control and satisfied with pain care, and hopeful about their recovery (Williams et al., 2019). Despite the supporting research and policy, a striking finding in this study was that clinicians perceived EMR designs and interfaces did not sufficiently support family and child active engagement in their pain care. Yet pain clinicians acknowledge the power of having children and families as equal team members fully engaged in person-centred pain care (Ismail et al., 2019; Pope et al., 2023). User-cantered approaches that uncover and prioritise addressing barriers and facilitators to child and family inclusion are necessary to guide stakeholder co-design work on novel ways to harness digital technology to facilitate person-and family-centred partnerships in pain care.

Limitations

This was the first survey study to examine the reported use of EMRs in paediatric pain care gathered from a sample of experienced nurses and medical clinicians. Study limitations, which point to directions for future research, are acknowledged. Due to the 26% response rate of potentially eligible clinicians in the five targeted paediatric hospitals, results are at risk of responder bias and not necessarily generalisable to all paediatric nurses and doctors using EMRs in Australia. Further research is needed to represent the perspectives of other clinicians involved in the interdisciplinary management of children's pain. We did not capture information about clinicians' clinical areas, and the use of EMRs may vary across different clinical areas. For example, responses may vary between emergency departments, medical and surgical inpatient units, and neonatal and paediatric intensive care units. In addition, only five ATPHs were eligible for inclusion. Yet, after this survey, the remaining non-included four of nine Australian tertiary paediatric hospitals have since begun implementing comprehensive EMR systems. The perspectives of clinicians working at these sites remain unknown.

There were some partially completed questionnaires; however, these still provided good intelligence for the questions answered. Although this survey allowed us to easily quantify how clinicians rate particular elements of EMR use in pain care, we are unable to understand how or why. Therefore, to better understand the individual experience using EMRs in pain care, we advocate for surveys to be complimented with personal narratives and future observational and ethnographic studies combined with EMR data interrogations to validate the clinicians' reported perceptions. Organisational environmental scanning work is also required to realise clinician-EMR workflow trends, pressures, and issues.

9.5 Conclusion

Hospital EMR systems offer tremendous opportunities to improve pain care quality, outcomes, and patient engagement. This survey identified how clinicians currently report using EMRs in caring for hospitalised children with pain. This leads to important recommendations for EMR designs that support clinicians' understanding of the multidimensionality of children's pain and drive comprehensive pain assessment and treatments. Results are directed towards stakeholders who implement and optimise EMRs in acute settings and those who provide pain care to hospitalised paediatric patients. Findings emphasised the importance of future work focused on harnessing patient-facing digital technologies as tools to support children and families as equal team members fully engaged in person-centred pain care. The real test of these systems is not their popularity but whether they produce valuable outcomes for children, families, and clinicians.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical approval

The study was approved by The University of Melbourne Research Ethics Board (2022-23409-33735-4).

Chapter Conclusion

The quantitative study within this chapter utilised a cross-sectional survey design to examine how paediatric clinicians use EMR systems in pain care for children hospitalised in an Australian tertiary paediatric hospital. Findings provide a unique contribution to the literature by providing insight into key recommendations for EMR designs that support clinicians' understanding of the multidimensionality of children's pain and drive comprehensive pain assessment and treatments. The manuscript presented an integrative discussion that positioned this study within the existing literature and pointed to the need for translational research on harnessing technology to support children and families as partners engaged in pain care.

Supplementary materials are provided in Appendix AA – Appendix DD.

10

Discussion, Future Directions and Conclusion

This thesis was underpinned by three research objectives, each addressed by three independent studies exploring how EMR and patient portal systems may be used to improve hospitalised children's pain care from the perspectives of experts, caregivers, youth, and clinicians. The first study was a qualitative examination of the perspectives of clinical pain experts about EMR designs to facilitate optimal pain care practices. The second was a qualitative study exploring the perspectives of PCGs of hospitalised children and of hospitalised youth about their role in using an inpatient portal to support their engagement in pain care. The final study was an online cross-sectional clinician survey about current EMR use in pain care in Australian tertiary paediatric hospitals. The results of this multiphase project have addressed the study objectives and the aim of this body of work, which was to examine recommendations, practices, and perspectives regarding EMR and patient portal use and designs to facilitate optimal pain care for hospitalised children and families.

Table 10.1 presents the research objectives and directs the reader to the chapters that report the results and provide a comprehensive discussion of the implications of the results of each study. This thesis's underpinning theoretical framework and research paradigm were the QHOM and pragmatic constructivist worldview. These theoretical underpinnings supported a comprehensive exploration of the phenomenon.

Table 10.1

Research objectives and the chapters that report the results and discussion

	Research Objective	Chapter
1	To explore the perspectives of international paediatric clinical pain experts about EMR designs that drive optimal child and family-centred pain care practices in hospitalised settings.	5
2	To examine the perspectives of primary caregivers of hospitalised children (0-18 years) and of hospitalised youth (12-18 years) about their potential use of an inpatient portal to support their engagement in their/their child's pain care.	7
3	To examine how paediatric clinicians use EMRs in hospitalised children's pain care in Australian tertiary paediatric hospitals	9

This final chapter comprises seven sections. First, data integration processes are outlined (Section 10.1). Next, in Section 10.2, this thesis is positioned within the conceptual framework to inform future recommendations and research directions regarding the use and design of EMR and patient portal systems in pain care. In Section 10.3, key findings are summarised, and new contributions to knowledge are presented. Reflexive perspectives from the researcher are presented in Section 10.4, and the strengths and limitations of the research work associated with this Ph.D. are outlined in Section 10.5. An integrative discussion addressing the implications of this project to inform recommendations for future directions is presented in Section 10.6. The chapter concludes with a description of the knowledge mobilisation plan (Section 10.7), and concluding remarks close this thesis.

10.1 Integration

Mixed-methods research data can be integrated at multiple levels across the research continuum. As discussed in Chapter Three of this thesis, in this Ph.D., data integration occurred at two levels (Figure 3.1): the design level (step 1) and the interpretation level (step 3). To address the project aim, both quantitative and qualitative-oriented objectives were formulated (step 1). Data were not integrated at the methods level; each study's data were handled and analysed separately according to their methodological considerations (step 2). Findings from qualitative and quantitative components were drawn together at the project's final stage (step 3) to address the overarching research aim, outline important knowledge contributions, and provide insights into future directions in EMR and patient portals systems in hospitalised children's pain care (Creswell et al., 2011). A table was developed to jointly display findings from all three studies to facilitate this final end-of-project integration (Table 10.2). This process is explained in the following section.

10.1.1 End-of-Project Integration

As data from three studies were generated and examined, trends and divergences in concepts were noted. An examination of the qualitative data from the first two studies showed that international clinical pain experts (Study One) and youth and PCGs from Australia (Study Two) shared similar hopes and concerns regarding hospital-based digital technologies in pain care. This was striking given that data were collected in separate studies, at different time points, and with participants from diverse settings, backgrounds, and experiences with hospital-based technology. Further, the quantitative data analysis (Study Three) showed analogous concepts regarding current and potential EMR pain care practices in Australian paediatric hospitals. Discussions within the published manuscripts incorporated in this thesis provide a comprehensive and critical examination of shared and divergent findings for each of the three studies and position these findings in relation to the existing literature.

In addition to these manuscript-based discussions, in line with step 3 (Figure 3.1), a table (Table 10.2) was constructed as an end-of-project- integration tool to; 1) enable the joint display of findings from all three studies, 2) demonstrate how data sets generated relevant insights to address the overarching aim 3) facilitate an in-depth examination of knowledge contributions and 4) inform future directions in EMR and patient portal systems in hospitalised children's pain care (Creswell et al., 2011). Secondary data analysis was not undertaken.

The table (10.2) contains data from each study. Column 1 contains Study One's final categories and associated participant verbatims. Similarly, Column 2 contains the final categories of Study Two and exemplar participants verbatim. Key findings from the quantitative survey (Study Three) and associated descriptive statistics are presented in Column 3. Column 4 comprised the PI researcher's reflective, interpretive comments, written in a stream-of-conscious manner (Kaplin, 2021), to represent the PI's natural flow of thoughts until they concluded. This table was presented to the supervisory team (DH, DC, MS, GP), comprising doctoral prepared, extensively published clinician researchers in children's pain (DH, DC, GP) and digital health (MS), providing a visual anchor for a consensus discussion about the results of this research project, and the overall implications of findings (Wendler, 2001). The table has been used in this Ph.D. thesis to frame the in-depth discussion addressing the unique knowledge contributions arising from this project and insights into implications and recommendations for clinical practice, policy, and research. These recommendations and future directions are presented in Section 10.6.

Table 10.2

Summary of Key Insights from the three studies

Study One	Study Two	Study Three	Interpretive end-of-project integration
Capturing the pain story *"We replaced things that had never been documented with more kid-friendly options like sleep, mood, behaviour, activity level, and mobility to give a more detailed assessment. We also added parent reports and expanded the patient-stated goals."* (Participant 4, Nurse) *"If I could track it and trend pain, like put it on a graph, to see any difference. Especially because many of* the *kids I see are neurologically impaired, they could get a really bad functional score. However, if that is their baseline, it would not be as helpful as knowing if it differs from their 'usual'."* (Participant 11, Doctor)	**Connecting and sharing knowledge about pain** *"[Seeing treatment plans within a portal] would be brilliant because you are so in the dark. You can't view anything, and [clinicians] come in with information and can go off and look on the system, and you [feel], 'That is my child! I would like to be able to see that information as well.' I have got no visibility. If I could see [pain treatment plans] and if there were changes made, that would help my understanding."* (Participant 8, Mother) *"Being able to write and check your mood with a portal that's important. Because* sometimes, *with pain, your mental health gets affected as well."* (Participant 12, Female youth)	Most clinicians (66%) report that EMRs incorporate pain assessment tools to support them in objective pain assessments. Most (61%) felt the EMR did not drive them to consider and record comprehensive pain assessments (beyond pain score) The majority (74%) of clinicians agreed the EMR supported the use of pharmacological interventions, but few agreed that the EMR supported the use of physical interventions (43%) or psychological interventions (37%)	There has been an emphasis on the ability of EMR and patient portal systems to drive evidence-based practice in timely and contextually appropriate ways. However, findings from these studies have shown that EMRs drive narrowly defined, biomedical-focused paediatric pain care practices, steering clinicians towards pursuing objective pain assessments and pharmacological interventions. Clinicians, patients, and families jointly acknowledge that EMR and portal designs must be optimised to drive biopsychosocial conceptualisations of pain assessment and treatment and foster child-family-clinician partnerships in pain care. User-centred, intuitive, evidence- and theory-informed designs can increase the visibility of pain and highlight pain as a priority.

Study One	Study Two	Study Three	Interpretive end-of-project integration
Working with user-friendly systems *"Any prompts and alerts need to be pertinent and* important*, so you are not getting pinged too often or constantly scrolling through prompts that are not relevant. We spent a lot of time filtering out and discussing prompts and drilling down the key ones that are important from a safety perspective. "* (Participant 14, Nurse)	**User-centred designs** *"As a parent, you get busy trying to entertain the child; you are trying to do your own thing and work with the nurses. So, a little app reminder that popped up would be good. But how frequently? You don't want it to constantly pop up. Like this (intravenous pump) machine drives us nuts because it constantly makes noise, like multiple times a night, it goes off and is like gahh. It is actually quite a lot."* (Participant 9, Father)	Few clinicians (39%) agreed the EMR improved how they treat children's pain compared to when they did not use an EMR. Few clinicians (44%) reported their EMRs had prompts to remind them about pain assessments. Even fewer reported there were prompts for pharmacological interventions (45%) or non-medicine interventions (8%). EMR prompts needed to be balanced to '*improve the visibility of required actions* but prevent *'prompt/click fatigue.'*	Results from these studies highlight that clinical decision support (CDS) tools should drive best practices for high-risk tasks, such as administering and monitoring medications. A shared concept across the studies was that CDS tools, especially prompts, can be overwhelming and stressful for clinicians, families, and children and counterproductive to pain care. These data demonstrate that prompts and care reminders must meet the end-user needs and contexts and safeguard high-risk practices without overwhelming clinicians, patients, and families. They also highlight the need for all end-users to be involved in decisions regarding operationalising prompts, ensuring they have control over their use. There are limited guidelines on the optimal use of these tools in pain care.

Study One	Study Two	Study Three	Interpretive end-of-project integration
Patient and family engagement and shared decision-making *"If that patient had a device, and you can have them use that device not only to report but also to learn strategies to help with the pain, that might be really beneficial."* (Participant 10, Doctor) *"What happens if [parents] enter information that is time critical that should be actioned? What would an appropriate way to enter information like, my pain is getting worse, and I am getting fevers, and it is a sign that they are getting an infection or some sort of complication?"* (Participant 6, Doctor)	**Preserving roles** *"I tend to like to have conversations. I wouldn't want [the portal] to be the only method of communication. In my view that the recording of information helps with efficiencies, helps with data storage, but doesn't take away that personal contact or questioning that I think is critical"* (Participant 3, Father) *"Being in here sometimes is challenging. Whenever my child is in pain, there would be pressure on us as parents. Most of the time, my child requires a lot of attention, and for us to record everything on an app would be challenging. We would attend to his needs most of the time, and then we can only get to do [the portal] whenever we are free, if we remember."* (Participant 10, Mother)	Very few (31%) clinicians agreed the EMR improved how they involve children and families in treating children's pain compared to when they did not use an EMR. Patient-facing portable devices could '*empower' and 'give ownership'* to patients and families in pain care.	These data suggest that EMR systems are currently limited in fully supporting family and patient-centred pain care. However, it is *encouraging*, from a patient-family centred pain care perspective, that clinicians, youth, and families have a shared conception about the importance of EMR and patient portal systems having the capacity to support partnerships in pain care. Devices that capture patient-generated pain data and care preferences in real time are necessary *to* realise the potential of patient-family-centred pain care. EMR systems should support workflows to optimise this process. Sharing detailed pain accounts via patient-facing devices helps to capture 'unseen' pain, helps understand and treat the whole patient and their whole pain experience, is focused on well-being, and fosters integrative pain care options. Patient-enabled devices place children and families *at* the centre of pain care and support their role as experts in the pain experience. This helps empower and engage children and families in pain care. Clinicians, patients, and families share concerns *about* the potential burden and repercussions of patients' and families' use of patient-facing systems. EMR and patient portal implementation must address issues related to the timely escalation of care, the balance of responsibilities, information burden, and workload. These systems must not replace human interaction, which is critical to pain care.

Study One	Study Two	Study Three	Interpretive end-of-project integration
Augmenting pain knowledge and awareness *"Looking at that data has been very good in guiding us to our deficits and where more education is needed."* (Participant 1, Doctor) *"The downside and danger are that you think, 'We can collect A, so why do not we also collect B, and while we are at it, let's collect C.' Instead of focusing on what is really important to make a difference, you start to collect a gazillion things. If you think about the user interface, that will make a huge difference."* (Participant 10, Doctor)	**Connecting and sharing knowledge about pain** ***Transparent information for empowerment*** *"Steering us to valid, authorized information would be better than people running off the Google highway. If I know there are certain signs and symptoms to watch out for and certain side effects. It would be great to know what the drug is, what it does, and the side effects."* *(Participant 4, Father)*		EMR systems are promising repositories for examining pain practices, trends, and patient pain-related outcomes in hospitalised children. These data can be used to monitor practice and inform practice, educational, and research priorities. Intelligent workflows and interfaces can support the capture of pertinent pain data. For patients and families, portals serve as repositories for trusted, evidence-based resources to support their understanding of pain and pain treatments. Portal access to these resources helped to inform and empower patients and families in pain care.

10.2 Pragmatic Research Paradigm and The Quality Health Outcomes Model

The use of EMR and patient portal systems in hospitalised children's pain care is a complex phenomenon in which a dynamic interplay of institutional and individual factors influences their implementation, design, and use. A multifaceted approach, informed by the pragmatist research paradigm, acknowledges that theory and clinical practice co-exist and can address complexities in paediatric pain research (Morgan, 2014). The QHOM, a pragmatic theoretical framework, was selected to underpin this thesis. The QHOM created the framework on which the three interrelated studies were mapped and offered a comprehensive lens that contributed to the aim of this thesis. As discussed in the research design section (Chapter 3), the QHOM has been applied in various contexts and to varying degrees to examine reciprocal interactions between healthcare and client characteristics, interventions, and care outcomes (Mitchell et al., 1998).

The new knowledge generated from this thesis informs future research inquiry guided by the QHOM. Positioning the thesis within the inquiry model allowed broad, synergistic exploration of the interrelated dynamic components. It provided direction for future studies of interrelationships among model components toward improving outcomes for hospitalised children and their families. Although measuring 'outcomes' was beyond the scope of this thesis, results help form the basis of the recommendations for future research focused on care quality and outcomes. These approaches could combine the QHOM with KT methodologies to explore the impacts of co-design EMR and patient portal-based interventions on implementation and patient outcomes.

10.3 Summary of Key Findings

The aim and the associated objectives of the research described in this thesis were addressed by conducting three independent studies. These three individually innovative studies contribute to the literature and, as a combined body of work, provide a comprehensive, multifaceted, and novel exploration of EMR and patient portal systems from the viewpoints of the clinician, youth, and primary caregivers. Results guide current and future pain care for hospitalised children in Australia and internationally.

The findings contributing to new knowledge have been discussed, critically analysed, and synthesised as study-specific findings (Chapters 5, 7, and 9). These findings are summarised as follows;

1. In Chapter Five, the first published manuscript presented recommendations for EMR designs that facilitate broad biopsychosocial pain assessments, multimodal treatments, and customised functionality to safeguard practice without overwhelming clinicians. This manuscript articulated multifaceted components regarding implementing, optimising, and using EMR and patient-facing technologies that can inform future translational research and clinical practice.
2. The second published manuscript (presented in Chapter Seven) offered qualitative insights from primary caregivers and youth outlining recommendations to inform the design and configuration of patient portals that augment person-centred pain care and support, engage, and empower children and families during hospitalisation. The novel work successfully delineated considerations for future design, development, and research on harnessing patient portals to improve pain care and outcomes.
3. In Chapter Nine, the manuscript that is under review post resubmission reported findings from the first national-cross-sectional survey examining perceptions of clinician EMR users about the current and potential use of EMR in children's pain care. Findings highlighted important recommendations for EMR designs that support clinicians' understanding of the multidimensionality of children's pain and drive comprehensive pain care. This novel contribution to the literature articulates future opportunities for translational research on digital technology to support children and families as equal partners fully engaged in pain care.

These findings offer a synergistic, multifaceted overview of recommendations, practices, and diverse perspectives regarding EMR and patient portal use and designs to optimise pain care and outcomes for hospitalised children and their families. Before this PhD research program, no research on EMR and patient portal systems in pain care had been conducted in Australia, and limited research had been undertaken and published internationally. Findings from this Ph.D. thesis are being translated into local clinical practice through strategies targeting multi-stakeholder groups, including interdisciplinary healthcare professional teams, informaticians, and unit and organisational leaders at Australian tertiary paediatric hospitals. The KT strategies aim to (1) generate awareness and interest and share knowledge with primary audiences and (2) inform decision-making and facilitate practice, research, and policy change through manuscript publications,

presentations (conferences, education sessions, webinars), and media (e.g., infographics). Details of KT activities are presented in Section 10.7.

Electronic medical records and patient portal research is a rapidly evolving area. This Ph.D. thesis uniquely contributes to the national and international literature on the design and use of these systems to improve pain care quality and outcomes. These findings delineate valuable recommendations for future investigation, intervention, and evaluation studies in hospital-based clinician and patient-facing technology in pain care. This thesis project has also presented an important basis for future national and international collaborative work to inform research on digital health initiatives to address specific challenges in paediatric acute and chronic pain. I have been invited to join the Australian Pain Society (APS) Pain in Childhood Special Interest Group (PinC SIG) executive committee. My role within the PinC SIG executive committee has been to provide expert advice on projects related to pain in childhood and promote communication and collaboration among multi-stakeholder groups interested in pain in childhood. I am contributing to formally embedding a satellite Pain in Child Health (PICH) within the PinC SIG to bring together the international paediatric pain research community across several collaborative efforts. I have been invited to attend an in-person, two-day meeting in Canada that aims to build a compelling collaborative strategy that engages people from different perspectives in moving the field of paediatric pain research forward to further improve the health and well-being of children in pain, their families, and communities. Most recently, I have been awarded a post-doctoral fellowship and additional funding awards where I will pursue a project to co-design and evaluate parent-orientated digital interventions addressing the needs of families of children with pain.

10.4 Reflexivity

This research's qualitative components (Studies One and Two) were situated within a pragmatic constructivist paradigm and relied on naturalistic methods (i.e., interviewing). The epistemological foundations of this naturalistic inquiry account for the acceptance that research is necessarily and inherently bound to the researchers' values and experiences (Varpio et al., 2017). Researchers are not passive in their work; they bring their own values through the choice of research focus, framing of research questions, and interpretive and analytical work, and hence, they shape the knowledge they create (Bradshaw et al., 2017; Lincoln & Guba, 1985). Throughout the design, data collection, analysis, and results reporting phases, I exercised a conscious analytical

scrutiny of myself as a researcher, allowing me to identify how my position, biases, and beliefs may have influenced the research. Collaborative reflexive discussions at regular supervisory team meetings helped to increase my awareness of subjectivity. Alongside these meetings, I kept a reflexive journal for each qualitative study to create self-awareness about how I constructed meaning and imposed meaning on research processes and how this shaped the consequent research findings. Journalling also helped to bring attention to aspects of the context that may have impacted study activities and ensured the focus remained on the research and its participants.

My professional work as a registered children's nurse in a hospital with an EMR, my nterest in pain and being a mother motivated me to examine the role of hospital-based digital health technologies to optimise children's pain care. In my reflexive journal for each qualitative study, I examined my rationality with the research, reflecting on how my unique perceptions, experiences, interests, and biases shaped the research processes and the data. These reflections are shared in the following sections.

10.4.1 Reflections on Study One

The first study was undertaken online, using video conferencing, and participants were from various countries. The fact that I had no previous relationship with participants helped assure me they did not feel coerced into participating in the study. Given that recruitment was via email, I took comfort in knowing that participants could choose to be involved only if it suited their commitments and interests. In my reflective journal, I noted: *"Although I am confident that study information and recruitment emails are reaching a broad group of paediatric pain clinicians, I am only getting interest from a few clinicians. This is disappointing and will probably prolong recruitment, but on the other hand, it is reassuring as I think it shows clinicians are not feeling pressured to participate."* This indicates how my study design, particularly the recruitment processes, curtailed ethical issues by giving potential participants an easy way to decline the study invitation.

Undertaking online interviews using a video conferencing platform had positive and negative implications. Positively, because I could see the participant and respond to nonverbal cues such as facial expressions and gestures, which was important to facilitate engagement, promote a natural and relaxed conversation, and establish rapport. Online interviews also enabled the global reach of participants and made it possible to engage participants who might have previously been inaccessible. While in-person interviews would have been ideal, they would not have been feasible, given the geographical

distance. Finally, because data collection was undertaken during the COVID-19 pandemic, there was a general acceptance, preference, and familiarity for online meetings. As I noted in my reflective journal, *"I feel so fortunate to have the opportunity to meet leading pain clinicians from so many diverse international settings. It seems the participants have felt comfortable being interviewed online, which probably reflects their interest and confidence in Zoom and that online meetings have become the norm for many people in light of the pandemic."* Negatively, I worried about potential interruptions caused by technical difficulties such as low internet bandwidth or webcam or audio issues and how this might impact interview dialogue. I also worried that some participants might prefer not to have their cameras on during the interviews. I used every opportunity to ensure participants knew their right to have the camera off and revert to phone interviews if preferred. I emphasised their right to withdraw at any time during the interview. The strength of this approach means data collection was effective. All participants chose to have their cameras on, and there were no issues with Zoom software. Ethically, participants had a choice about the extent of their participation.

I reflected on how my position as a children's nurse could potentially complicate my role as a researcher and vice versa. Being a nurse with experience using EMRs in caring for hospitalised children with pain meant that I could bring an emic (insider's) perspective. I shared with participants a mutual experience of caring for children with pain and knowledge about best practices in pain care for hospitalised children. My position as a nurse and researcher had the potential to influence analysis. In my reflective journal, I noted my thoughts, *"My clinical experience and theoretical knowledge about what best pain care for children should look like is helpful as it gives some context and greater insight into the findings. But I need to be conscious that I am only reporting what participants have shared in the results, not my own experiences".* Working through data analysis with an experienced qualitative researcher, being led by an expert supervisory team, and constantly returning directly to the data helped me to overcome this and ensured that the data analysis and collection process were rigorous.

10.4.2 Reflections on Study Two

The second study was undertaken in the hospital where I was employed as a clinical nurse; however, participants were not recruited from the ward where I worked. I took comfort in knowing this would help ensure that patients and families did not feel coerced into the study because I had no previous relationship with them or their children. However, I could not be certain that this was the case. I found it reassuring that some patients and

families chose not to participate, as this reflected that those who participated did so freely. In my reflective journal, I noted: "*Most patients and families seem pretty interested in being involved in this study, but for some [families and patients], the timing just isn't right – which is understandable given that hospitalisation is stressful, and a lot is going on for them. I guess it shows that they don't feel pressured to agree to take part, which is a good thing. This is all part of recruiting for research, especially hospitalised patients".*

Knowing that I was a nurse at the hospital, clinicians working there wanted to help me. They suggested ways to improve recruitment, such as where to place the study advertising materials. I wrote in my journal: "*The clinicians are so generously offering me time in their busy day to hear about my research and to help spread the word about it to their colleagues. It's so nice to know they see this work as important, too."* I also felt that patients and their families were genuinely interested in this study and generously shared their time, personal experiences, and expertise. I wrote: *"I feel as though parents and kids see pain and pain care as an important part of their hospital experience. They seem keen to share both positive and negative experiences of pain. The idea of using technology to better their pain care experiences seems to have drawn a particular interest among many families. I think they might see it as pretty innovative, but I don't think they are surprised that this might be the next step in pain care."* I worked hard to describe my research clearly, generating interest and demonstrating it as worthy work.

In some instances, I felt that my professional credentials made parents and children agree to the interaction and even want to talk with me about their/their child's medical condition. Many of the conversations were about pain treatments. During the initial interviews, I was hesitant to engage in these conversations since I was concerned about separating my role as a researcher from that of a nurse. A reference to reflexivity in the literature eased my concerns. An interactive approach to interviews was essential to establish rapport and encourage participants to share more about their pain experiences and how a patient portal might help support them. I felt that families welcomed me instead of regarding me with scepticism. In my reflective journal, I wrote: "*An unexpected bonus that I hadn't thought of was that they [families and children] seem to feel comfortable sharing information with me about their/their child's condition or about what brought them into hospital. I get the sense that these conversations are helping them [parents and children] feel more comfortable and more freely discussing their perspectives about their potential use of a portal for pain care."* However, I was careful to ensure that I remained within my scope as a researcher during these interviews and did not undertake any clinical

nursing tasks. I called the treating nurse if concerns arose that required clinical attention (i.e., a child feeling nauseous). Maintaining transparency about my dual roles and limitations supported integrity in my research and clinical work.

10.5 Strengths and Limitations

Each study's specific strengths and limitations have been addressed in their respective manuscripts in Chapters Five, Seven, and Nine of this thesis. This section summarises strengths and limitations and addresses specific strengths and limitations related to the body of work.

Strengths

As previously noted, little research has been conducted on hospital-based digital technology in paediatric pain care nationally and internationally. This multiphase study provided a comprehensive examination of the role of EMR and patient portal systems in hospitalised children's pain care not previously explored or reported in this detail. This body of work is relevant and timely given that Australian paediatric hospitals are increasingly implementing EMRs and are demonstrating emerging interest in patient portal systems. This is the first work of its kind to be undertaken in Australia and published internationally. The novel insights into how EMR and patient portal designs can be harnessed to optimise pain care and support patient-family engagement can be widely shared with international settings. The impact of this novel and innovative work lies in the ability of findings to be translated into other paediatric hospital settings.

The mixed methods approach to this research is a major strength that enabled detailed, multidimensional insights into EMR and portal designs and functionality from the perspectives of clinicians, PCGs, and youth, which can improve paediatric pain care and outcomes in hospital settings. The insights gained through the qualitative data in Study One provide strong evidence for optimising EMRs to drive clinicians beyond searching for objective measures of pain and pharmacological interventions toward including psychological, social, and developmentally targeted assessments and treatments. Recommendations for customising EMR interfaces to draw clinicians to pertinent pain data and to safeguard high-risk practices were offered. The online recruitment and data collection approach identified diverse participants from several international settings who worked with different EMR systems, allowing various perspectives to be represented. In Study Two, the qualitative PCG and youth interviews enabled consumers to discuss, in-depth, their pain experiences and expectations of patient portal systems to optimise their

engagement in pain care during hospitalisation. Findings offered a unique contribution to the literature regarding patient portal designs and functionality to deeply engage and empower youth and families in pain care through multidirectional knowledge sharing about pain experiences and treatments. Purposive sampling ensured a diverse sample of participants regarding pain experiences (e.g., postoperative pain, pain due to injury or illness, procedural pain), previous hospitalisation, youth age, and PCG and youth sex. In both Studies One and Two, the rigorous application of qualitative content analysis and adherence to the principles of Information Power in the sample size assessment strengthened the quality of results.

This thesis was further strengthened by the combination of a cross-sectional survey examining clinicians' practices and perspectives using EMRs in the care of hospitalised children with pain. Clinician EMR use in pain care had not been previously explored in Australia. These survey data provided further information on clinical practice and recommendations for EMR designs to optimise pain care for hospitalised children and improve outcomes. The recruited participants were likely to represent the broader population of nurses and doctors using EMRs because the sample was heterogenous, with participants from various sites and with various experiences using EMRs in paediatric hospitals. The results of this survey study delineated important recommendations for EMR designs that support clinicians'understanding of the multidimensionality of children's pain and the use of multimodal pain treatments.

Limitations

Involving parents and youth patient partners in guiding aspects of Study Two was an important step to ensure interview questions were relevant and meaningful to participants. Yet, this degree of engagement may be deemed as low-level, didactic involvement. High-level co-design approaches, such as participatory action research, would have fostered an enhanced partnership and shared leadership between patient partners and the researchers. However, resource and time constraints associated with conducting a Ph.D.-level project limited the feasibility for high-level patient partner engagement in this project. Also, this Ph.D. research was undertaken at the height of the COVID-19 pandemic, which made it extremely challenging to engage with parent and youth partners who were already facing unique and complex challenges in their daily lives.

Study Two was a Victorian-based study undertaken at one tertiary paediatric hospital. The differences in hospitals across Australian states and internationally may limit the wider applicability of results. However, a detailed description of the research context

allowed the reader to assess the transferability of the findings. Due to resource limitations, it was not feasible to include participants who could not speak or understand English. All participants were cognitively intact and had no communication impairments. Therefore, the voices of cognitive and communication-impaired populations are not represented.

In Study Three, only 26% of the estimated potential participants provided survey responses, and those who did respond did not answer every question. Therefore, results are at risk of responder bias and not necessarily generalisable to all paediatric nurses and doctors using EMRs in Australia. Nevertheless, it is important to note that this was the first study to explore clinicians' EMR practices related to hospitalised children's pain care in Australia.

10.6 Recommendations and Future Directions

The results of this Ph.D. research have implications for clinical practice, policy, and research. Although results from the three studies contribute important knowledge and understanding about the practice, design, and use of EMR and patient portal systems in paediatric pain care, the research also identified several important recommendations. These recommendations provide a catalyst, contributing to the optimal use of hospital-based digital technologies and creating opportunities to improve pain care for hospitalised children and their families. There are three key recommendations.

10.6.1 Recommendation 1

> Leverage EMR and patient portal technologies as collaboration tools that increase visibility of the multidimensionality of pain.

The complexity of pain requires a reliable, valid, and comprehensive assessment to plan multimodal management and evaluate the effectiveness of pain treatments. For hospitalised children, optimal pain management is difficult in the absence of a valid multidimensional assessment that captures sensory (intensity, quality, location), affective (emotional), and functional (interference with sleep, mobility, and other daily activities) dimensions of their pain (Health Standards Organization, 2023; Raja et al., 2020). Findings from this program of research demonstrate that clinicians generally placed greater emphasis on sensory dimensions of pain and that EMR designs contributed to this problem. Pain being represented as only a sensory experience is an enduring battle that children living with pain face (Fleegler & Schechter, 2015; Wakefield et al., 2021) and one that KT initiatives and paediatric pain clinicians and researchers strive to address

(Stocki et al., 2018). Leveraging EMR designs to guide clinicians to consider acute pain's psychological and social ramifications and contextual and developmental factors provides an innovative approach to improving how pain is understood and treated and is a crucial step toward addressing the Lancet Commission's goals to increase visibility and holistic understandings of pain (Eccleston et al., 2021).

Recommendations for EMR modifications derived from this work included optimising navigation (i.e., drop-down menus and search functions), designing intuitive and engaging interfaces and dashboards, and tailoring functionality to end-user clinical contexts. Prioritising and preserving prompts and decision support tools to safeguard high-risk practices (i.e., reproducible and quality medication prescription) was another critical recommendation because prompts were perceived to negatively impact clinician and PCG roles and wellness (i.e., overwhelming, stressful, and contribute to burnout) and their ability to care for hospitalised children with pain (i.e., distracting, time-consuming). These findings align with existing reports demonstrating that clinicians are overwhelmed by EMR alert fatigue, which detrimentally affects their well-being and clinical practice. (McGreevey et al., 2020; Van Dort et al., 2021). To protect clinicians from alert fatigue, CPGs for hospital EMRs should include recommendations on how and when to use EMR prompts and the need to systematically review and update alerts to ensure their relevance (Van Dort et al., 2021). Future translational, multistakeholder-driven work should focus on testing the effects of context-specific EMR functionality tailoring to clinician-(clinical practice, acceptability, appropriateness, fidelity) and patient-based outcomes (pain intensity, interference, function, recovery).

This Ph.D. has also demonstrated how patient portals offer new possibilities for assessing and managing hospitalised children's pain. Patients are increasingly accessing health information through portal-based systems, particularly in ambulatory settings (Dendere et al., 2019), and children are very amenable to using smartphone technology across almost all facets of their lives (Australian Communications and Media Authority, 2021). This presents propitious circumstances to advance hospital portal use to optimise pain care for children. This work highlighted that portals with functionality for patients to view and contribute to their EMR data might help drive patient and family engagement, enabling detailed pain assessments and timely access to the right, multimodal pain interventions.

Patient-generated, real-time portal data entry might represent a superior and feasible method for capturing a more complete picture of children's pain symptoms and how symptoms fluctuate within and across their hospitalisation. This would represent a crucial

shift from lack of transparency in pain care to collaboration. To date, patient-generated data and using EMRs and portals as collaborative tools in hospitals is not routine practice. Having said that, web-and smartphone-phone-based digital initiatives supporting routine, multidimensional pain assessment have proven successful in capturing momentary pain reports in youth with chronic pain, with high compliance and satisfaction rates reported (Jibb et al., 2017; Slater et al., 2020).

As well as patient-clinician collaboration tools, portal-enabled pain assessment that captures (patient-generated) momentary reports of pain, including intensity, unpleasantness, interference, and linear pain trends during hospitalisation, would provide insight into the nature of pain, draw attention to its sensory, affective, and cognitive dimensions and inform treatment approaches. Furthermore, momentary pain data entry would facilitate capturing 'unseen' and 'missed' pain, minimise recall bias issues, and maximise the validity of subjective pain reports (Birnie et al., 2019). Finally, multiple momentary reports per day and across days, combined with clinician-EMR pain assessment data, would enable longitudinal examination of hospitalised children's pain, provide critical data about treatment effects and recovery journeys, and identify risk factors for chronic pain trajectories.

Consistent with evidence from a systematic review of mobile health technologies for chronic disease management in young people (Slater et al., 2017), recommendations for effective portal implementation derived from this Ph.D. project highlight the importance of user-centred co-design from inception. Future co-design work should employ a policy-into-practice approach (Briggs et al., 2012) and be aligned to contemporary models of care (Health Standards Organization, 2023) to design and comprehensively study implementation (acceptability, adoption, feasibility, fidelity) and patient outcomes (pain intensity and interference, affective and emotional, overall well-being) of inpatient portals.

Despite the potential benefits, findings from this Ph.D. also illustrate that ill-designed and poorly implemented portals could negatively impact patients, families, clinician roles and well-being, and pain care. These findings contribute to the emerging evidence of the harmful consequences of technology on psychological well-being outcomes in youth (Limone & Toto, 2022) and that digital health technologies, especially patient-facing digital technologies, can lead to unintended multifactorial consequences (Ellis et al., 2022). Although acute care patient portals are moderated and regulated, hospitalised children with pain are at greater risk of unintended harmful consequences, given that hospitalisation and painful conditions present a crisis for children and their families

(Delvecchio et al., 2019; Khadij et al., 2021). To date, no research has explored the relationship between digital technology for pain and children's psychological and emotional well-being. This points to the critical need to examine the impact and association of portal use, particularly pain symptom reporting and tracking, on psychological health, and constructs such as pain rumination and catastrophising, to inform guidelines on portal design and implementation that safeguard unintended and adverse consequences and outcomes.

10.6.2 Recommendation 2

> Leverage EMR and patient portal technologies to empower children and families and support self-management.

In keeping with existing evidence (Jepsen et al., 2019; Page, Stinson, et al., 2012), in Chapter Seven, the qualitative PCG and youth study identified that poor visibility and lack of information about treatment plans contributed to patient and family disempowerment, anxiety, and feeling 'in the dark' during hospitalisation. Although understandable in the context of hospitalisation, parental and child anxiety and distress are notable predictors impacting paediatric pain severity and pain-related disability (Lund et al., 2021; Raja et al., 2020). Improving timely access to personal health information and credible and trusted resources was a top priority for patients and their families. This is particularly relevant given the fundamental right proposed for hospitalised children and families to access complete, unbiased care information in affirming and useful ways (Uniacke et al., 2018). Patient portals provide an excellent modality for keeping children and caregivers abreast of treatment plans and progress (Dendere et al., 2019). Access to personal hospital information (i.e., care plans, medication charts, test results) would address patients' and families' information needs and rights and help alleviate uncertainty and anxiety because they would be better able to monitor and make informed decisions about pain care.

Patient portals also present an innovative approach to empower children and families in their pain care during hospitalisation through access to contemporary, evidence-based resources on pain mechanisms (i.e., pain neuroscience, making sense of pain, pain education) and multimodal treatment options (i.e., physical, psychological, and appropriate use of medicines). Access to health information can empower patients and families to better understand their condition and, as a result, to better communicate their

needs with clinicians (Hagström et al., 2022). Access to trusted information is especially relevant in children's pain care, given that misconceptions about pain and pain interventions (medicine and non-medicine) influence families' willingness to accept opioid medication (Chng et al., 2015; Kaminsky et al., 2019; Khin Hla et al., 2014) and non-medicine pain interventions (Ismail et al., 2019) to treat pain. Portal access to evidence-based resources will also address the challenges children and families face when independently finding information about their/their child's health condition on the internet, which may be outdated and unreliable.

There is innovation to leverage portals as self-management tools by providing patients and families access to a digital toolkit of credible and practical pain coping strategies (i.e., interactive CBT - deep breathing and relaxation), interactive modules, and on-demand videos. This could promote self-management through enhanced pain self-efficacy and skill development related to managing pain intensity and interference and increase the use of multimodal interventions for pain in hospitalised children. Although there are clear benefits of promoting self-management through patient portals, portals should not replace the care clinicians provide. This concern has been reported in other studies examining smartphone and web-based digital self-management programs for youth with persistent pain conditions (Palermo et al., 2020; Slater et al., 2020; Stinson et al., 2014). Operationally, future use of portals should focus on serving as complementary digital tools for hospitalised patients and families. Such an approach offers flexibility in tailored self-management critically and explicitly linked to best practice guidelines (Health Standards Organization, 2023) and does not replace trained clinicians or human interaction integral to pain care. Future research should co-create (with multistakeholder groups including patient and family patient partners) portal designs with content and formats that are relevant and acceptable and meet the needs of hospitalised children with pain and caregivers and subsequently rigorously evaluate their impact on clinical health outcomes. Employing these user-centred design and implementation science methods from inception can mitigate the risk of portal burden, low rates of portal engagement, and associated research waste.

Despite the benefits, this Ph.D. research highlighted that inpatient portals might not appeal to all hospitalised children and their families, and many factors can prevent their use and engagement with portals. Although the idea of using technology did not seem to be overwhelming for families, in keeping with previous work (Dendere et al., 2019), the risk of too much information burdening children and families was a foreseen potential

barrier to using the portal. There remain gaps in the literature about how portal designs could ensure patients and families can control the timing and content of the information they access.

Although not a substantial issue identified in this research, several previous studies have indicated that income, race, and educational level predict digital technology adoption, including portals (Lin et al., 2019; Paccoud et al., 2021; Sarkar et al., 2011). Disparities have been described on two levels: 1) accessing technology and 2) the skills and abilities required to use technology (Paccoud et al., 2021). Equity-seeking groups and those with less advantaged socioeconomic backgrounds have less access, are less likely, and have fewer skills to adopt digital technology than individuals from higher socioeconomic backgrounds (Sarkar et al., 2021). Providing portal access to patients via hospital-supplied devices may help some families but would not necessarily address broader access barriers (Hagström et al., 2022). More research is needed to examine the connection between portal engagement and utilisation and to understand specific behaviours that lead to patients' and families' acceptance and intention to use a patient portal in pain care during hospitalisation.

An often-cited challenge not echoed in this study is balancing confidentiality and information privacy for youth patients with the need for parental involvement in the youths' care (Hagström et al., 2022). Concerns about data confidentiality identified in this research referred to external parties accessing patient information rather than parents being a threat to the youths' privacy. Still, shared access to patient portal information for parents and youth presents potential ethical dilemmas for clinicians (Collins et al., 2017). For example, youth may regard certain health information as sensitive, such as disclosing substance use and sexual activity, and withhold it if they are unsure who will access it (Campos-Castillo & Anthony, 2014). In Study Two's hospital setting, age and privacy policies depend on state laws that stipulate that youth (aged 12-16 years) have shared access to health information with their parents (Australian Institute of Health and Welfare, 2021). To date, providers and countries have approached access for parents, children, and youth differently; access age for the child varies. Although youth and PCGs showed enthusiasm and a strong interest in using a portal to engage in pain care during hospitalisation, more research is needed to examine their perceptions of shared portal access. Due to the current scarcity of inpatient portal implementation in hospitals outside the USA and Nordic countries (Hagström et al., 2022), investigations focused on confidentiality in adolescent outpatient populations are suggested.

10.6.3 Recommendation 3

Leverage EMR technologies and data to increase clinician pain knowledge and awareness and quality care.

A growing evidence base demonstrates the benefits of EMRs in supporting efficient workflows, facilitating compliance with evidence-based practices, and improving care quality and safety (Goldstein et al., 2014; South et al., 2022; Sutton et al., 2020). Findings from this research extend the literature by providing insight into how EMRs can be leveraged to increase clinician knowledge and awareness about pain and drive quality pain care for hospitalised children. In keeping with existing research (Horton et al., 2020), findings illustrate that point-of-care CDS tools can guide compliance with evidence-based pain care through features such as prompt reminders for pain assessments and order sets for safe medication administration and management. Intuitive, interactive interfaces also draw clinicians' attention to pertinent pain information and should, therefore, be leveraged to raise awareness about pain, its multidimensionality, and its priority.

To optimise the use of EMRs in increasing pain knowledge, awareness, and quality care, a critical recommendation arising from this work was for EMR interfaces to allow clinicians to engage with the data in multiple ways and provide a format for rapid, actionable, at-a-glance information. Improved clinician-facing interfaces offering a graphical representation of longitudinal pain data and the ability to interactively consult, visualise and explore detail would give clinicians a clearer picture of pain and pain trends and serve as a visual reminder to prioritise pain. Graphical timeline data are well-known tools that help clinicians visualise, analyse, and understand EMR information (West et al., 2014). Still, graphical timelines are not always suitable to be visually contained on EMR interfaces, and EMR patient data often spans several screens. This can create display fragmentation and contribute to inefficiency, fatigue, and increased risk of clinical errors (Senathirajah et al., 2020). Human-centred interfaces that support customisable, seamless data visualisations can optimise clinicians' engagement with EMR data (Bucalon et al., 2022). This could help draw clinicians' attention to pain, its multidimensionality, and its priority. Future work should incorporate multi-stakeholder design perspectives to explore, co-develop, and test context-specific EMR interfaces and visualisation techniques that present a holistic view of a child's pain and support holistic pain understandings.

Audit and feedback are established processes for quality improvement (QI) and improving professional practice by examining data based on best-practice benchmarks (Ivers et al., 2012). Findings from this research demonstrate how EMRs provide a rich data source to review pain care practices, identify QI opportunities, and inform education priorities for clinicians and families, provided the data are accessible. Pain assessment and management data are recorded in EMRs in structured (i.e., pain intensity scales such as NRS) and unstructured formats (i.e., clinical notes). With standardised and consistent entry, structured EMR data provide clinicians with valuable practice-level pain care information. Still, an emerging criticism of using structured data is its insufficiency to support clinical understandings compared to approaches that leverage unstructured clinical text data (Hernandez-Boussard et al., 2019). Increasing reports demonstrate the value of harnessing unstructured data as *real-world evidence* to examine, understand, and change practice (Hernandez-Boussard et al., 2019; Kong, 2019; Tayefi et al., 2021). In paediatric pain care practice, details in clinician notes can offer real-world insights into children's pain experiences, such as a child's own words to describe their pain experience or a caregiver's perspective on the child's pain. Although unstructured notes have obvious value in understanding a child's clinical story, unstructured texts cannot be readily translated into analysable data since there is inherent variability in how clinicians record pain symptoms and treatments in their clinical notes (Rashotte et al., 2013). Concerns over the accuracy, quality, and availability of EMR unstructured data have prompted calls for standards for their use (Miksad & Abernethy, 2018), which is particularly critical given that these data influence treatment decisions. To address these issues, artificial technologies (AI), such as natural language processing and machine learning models, are increasingly used to extract meaningful information from unstructured EMR clinical text data (Edmondson & Reimer, 2020; Lee et al., 2021; Tayefi et al., 2021; Uyeda et al., 2022). Moving forward, multi-stakeholder teams should explore opportunities to harness AI technologies in examining and understanding pain data patterns, pain care quality, and practice. Longitudinal interrogation of quality pain data could offer clinicians and researchers a deeper understanding of hospitalised children's pain and how interventions make a difference in the child's experience. Examining these data could also help identify risk factors for pain and improve the early detection of chronic pain trajectories. This could catapult us into a new era of understanding and addressing hospitalised children's pain.

Findings from this Ph.D. work also provide evidence that routinely collected EMR pain data are valuable data sets for reflective practice and learning. Indeed, reflective practice is critical to continuing clinician professional development frameworks mandated by healthcare regulatory boards worldwide, which endorse using practice data for clinical

audits and reflection (Australian Nursing and Midwifery Federation, 2019; Royal Australasian College of Surgeons, 2023). Interactive EMR interfaces and visualisation dashboards presenting pain data innovatively and engagingly hold tremendous potential for reflection. They may help clinicians examine and generate new insights into their pain care and uncover new questions about individual and team pain care practice. Visualisation dashboards for QI have been widely studied (Ivers et al., 2012), including their use in pain care QI in adult settings (Opie et al., 2021; Roos-Blom et al., 2019). Still, research examining dashboards to support clinician reflective practice is limited (Tuti et al., 2017). Future research is needed to explore visualisation interfaces and design features that support long-term self-reflection and their effects on professional practice, pain care, and subsequent patient outcomes.

Despite the tremendous potential of EMR data, this Ph.D. research highlighted insufficient resource capacity as an important barrier to EMR data extraction and use. This challenge has been widely echoed in previous studies (Barbazza et al., 2021; Edmondson & Reimer, 2020) and is a consequence of the complex, time-intensive EMR data retrieval processes that demand specialist expertise often beyond the scope of busy, bedside clinicians. Problems extracting data are also complicated by how EMR data are collected and recorded. Consistent with previous research (Keasberry et al., 2017; Samuels & Kritter, 2011), findings from this Ph.D. demonstrated there were several sections of an EMR to input pain-related information; in some cases, this contributed to clinicians perceiving it necessary to provide narrative notes that duplicated other documentation, such as recording pharmacological interventions in free-text progress notes as well as the eMAR, increasing documentation burden. Youth and PCGs also called for streamlined ways to document pain-related information in a patient portal to address the potential documentation burden associated with these systems. Although different sources of pain information may support care continuity, they can also contribute to wasted time and work overload (Gesner et al., 2019). Implications of consistent approaches to capturing detailed pain-related information and reducing unnecessary duplication include limiting and streamlining where pain-related information can be documented. This may improve the quality of EMR pain data, system navigation, the retrieval of pain-related information, and interdisciplinary communication about pain care. It may also optimise and expedite data extraction and interrogation processes, support meaningful use of archived EMR and portal data, and accelerate system- and individual-level QI and research initiatives focused on improving pain care, outcomes, and health service efficiency.

10.7 Knowledge Mobilisation

The knowledge mobilisation activities associated with this project will ensure that clinical practice and research implications reach knowledge users. Parts of the strategy have been undertaken; others are in progress. The strategy includes integrated and end-of-project knowledge mobilisation activities guided by the Melbourne Children's Knowledge Translation and Impact Network's Template (Melbourne Children's Research Institute, 2020). The research team includes key audiences, encompassing multidisciplinary healthcare professionals, hospital information technology experts, and knowledge mobilisation experts. Other key audiences to whom this knowledge mobilisation strategy is targeted include hospitalised children with pain and their families, local administrators, and research funding agencies.

The key messages are that user-centred EMR and patient portal designs offer tremendous opportunities to improve clinician-patient-family partnerships in pain care and improve pain care practice, quality, and outcomes. As rich data sources, these systems could help deepen our knowledge of children's pain and how interventions impact a child's pain experience. The knowledge mobilisation goals are to; 1) increase awareness of the potential of EMR and patient portal systems for pain care among HCPs and patients and families, 2) generate interest in optimising EMR systems to optimise pain care, 3) increase attention to the priority of paediatric pain 4) generate interest in the implementation of patient portal systems with functionality that deeply engages patients as partners in pain care.

Integrated and end-of study knowledge mobilisation activities (Ahmad et al., 2022) have been selected to effectively achieve the knowledge mobilisation goals. The integrated knowledge mobilisation approach (Ahmad et al., 2022) involved partnering with knowledge users, including clinicians and parent and youth patient partners, throughout this research project. During the preliminary stages, paediatric pain and information technology experts assisted in conceptualising the project. During Study Two, youth and PCG patient partners provided qualitative feedback on the study protocol and helped to construct the interview questions to ensure ease of understanding and that questions were appropriate and relevant.

End-of-study knowledge mobilisation involved disseminating and communicating results to a variety of audiences (Ahmad et al., 2022). Interdisciplinary healthcare teams were targeted. Scientists interested in paediatric pain and digital health technologies and

unit and organisational leaders at The Royal Children's Hospital also represent audience targets. End-of-study knowledge mobilisation already undertaken include;

1. Webinars and conference presentations - open to international and national knowledge user audiences as outlined in the thesis preface. Such as a webinar presented within the Pain in Child Health (PICH) 'PICH2GO' series. Presentations and workshops at the International Association for the Study of Pain (IASP), Pain in Childhood Special Interest Group Symposium, Toronto (2022), The Australian Pain Society's Annual Scientific Meeting, Canberra (2023), and the IASP International Symposium for Paediatric Pain, Halifax (2023). Impact indicators include awareness, reach, and usefulness indicators (e.g., number of attendees, conference evaluations)
2. Social media campaigns - (Instagram and Twitter) comprising posts with information about manuscripts and presentations. Partner hashtags were leveraged for the greatest reach and visibility (i.e., #IASP #PICH #PrioritzePain #BeSweettoBabies). Impact indicators include reach indicators (e.g., analytics, number of views).
3. Peer review publications and plain language summaries - available electronically and in print, including posters, linked to social media campaigns. Impact indicators will include the number of downloads and citations.

The final end-of-study knowledge mobilisation will be the research agencies that have supported this project. This work has already begun. End-of-grant reports and oral presentations detailing study methods, results, and implications have been prepared and sent to The Vera Scantlebury Brown Child Welfare Memorial Trust and The Australian Nurses Memorial Centre.

Concluding Statement

The catalyst for this project was the clinical and research experience of the Ph.D. Candidate. This experience demonstrated how the multidimensionality of children's pain calls for multimodal management. Yet, despite widespread knowledge of effective pain treatment methods, children continue to suffer undertreated pain in hospitals. It was evident that models of pain care were rapidly evolving with the use of modern digital technology, and the Candidate was interested in creating a research project that examined how EMR and patient portal systems could be leveraged to improve pain care and outcomes for children and their families. This thesis presents a synthesised account of three unique and innovative studies. It contributes insightful and novel findings to the literature on leveraging EMR and patient portal systems to drive optimal pain care for

hospitalised children and families. It provides direction for potentially transformative future research, policy, education, and clinical practice.

The unique methods of the multiphase project addressing a complex research problem are described, and findings are presented as three manuscripts (two published, one under second review). These data uniquely contribute to national and international evidence addressing optimising pain care for hospitalised children through harnessing EMR and patient portal designs, functionality, and use. Proposed recommendations provide pragmatic, translational guidance for future endeavours to improve pain care and outcomes for hospitalised children and their families.

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Every reasonable attempt has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

APPENDICES

Appendix A
The Melbourne Research Scholarship

Student ID	1217890
Application ref	625544
Name	Mrs Nicole Pope
Offer issued	08 July 2021

Melbourne Research Scholarship

Offer year	2021
Course commencement	January-June commencement

Dear Mrs Pope,

It is with great pleasure that I offer you the Melbourne Research Scholarship for commencement in 2021.

You are offered this scholarship to undertake the Doctor of Philosophy - Medicine, Dentistry and Health Sciences at the University of Melbourne.

The Melbourne Research Scholarship was established by the University of Melbourne and is offered to high-achieving students undertaking research study.

Benefits

The scholarship provides the following benefits:

- Living allowance of $31,200 per year pro rata (2021 full-time rate) for up to 2 years for Master by research students and up to 3.5 years for Doctoral students. This includes limited paid sick, maternity and parenting leave. The duration will be reduced by any study completed towards your course prior to receiving this scholarship.
- Relocation grant of $2,000 for students moving from States or Territories other than Victoria or $3,000 for students moving from outside Australia.
- Visa length Overseas Student Health Cover (single membership) for students who require a student visa to study in Australia.

Conditions

This scholarship is subject to the Graduate Research Scholarships Terms and Conditions.

Page 1 of 2

In addition:

- Commencement of the scholarship may be deferred to a following year under certain circumstances, as determined by your Faculty.
- You must acknowledge the contribution of this scholarship in any published or produced material which relate to the research project for which the scholarship was awarded.

Should you have any queries, please refer to Manage your scholarship or contact us.

Sincerely,

Retracted

Joanne Ligouris

Executive Director, Student and Scholarly Services and Academic Registrar

The University of Melbourne

CRICOS Provider Code: 00116K

The University of Melbourne acknowledges and pays respect to the Traditional Owners of the lands upon which our campuses are situated.

Page 2 of 2

Appendix B
The *Be Sweet to Babies* Studentship

THE UNIVERSITY OF MELBOURNE

To: Mrs. Nicole Marie Pope
1/16 Alfred Road, Glen Iris,
3146

August 4th 2020

Re: Be Sweet to Babies PhD Studentship

Dear Nicole,
It is with great pleasure that I inform you that your application for the PhD Be Sweet to Babies Studentship was successful.

I therefore wish to offer you the studentship for a period of 3 years full time with the option of 6 months full time extension subject to satisfactory progress.

This offer is conditional upon:

- You notifying me in writing of your intention to take up the offer by 5pm on August 31st, 2020;
- You successfully gain entry to the Doctor of Philosophy program by January 18th 2021;
- Continue to meet the requirements of the studentship as outlined in the attached Terms and Conditions for the duration of your candidature.

The academic department for the duration of your candidature shall be the Department of Nursing, Melbourne School of Health Sciences.

Should you have any questions at all about this offer please email me directly at deniseh@unimelb.edu.au

Congratulations Nicole on being awarded this prestigious studentship. We look forward to welcoming you to the Department of Nursing.

Denise Harrison | Professor, Department of Nursing
Melbourne School of Health Sciences, Faculty of Medicine, Dentistry and Health Sciences
Level 6, Alan Gilbert Building, 161 Barry Street, Parkville
The University of Melbourne, Victoria 3010 Australia
E: deniseh@unimelb.edu.au

Melbourne School of Health Sciences
The University of Melbourne Victoria 3010 Australia
T: +61 3 8344 4171 **F:** +61 3 8344 5391 **W:** www.healthsciences.unimelb.edu.au

Appendix C
Vera Scantlebury Brown Memorial Trust Scholarship

28 July 2021

Dear Nicole,

On behalf of the Vera Scantlebury Brown Child Welfare Memorial Trust committee panel members, I would like to congratulate you on your successful application.
The Panel were most impressed with your application and came to the unanimous decision that you should be awarded the full Vera Scantlebury Brown Scholarship (UTR6.225) for 2021, valued at $8,000.

Acceptance of this scholarship requires you to provide a report for the committee detailing your work for the scholarship within 12 months of completing the work. We are also very keen for you to share your results with us at a future meeting of our committee in due course.

Your report should include the following:

1. Benefits you have received by being awarded this Scholarship
2. Some of the tangible outcomes to your academic career
3. Your plans once you complete your studies
4. Photos of yourself from your award activity (travel/conference, etc.) – optional.

Your report will be made available to the committee members and donors.

Would you please complete the acceptance form to provide us with the confirmation that you have accepted the award?
We wish you every success for your scholarship year and look forward to hearing from you.

Sincerely,

Retracted

Professor Sarath Ranganathan
Stevenson Chair and Head, Department of Paediatrics
The University of Melbourne

Dept of Paediatrics | Level 2 West | 50 Flemington Road Parkville Victoria 3052 Australia

Appendix D
Pain In Childhood (PICH) Travel Award

Wednesday, July 27, 2022

Nicole Pope
Trainee
The University of Melbourne

Dear Nicole,

Congratulations! The PICH x IASP 2022 Review Committee of the Pain in Child Health (PICH) program has selected your abstract for an oral presentation at the Pain in Childhood SIG symposium on Sept 19, 2022 as part of the IASP 2022 World Congress on Pain, that will take place Sept 19 - 23, 2022 in Toronto, ON, Canada. In addition to being selected for the oral presentation, you will also receive a $1,000 CAD travel stipend to attend the event.

Presentation Information

- Registration for the Pain in Childhood SIG symposium event on Sept 19, 2022 will be waived and more information will be provided on the registration process.
- Your oral presentation will take place on Monday September 19, 2022 during the Pain in Childhood SIG symposium at the following time:
  13:40-14:40 *–Trainee Data Blitz: 4 Pediatric poster presentations (10 mins + 5 mins Q&A*
- Please prepare slides for your oral presentation – additional information on slide formatting and due dates will be provided

Stipend Information

- A cheque will be provided to you on the event date. Please provide your full name, mailing address, and phone number (as it appears on your banking information) to Cynthia Nguyen for cheque processing.
- **Eligible costs include:** travel to/from Toronto, airport transfer, accommodation in Toronto during the SIG symposia and IASP conference, IASP conference registration
- Please provide receipts for the costs incurred for reporting purposes by emailing them to Cynthia Nguyen after the conference.

If you have any questions, please contact Cynthia Nguyen at cynthia.nguyen@sickkids.ca.

Sincerely,

Retracted

Dr. Lindsay Jibb
PICH Co-Chair

Retracted

Dr. Meghan McMurtry
PICH Co-Chair

Appendix E
Melbourne Abroad Travel Scholarship

THE UNIVERSITY OF MELBOURNE

Nicole Pope <nppop@student.unimelb.edu.au>

Outcome for 2022 Melbourne Abroad Travel Scholarship
6 messages

shs-research <shs-research@unimelb.edu.au> Thu, May 12, 2022 at 10:35 AM
To: Nicole Pope <nicole.pope@student.unimelb.edu.au>
Cc: shs-research <shs-research@unimelb.edu.au>, Marie Gerdtz <gerdtzmf@unimelb.edu.au>, Denise Harrison <deniseh@unimelb.edu.au>, Snezana Kusljic <skusljic@unimelb.edu.au>

Dear Nicky,

Thank you for your recent application for 2022 Melbourne Abroad Travel Scholarship.

On behalf of the Nursing Research Committee, we are delighted to advise that you have been awarded $1,000 from the department's allocated share of funding. The funds will be deposited into your nominated bank account shortly.

We hope that this funding will assist you with the rising cost of international travel as well as broaden and enhance your research training experience as part of your PhD program with the School.

We also look forward to your research presentation at the School's 2022 Graduate Research Colloquium (a criteria for eligibility of this award).

Best wishes,

Peter Blight | Academic Programs Coordinator (Research)

Melbourne School of Health Sciences | Faculty of Medicine, Dentistry and Health Sciences

Level 7, Alan Gilbert Building, Grattan St

The University of Melbourne, Victoria 3010 Australia

T: +61 (03) 8344 6160 **E: shs-research**@unimelb.edu.au

facebook.com/melbuni | twitter.com/unimelb | unimelb.edu.au

I acknowledge the Traditional Owners of the land on which I work, and pay my respects to the Elders, past and present.

THE UNIVERSITY OF MELBOURNE

CRICOS: 00116K

Nicole Pope <nicole.pope@student.unimelb.edu.au> Thu, May 12, 2022 at 10:58 AM
To: shs-research <shs-research@unimelb.edu.au>
Cc: shs-research <shs-research@unimelb.edu.au>, Marie Gerdtz <gerdtzmf@unimelb.edu.au>, Denise Harrison <deniseh@unimelb.edu.au>, Snezana Kusljic <skusljic@unimelb.edu.au>

Dear Peter and the Nursing Research Committee,

It is a huge honour to receive the Melbourne Abroad Travel Scholarship - thank you so much.
I am so excited to be travelling to Canada to connect (in person!!!) with leaders in my field, and share my work.

It will also be great to share my work, and stories of my travels at the GR Colloquium.

Thank you,
[Quoted text hidden]
--

Nicky

Nicole Pope | (RN, MPhil) | PhD Candidate
Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

The University of Melbourne, Victoria 3010 Australia

m: +61 400 981 610 | **e:** Nicole.Pope@student.unimelb.edu.au
Twitter: @NickyPope16 | ORCID: 0000-0001-7617-8778
[Quoted text hidden]

---

shs-research <shs-research@unimelb.edu.au> Thu, May 12, 2022 at 11:27 AM
To: Nicole Pope <nicole.pope@student.unimelb.edu.au>
Cc: Marie Gerdtz <gerdtzmf@unimelb.edu.au>, Denise Harrison <deniseh@unimelb.edu.au>, Snezana Kusljic <skusljic@unimelb.edu.au>

You're most welcome!

[Quoted text hidden]

---

shs-research <shs-research@unimelb.edu.au> Mon, May 23, 2022 at 5:01 PM
To: Nicole Pope <nicole.pope@student.unimelb.edu.au>
Cc: shs-research <shs-research@unimelb.edu.au>

Dear Nicky,

I've processed the payment via Finance, it's just awaiting approval. Once that's happened, you should receive an auto-email asking to confirm your account details for payment and you'll be paid within 1-2 weeks.

[Quoted text hidden]

Nicole Pope <nicole.pope@student.unimelb.edu.au> Mon, May 23, 2022 at 6:50 PM
To: shs-research <shs-research@unimelb.edu.au>

Hello Peter,

Thanks very much for processing this for me.
[Quoted text hidden]
[Quoted text hidden]

4 attachments

image001.jpg
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image001.jpg
4K

image001.jpg
4K

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shs-research <shs-research@unimelb.edu.au> Tue, May 24, 2022 at 9:10 AM
To: Nicole Pope <nicole.pope@student.unimelb.edu.au>

You're welcome.

[Quoted text hidden]

Appendix F
Prince Henry's Affiliates Scholarship

Nicole Pope
1/16 Alfred Road
Glen Iris, VIC 3146

21/12/2022

Dear Nicole,

Prince Henry's Affiliates Scholarship

The President and Directors of the Australian Nurses Memorial Centre have pleasure in advising that you have been awarded the **Prince Henry's Affiliates Scholarship to the value of $5,000** to assist with fees for your postgraduate nursing studies in 2023.

The Scholarship will be made available in two (2) equal payments of $2,500. The first payment will be made in March with the second payment to be made end of July 2023. Please forward evidence of satisfactory study progress in December and June in the form of a university transcript of results or a thesis progress report. To enable us to transfer the funds, please complete the bank account details form.

Please read and indicate your understanding and acceptance of the Terms and Conditions by signing the attached document.

Acceptance of the Scholarship is contingent upon your agreement to the Terms and Conditions included in this package.

We look forward to seeing you and your guests at the Scholarship Awards evening scheduled for **Thursday the 2nd of March 2023**. Further details of the function will be provided closer to the day.

We congratulate you on your achievement and wish you every success for your studies.

Yours sincerely,

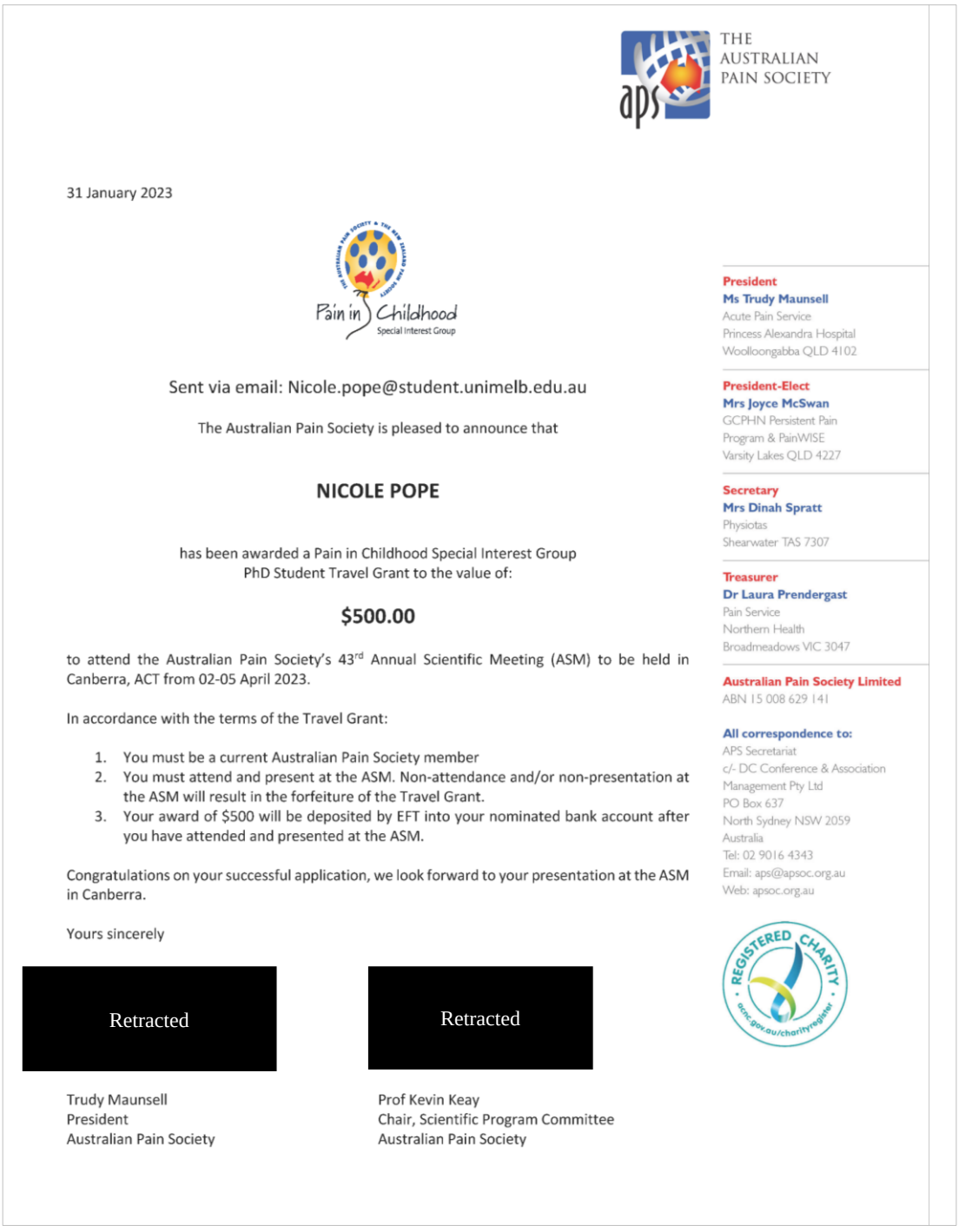
Retracted

Emeritus Professor Maxine Duke AM

Chair, Scholarship Committee

Suite 11, 431 St Kilda Road, Melbourne Vic 3004
m: 0429 602 144 • **e:** admin@nmc.org.au
w: www.australiannursesmemorialcentre.org.au
ACN: 004 285 956 • **ABN:** 11 004 285 956

Appendix G
Australian Pain Society Travel Award



THE AUSTRALIAN PAIN SOCIETY

31 January 2023

Pain in Childhood
Special Interest Group

Sent via email: Nicole.pope@student.unimelb.edu.au

The Australian Pain Society is pleased to announce that

NICOLE POPE

has been awarded a Pain in Childhood Special Interest Group
PhD Student Travel Grant to the value of:

$500.00

to attend the Australian Pain Society's 43rd Annual Scientific Meeting (ASM) to be held in Canberra, ACT from 02-05 April 2023.

In accordance with the terms of the Travel Grant:

1. You must be a current Australian Pain Society member
2. You must attend and present at the ASM. Non-attendance and/or non-presentation at the ASM will result in the forfeiture of the Travel Grant.
3. Your award of $500 will be deposited by EFT into your nominated bank account after you have attended and presented at the ASM.

Congratulations on your successful application, we look forward to your presentation at the ASM in Canberra.

Yours sincerely

Retracted

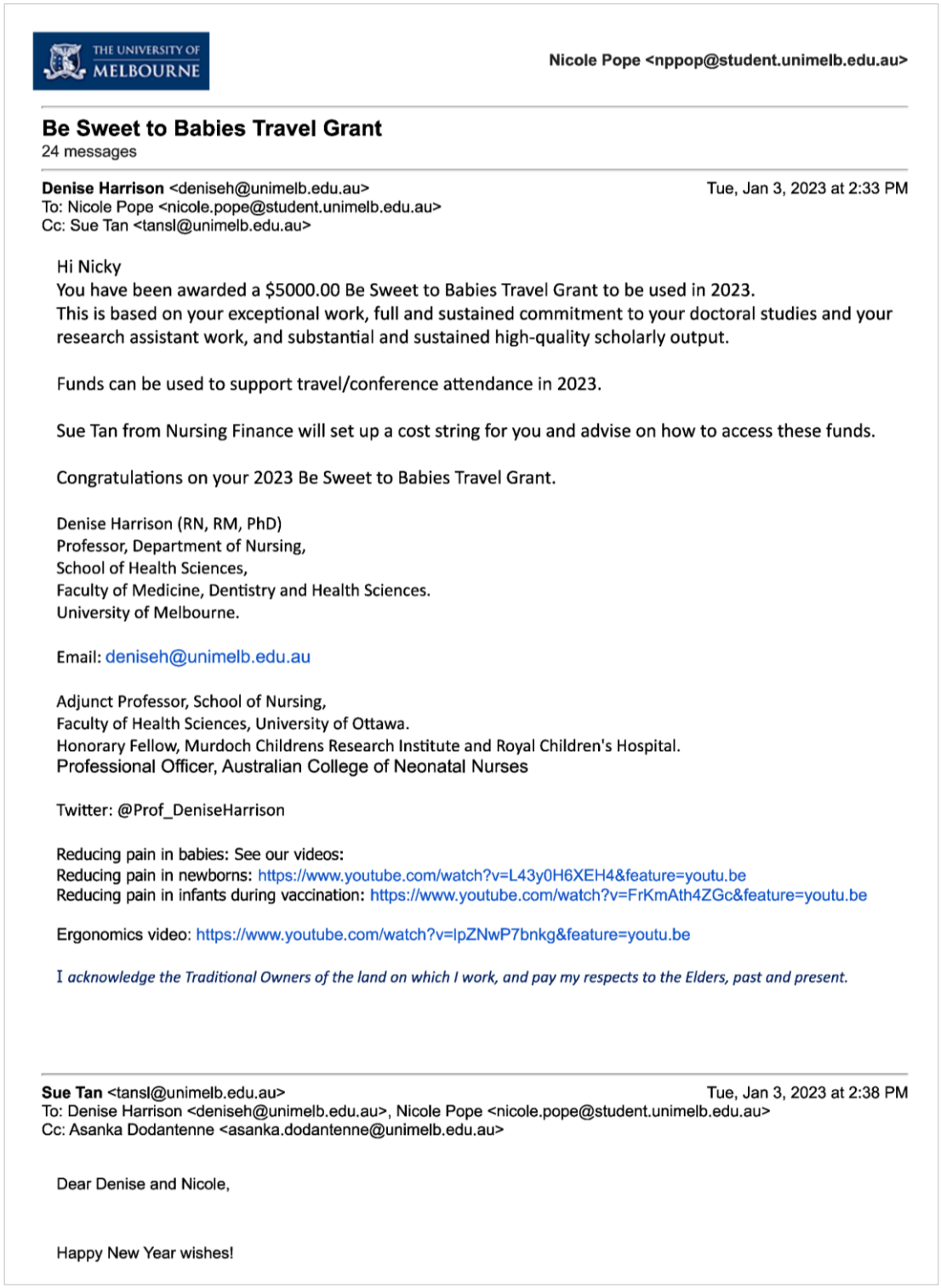
Trudy Maunsell
President
Australian Pain Society

Retracted

Prof Kevin Keay
Chair, Scientific Program Committee
Australian Pain Society

Appendix H

Be Sweet to Babies Travel Scholarship



THE UNIVERSITY OF MELBOURNE

Nicole Pope <nppop@student.unimelb.edu.au>

Be Sweet to Babies Travel Grant

24 messages

Denise Harrison <deniseh@unimelb.edu.au> Tue, Jan 3, 2023 at 2:33 PM
To: Nicole Pope <nicole.pope@student.unimelb.edu.au>
Cc: Sue Tan <tansl@unimelb.edu.au>

Hi Nicky
You have been awarded a $5000.00 Be Sweet to Babies Travel Grant to be used in 2023.
This is based on your exceptional work, full and sustained commitment to your doctoral studies and your research assistant work, and substantial and sustained high-quality scholarly output.

Funds can be used to support travel/conference attendance in 2023.

Sue Tan from Nursing Finance will set up a cost string for you and advise on how to access these funds.

Congratulations on your 2023 Be Sweet to Babies Travel Grant.

Denise Harrison (RN, RM, PhD)
Professor, Department of Nursing,
School of Health Sciences,
Faculty of Medicine, Dentistry and Health Sciences.
University of Melbourne.

Email: deniseh@unimelb.edu.au

Adjunct Professor, School of Nursing,
Faculty of Health Sciences, University of Ottawa.
Honorary Fellow, Murdoch Childrens Research Institute and Royal Children's Hospital.
Professional Officer, Australian College of Neonatal Nurses

Twitter: @Prof_DeniseHarrison

Reducing pain in babies: See our videos:
Reducing pain in newborns: https://www.youtube.com/watch?v=L43y0H6XEH4&feature=youtu.be
Reducing pain in infants during vaccination: https://www.youtube.com/watch?v=FrKmAth4ZGc&feature=youtu.be

Ergonomics video: https://www.youtube.com/watch?v=lpZNwP7bnkg&feature=youtu.be

I *acknowledge the Traditional Owners of the land on which I work, and pay my respects to the Elders, past and present.*

Sue Tan <tansl@unimelb.edu.au> Tue, Jan 3, 2023 at 2:38 PM
To: Denise Harrison <deniseh@unimelb.edu.au>, Nicole Pope <nicole.pope@student.unimelb.edu.au>
Cc: Asanka Dodantenne <asanka.dodantenne@unimelb.edu.au>

Dear Denise and Nicole,

Happy New Year wishes!

Appendix I
Pain in Child Health (PICH) Travel Award

Friday, June 16, 2023

Nicole Pope
Trainee
University of Melbourne

Dear Nicole,

Congratulations! The PICH2GO Halifax 2023 Planning Committee of the Pain in Child Health (PICH) program has considered your application for the PICH Travel Award and has approved your application.

Based on the budget you provided, you are approved for reimbursement of up to $1,500 CAD towards your travel and $100 CAD towards registration for the Pain Education Day (October 1, 2023).

Funding Guidelines and Eligible Costs

- All travel must occur by October 8, 2023 to be eligible for reimbursement.
- Hotel costs will be reimbursed for up to two nights for trainees.
- *Eligible costs:* hotel accommodation (2 nights max), travel costs to Halifax (e.g. flight, train, etc.), travel costs from the airport/train station to hotel accommodation (e.g., cab, Uber, bus ride), Pain Education Day trainee registration costs
- *Ineligible costs:* meals, poster printing, ISPP registration costs

Reimbursement Process

Please keep a copy of all receipts, as require original copies of receipts. Please complete the following sections in the attached AP-2 form (Non-Staff Reimbursement Form) as this will be used to mail the cheque for reimbursement:

- Name
- Date
- Address
- Province
- Postal Code
- Type of expense
- Description
- Date incurred
- Amount

Please email your original receipts and completed AP-2 Form to Cynthia Nguyen at cynthia.nguyen@sickkids.ca.

If you have any questions, please contact Cynthia Nguyen at cynthia.nguyen@sickkids.ca.

Sincerely,

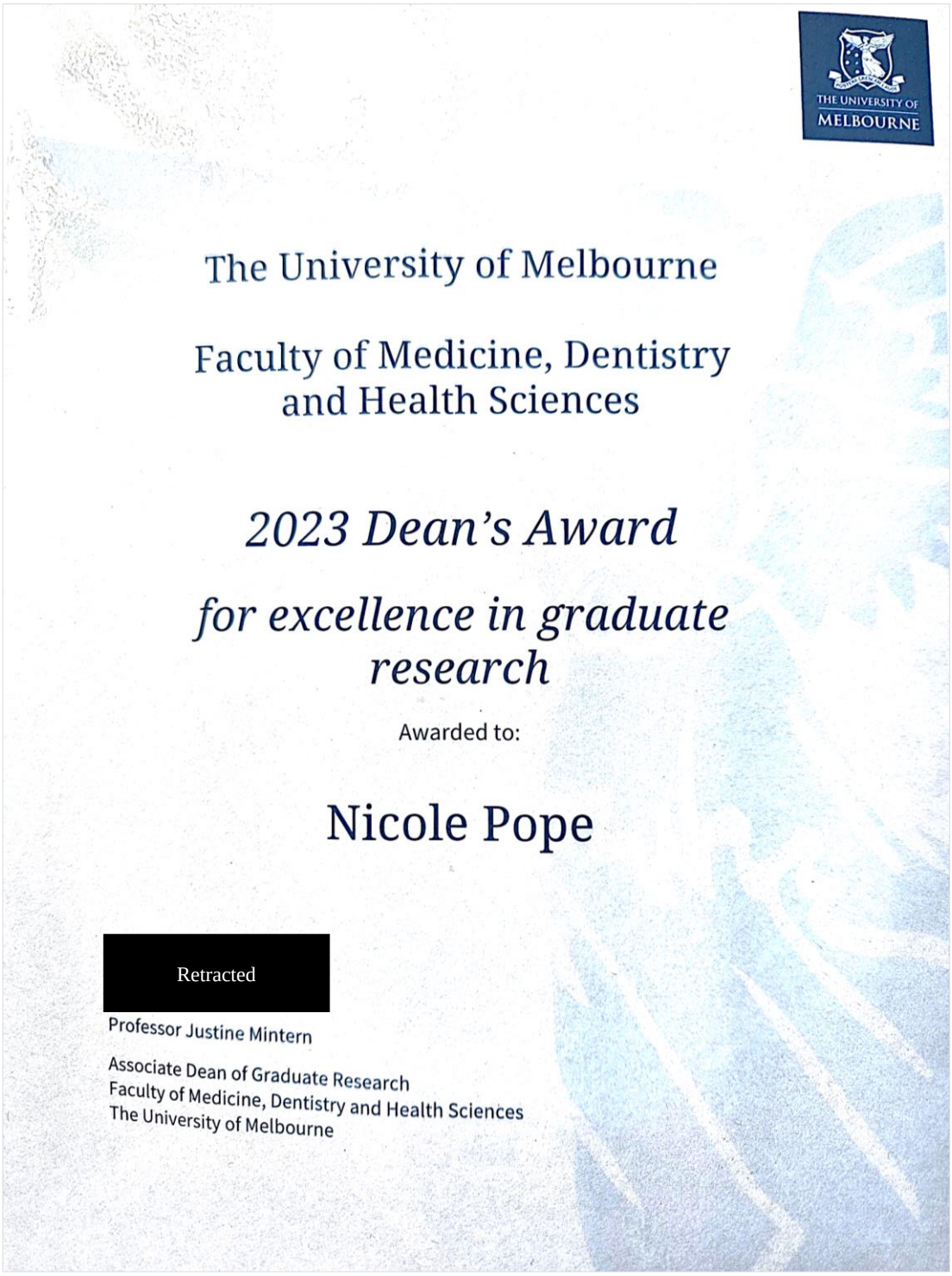
Retracted

Dr. Lindsay Jibb
PICH Co-Chair

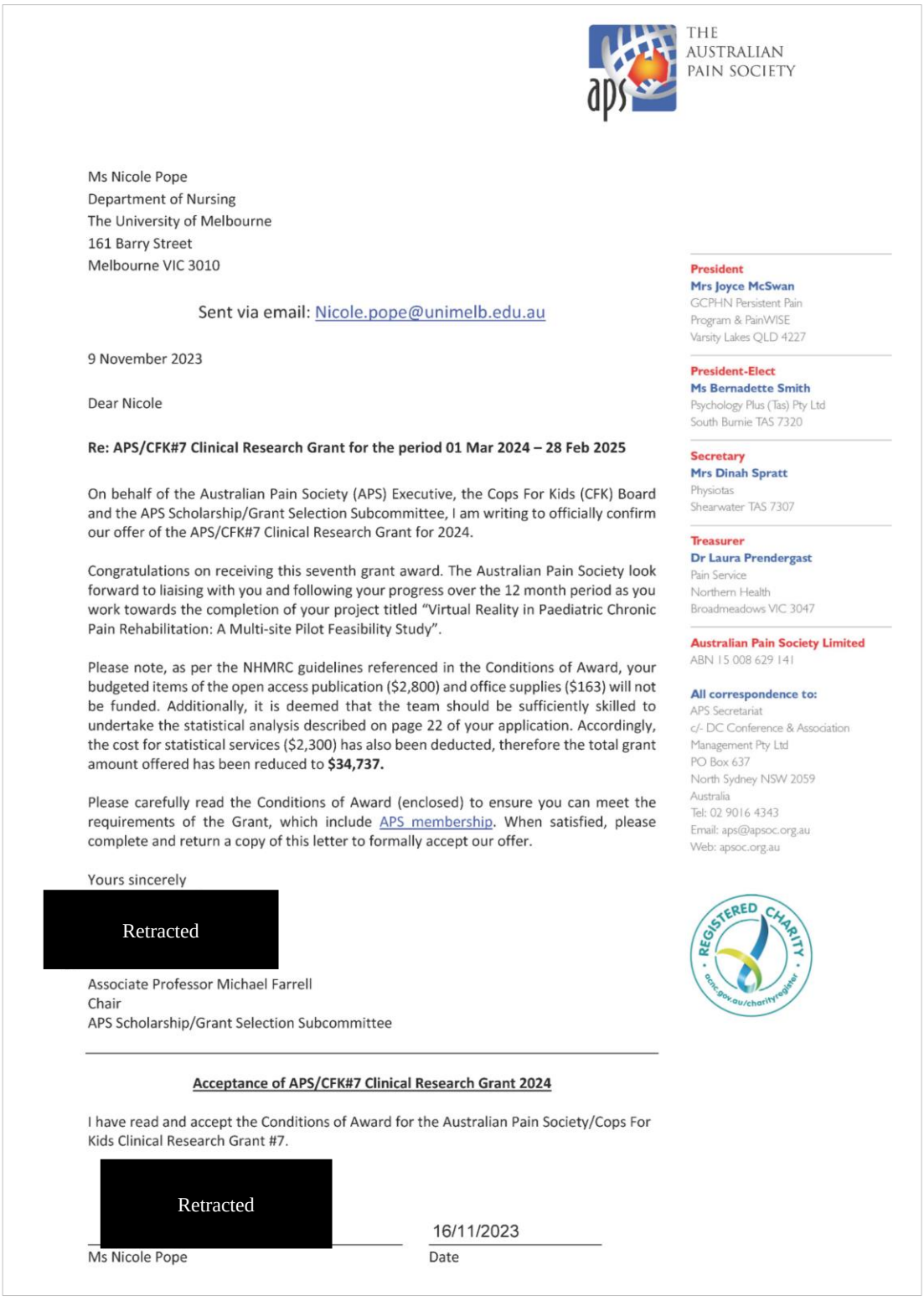
Retracted

Dr. Meghan McMurtry
PICH Co- Chair

Appendix J
Dean's Award for Excellence in Graduate Research



Appendix K
Cops for Kids (CFK) Clinical Research Grant



THE AUSTRALIAN PAIN SOCIETY

Ms Nicole Pope
Department of Nursing
The University of Melbourne
161 Barry Street
Melbourne VIC 3010

Sent via email: Nicole.pope@unimelb.edu.au

9 November 2023

Dear Nicole

Re: APS/CFK#7 Clinical Research Grant for the period 01 Mar 2024 – 28 Feb 2025

On behalf of the Australian Pain Society (APS) Executive, the Cops For Kids (CFK) Board and the APS Scholarship/Grant Selection Subcommittee, I am writing to officially confirm our offer of the APS/CFK#7 Clinical Research Grant for 2024.

Congratulations on receiving this seventh grant award. The Australian Pain Society look forward to liaising with you and following your progress over the 12 month period as you work towards the completion of your project titled "Virtual Reality in Paediatric Chronic Pain Rehabilitation: A Multi-site Pilot Feasibility Study".

Please note, as per the NHMRC guidelines referenced in the Conditions of Award, your budgeted items of the open access publication ($2,800) and office supplies ($163) will not be funded. Additionally, it is deemed that the team should be sufficiently skilled to undertake the statistical analysis described on page 22 of your application. Accordingly, the cost for statistical services ($2,300) has also been deducted, therefore the total grant amount offered has been reduced to **$34,737.**

Please carefully read the Conditions of Award (enclosed) to ensure you can meet the requirements of the Grant, which include APS membership. When satisfied, please complete and return a copy of this letter to formally accept our offer.

Yours sincerely

Retracted

Associate Professor Michael Farrell
Chair
APS Scholarship/Grant Selection Subcommittee

Acceptance of APS/CFK#7 Clinical Research Grant 2024

I have read and accept the Conditions of Award for the Australian Pain Society/Cops For Kids Clinical Research Grant #7.

Retracted

Ms Nicole Pope

16/11/2023
Date

Appendix L
Pain in Child Health (PICH) Postdoctoral Fellowship Award

PICH
Pain in Child Health
Global Research Training

Tuesday, July 25, 2023

Nicole Pope
Nicole.pope@student.unimelb.edu.au

Dear Nicole,

Congratulations on being awarded the Pain in Child Health (PICH) Postdoctoral Fellowship Award supported by the Louise and Alan Edwards Foundation. This is a significant accomplishment, which is endorsed by the PICH Review Committee who felt that your candidacy for this award was very strong. This letter to confirm the terms of your fellowship.

The term of your fellowship is applicable for one year, for the amount of $50,000 CAD. The start date for your postdoctoral fellowship will commence upon proof that you have completed your PhD. Please submit proof of completion of your PhD to: pain.childhealth@sickkids.ca. Please also submit a final report to this email address.

On behalf of the PICH review committee and PICH National Collaborators, we would like to congratulate you on winning this prestigious award. We look forward to supporting you as you contribute to the field of research in pain in child health.

Sincerely,

Retracted

Dr. Lindsay Jibb
PICH Co-Chair

Retracted

Dr. Meghan McMurtry
PICH Co-Chair

Appendix M
Melbourne Manchester Toronto Joint Research Fund 2023

Application

MMT Joint Research Fund 2023: Application Form

Application Information

Type of collaboration
Manchester - Melbourne - Toronto

Co-Investigator Information (Manchester)

Personal details of applicant	
Title (Mr/Mrs/Miss/Ms/Dr/Prof)	Prof
First Name	Dawn
Last Name	Dowding
Position	Professor in Clinical Decision-Making, Digital Health Theme Lead
Email	dawn.dowding@manchester.ac.uk
Contact Phone No	+44 (0)161 306 7755

Faculty
Faculty of Biology, Health and Medicine

School
School of Health Sciences

Co-Investigator Information (Melbourne)

Personal details of applicant at partner university	
Title (Mr/Mrs/Miss/Ms/Dr/Prof)	Dr
First Name	Sophie
Last Name	Jones
Position	Lecturer/ Digital Health Education & Workforce lead (Nursing)
Email	sophie.jones@unimelb.edu.au
Contact Phone No	+61 3 844 1472
Link to Primary Supervisor website/profile	https://findanexpert.unimelb.edu.au/profile/4015-denise-harrison

Faculty
Medicine, Dentistry and Health Sciences

School
Department of Nursing, Melbourne School of Health Sciences

Please confirm one of the following statements.
I confirm that I am a University of Melbourne academic staff member (minimum appointment A6 and 0.5 FTE) **Primary employer:** UoM

Career stage (highlight one)
Within five years FTE of PhD conferral

Gender identification
Woman

Do you identify as Aboriginal and/or Torres Strait Islander
No

Co-Investigator Information (Toronto)

Personal details of applicant at partner university	
Title (Mr/Mrs/Miss/Ms/Dr/Prof)	Dr
First Name	Jennifer
Last Name	Stinson
Position	Professor; Senior Scientist
Email	jennifer.stinson@sickkids.ca
Contact Phone No	(416) 813-7654 ext 304514

Division
Nursing **Department/School** Lawrence S. Bloomberg Faculty of Nursing

Additional questions

	Yes	No
Can the Lead/Co-lead Hold Research Funds at U of T?	X	
What is the lead/co-lead's SGS Membership Status?	X	
Does the Lead/Co-lead Have a Continuing Faculty Appointment at U of T?	X	
Is the lead/co-lead U of T Tenure-stream/Tenured?		X
Is the Lead/Co-lead a Faculty Member Who Has Received Their Appointment Less Than Five Years Ago?		X

Research Proposal

Q1. Title of Research Project (Maximum 10 words)

Standards for reporting and auditing children's pain in EHRs

Key Words
Please provide 4-8 keywords to represent the main topic of your proposed project

1 acute pain
2 children
3 electronic health records
4 pain management
5 auditing
6 standards
7 nurses
8 -

Q2. Abstract (max 150 words)

Please provide a brief description of the project.

The management of acute pain in hospitalised children is supported by quality evidence, but children's pain is often inadequately managed. Poorly managed pain is associated with short and long-term sequelae.
Hospital electronic health records (EHRs) can enhance pain assessment and management and shared decision-making by children, families, and clinicians. New national Canadian standards for paediatric pain management include recommendations for the systematic collection of data to improve pain management. Whilst standards exist for quality improvement in paediatric pain management, these do not provide any guidance on the use of EHRs to do this. Without such guidance and the collection of quality pain data, an audit-feedback cycle for quality improvement cannot occur.
A collaboration of experts in neonatal/paediatric pain and digital health is proposed to develop guidelines for nurses reporting, auditing and feedback of hospitalised children's pain in EHRs. The focus is on nurses as they care for paediatric patients 24/7.

Q3. Project timeline and planned activities (max 200 words)

Project Start 04/09/2023

Project Completion 04/03/2025

Please give details of the project timeline and activities to be undertaken.

1. Online meetings to support collaboration activities, including establishing terms of reference, schedules, deadlines, task allocation (monthly September 2023 - March 2025).
2. Environmental scan of how neonatal/paediatric pain data is captured, processes of audit/feedback by nurses related to the EHR (Epic) used by partner hospitals of UoM, UniMelb, UofT, and in EHRs internationally (months 1-3).
3. Design of Delphi survey for pain clinicians exploring the documentation and audit/feedback of pain assessment and management in EHRs (months 4-6) based on environmental scan.
4. Delphi survey of paediatric pain clinicians exploring preferences for pain reporting and auditing pain in EHRs (months 6-9).
5. In-person meetings at each site, coinciding with the following meetings:
a. Australian Pain Society (Darwin, April 2024).
b. Pain in Child Health (PICH) Program Meeting (Hosted at UofT in early 2024).
c. International Congress of Nursing Informatics (Manchester, July 2024)
6. Three virtual/in-person seminars, held during each site meeting, delivered by ECRs.
7. Based on Delphi study, develop funding proposals for; a) larger meeting of pain experts (outlined in section 8; CIHR - ICS-Planning and Dissemination competition) and b) exploring standardised reporting and audit/feedback using EHRs (all meetings).
8. Conference presentations/workshops (coinciding with planned activities).

Q4. Collaborator complementarity (max 250 words)

A description of how the proposed activities combine mutual areas of interest and strength and the added value of these combined expertise.

Expertise of the collaborators includes neonatal and paediatric pain management; use of digital technologies to improve pain assessment and management; and the development, implementation, and evaluation of digital technologies.

Prof. Dowding is an expert in the development and implementation of clinical decision support systems in nursing, including the assessment and management of pain in older adults.

Prof. Harrison and Dr. Stinson are experienced neonatal and paediatric pain researchers, respectively. Dr. Stinson's research area is pain and symptom management and the use of digital technologies to improve the assessment and management of pain in children. Dr. Stinson and Campbell are co-directors of Pain Centre at SickKids. Prof Harrison's research involves knowledge translation of pain management interventions. Ms Pope is a PhD candidate focusing on the use of EHRs for pain care for hospitalised children and families.

Dr Jones and Dr Merolli are ECRs building health professionals' digital capability. Dr Jones has explored how digital technologies/ virtual workflows empower patients and families and promote patient self-management. Dr Merolli has explored the use of social media and patient-reported outcomes for people with chronic pain.

Dr. Pham is an ECR and health services researcher specialising in the development of equitable digital therapeutics for chronic disease management. She is the Director of the Centre for Digital Therapeutics. Dr Lee is an ECR and academic health psychologist with expertise in developing digital tools as well as behaviour change interventions to improve healthcare professional capabilities, opportunities, and motivations to discuss pain in clinics.

Q5. Potential scholarly impact (max 250 words)

Description of the expected academic gains for the project as a result of the proposed cooperation and mobility, and the identification of corresponding performance indicators e.g. a publication, blog, meeting report etc.

Improving the management of paediatric pain and making pain visible is widely acknowledged as a research and patient care priority, as is the role of digital technologies in enhancing pain care. A standard for quality improvement for paediatric pain management has been set, but how to apply this standard using EHRs has not been delineated. The goals of this collaboration are to:
Goal 1: Conduct and publish the results of an environmental scan of how children's pain assessment and management data is captured and used in EHRs to improve pain care.
Goal 2: Conduct a Delphi survey with expert paediatric pain clinicians/researchers exploring the documentation and audit/feedback of pain assessment and management in EHRs using Paediatric Pain (hosted by the Canadian Centre for Pediatric Pain Research) and PICH mailing list with more than 1200 members internationally.
Goal 3: Publish the Delphi survey results and use this information to support applications for further funding to generate recommendations for standards for reporting, as well as audit and feedback using EHRs for quality improvement in paediatric pain management.
Goal 4: Deliver a co-produced seminar series: Three online/in-person seminars (one hosted by each university) will be held to engage key parties and seek participation in an ongoing international community of practice.
Goal 5: Conduct virtual/in-person workshops at national and international conferences to facilitate the Delphi survey and expand collaborations (International Congress of Nursing Informatics, July 2024, International Association for the Study of Pain, October 2023/August 2024 and the Australian Pain Society, April 2024).

Q6. Potential broader impact (max 250)

Describe how your proposal aligns with the strategic priorities of the participating institutions and the anticipated benefits of the activities to local or international communities.

This collaboration aligns with the goals of the International Centre for Translational Digital Health by leveraging EHRs to audit practice and inform improved reporting of paediatric pain management. Despite strong evidence to guide best practices for children's acute pain management, there is a disconnect between knowledge and practice. Impact includes:
Children and their families: Auditing/feedback of acute pain care practices identifies:
• Where improvements are required to prevent untreated/ unmanaged pain.
• How patients and parents can be involved in shared decision-making.
• What resources nurses require to provide comprehensive pain management for patients.
Healthcare system: Generating quality pain data via standardised reporting (within EHRs) and audit/feedback will improve paediatric pain care and lead to:
• Less risk of unmanaged pain and enhanced management of pain for all hospitalised children.
• Improved recording adverse events and poorly managed pain.
• Identification of priority areas for practice improvement, reducing the risk of adverse outcomes for children in pain.
• Reduction of the short and long-term consequences of unmanaged acute pain in children, such as delayed recovery, prolonged hospital admissions, development of chronic pain, and reduced overall healthcare costs.

Wider society: Unmanaged acute pain in children can lead to chronic pain and psychological consequences that impact a child's willingness to receive vaccination and future medical treatments. These sequelae have lasting repercussions for the child, potentially across their lifetime, their family and society. Developing and implementing standards for EHRs will enhance the assessment and management of children's pain and thus reduce the global burden of poorly managed pain.

Q7. Early career and graduate researcher involvement (max 250 words)

Any opportunities for their engagement and anticipated benefits to the project and the early career and graduate researchers themselves, as applicable.

The project will identify research questions related to the design of EHRs, the use of EHRs to optimise reporting of children's pain and management of children's pain during hospitalisation. Such questions may be addressed by PhD students, co-supervised by Professors Dowding, Harrison and Campbell, Dr. Stinson, Dr. Jones, Dr. Merolli, Dr. Lee and Dr. Pham. For graduate researcher, Nicole Pope, this collaboration aligns with her Ph.D. studies and presents an opportunity to establish connections for post-doctoral opportunities (with Dr. Stinson).
The proposed co-supervision arrangement for potential Ph.D. students provides exposure to an international collaboration of researchers and clinicians with extensive research experience in pain management, digital health, clinical decision making, and knowledge translation. For the ECRs involved in this collaboration, this presents an opportunity to develop connections and networking to support future funding applications and learn from experts, more advanced in their careers. Visits to collaborators will build each ECRs profile in this space and generate other opportunities for collaboration and co-supervision of students.
To enable future questions to be addressed by PhD students, the activities of this collaboration include writing funding proposals for larger grants to facilitate ongoing work (outlined in section 8). The experience of contributing to such proposals, with guidance from experts in digital therapeutics/ clinical decision support and pain management, will be invaluable to the ECRs.
Prof. Harrison and Dr. Jones, currently teaching in the Master of Advanced Nursing Practice, can facilitate student engagement with elements of the proposed work within the independent research study unit.

Q8. Capacity for Future Collaboration (max 250 words)

A description of the potential future collaborations and outcomes that will be possible as a result of having undertaken the current collaboration. For example: joint publications, joint supervision of graduate researchers, joint teaching (including Global Classrooms - please see guidelines for full description), joint patent applications, joint reports to governments, joint funding applications, growth of research team size at each partner, collaborations with corporate partners.

Goal: To bring together stakeholders from the leading organisations invested in paediatric pain management (International Society for the Study of Pain, Childhood Special Interest Group; Australian Pain Society, Pain in Child Health), consumer groups (children and parents of children experiencing pain), pain researchers, digital health experts, and clinicians, to form a community of practice. This is a clinical and academic collaboration between hospital-based and university-based clinicians and researchers.

Objective: To produce a standard for reporting and audit/feedback of paediatric pain data in EHRs.
The collaboration is the starting point for ongoing work using EHRs to standardise the assessment and management of children's pain by the multi-disciplinary team. The UoM, UniMelb and UofT partner with hospitals using the same EHR (Epic). Achievement of standards in reporting and audit/feedback of children's pain management data within EHRs will identify barriers to knowledge translation and practice issues, providing opportunities for research and quality improvement. The outputs of this initial collaboration (environmental scan and Delphi survey) support future funding applications. The team members will write funding proposals during visits to partner sites and online meetings. Proposed funding schemes that will be targeted:
• Medical Research Future Fund (Clinician/ ECR schemes, Australia)
• National Institute of Health Research (UK) – Research for Patient Benefit (RfPB) and Health Services and Delivery Research (HS & DR) streams
• Canadian Institutes of Health Research (Planning and meeting grant led by Dr. Stinson for consensus meeting in 2024).

Q9. Equality, Diversity and Inclusion (max 100 words)

Please provide an outline of how the proposed project will address the EDI priorities of the involved institutions

Groups known to have inequitable access to pain management are indigenous communities, children with sickle cell disease, children with disabilities and newborns. The true extent of inequity in children's pain management is unknown. This collaboration will establish how children's pain is reported in EHRs and identify best practices for reporting and auditing pain. Children who have historically had unmanaged/ poorly treated pain will be identified by doing so. Adequate reporting and auditing of EHR pain data provides crucial information about children's pain care and highlights where the inequities exist. Efforts can be made to treat all children's pain appropriately.

Budget: A breakdown of the cost of the activity

Please provide breakdown of costs to be charged to The University of Manchester.
You should use a line for each different item e.g. flights, hotels etc.

	Item(s)	Amount (£)
1	Lee - Manchester to Darwin, Darwin to Melbourne, Melbourne to Manchester	2500.00
2	Accommodation – 8 nights Australia	£160 per night x 8 = £1280
3	Subsistence Australia (including transportation)	£80 per day x 8 = £640
4	Dowding and Lee to Toronto for planned meeting	£800x 2 - £1600
5	Accommodation–5 nights	150 per night x 2 x 5 = £1500
6	Subsistence Toronto	£75 per day x 2 x 5 = £750
7	Room booking – meeting at Manchester (AMBS)	£350
8	Refreshments – meeting at Manchester	£240

Total Funding Sought from Manchester (up to a maximum of GBP 9,000)
8860

Please provide breakdown of costs to be charged to The University of Melbourne
You should use a line for each different item e.g. flights, hotels etc.

	Item(s)	Amount (AUD)
1	Airline flights Melbourne-Manchester-Melbourne for Jones & Pope	5186.00
2	Subsistence for (expenses for 6 days) including ground transportation in Manchester	150 per day x2 = 1800
3	Accommodation for (2 rooms for 6 nights), Hyatt House, Manchester	3624.00 (302 per night x2 rooms)
4	Return flight Manchester to Toronto for 1 team member	1500
5	Accommodation Toronto (3 nights) x1 room (Radisson Blu)	1050 (350 per night)
6	Subsistence for (expenses for 3 days) including ground transportation in Toronto	600.00
7	Room booking - meeting at Melbourne (half day)	650.00
8	Refreshments – meeting at Melbourne	550.00

Total Funding Sought from Melbourne (up to a maximum of AUD 15,000)
14960

Please provide breakdown of costs to be charged to The University of Toronto
You should use a line for each different item e.g. flights, hotels etc.

	Item(s)	Amount (CAD)
1	Return fight Toronto to Manchester for 2 team members	2800
2	Accomodation in Manchester for 5 nights for 2 team members	2660 (266 per night x2 x5 nights)
3	Subsistence Manchester (including transportation) for 2 team members	1300
4	Flight Toronto to Darwin, Darwin to Melbourne, Melbourne to Toronto for 1 team member	3950
5	Accommodation in Darwin & Melbourne for 8 nights for 1 team member	1300 (175 per night x5 in Darwin and 250 per night x2 in Melb))
6	Subsistence Australia (including transportation)	950 (135 per day)
7	Room booking - meeting Toronto	550
8	Refreshments - meeting Toronto	350

Total Funding Sought from Toronto (up to a maximum of CAD 14,000)
13860

Project Team

Manchester - Please provide details of Manchester researchers involved in the project.

To be eligible, a proposal must include at least 2 researchers from each partner university (the co-PI counts as one) and must be led by, or include in a significant role, ECRs (as defined by their institution of employment).

	Title & Full Name	Position	Dept/Faculty/School
1	Prof Dawn Dowding	Professor in Clinical Decision Making	Division of Nursing, Midwifery and Social Work/School of Health Sciences/Faculty of Biology, Medicine and Health
2	Dr Rebecca Lee	Research Fellow	School of Biological Sciences/Faculty of Biology, Medicine and Health
3	-	-	-
4	-	-	-
5	-	-	-
6	-	-	-
7	-	-	-
8	-	-	-
9	-	-	-

The budget holder and approver for this fund is Joanne Jacobs, International Relations. Please tell us the name of the PS member of staff in your School/Institute who will be responsible for the financial administration of your award e.g. raising requisitions, setting up casual staff etc.
Sarah Moxon (sarah.moxon@manchester.ac.uk)

Melbourne - Please provide details of Melbourne researchers involved in the project.

To be eligible, a proposal must include at least 2 researchers from each partner university (the co-PI counts as one) and must be led by, or include in a significant role, ECRs (as defined by their institution of employment).

	Title & Full Name	Position	Dept/Faculty/School
1	Dr Sophie Jones	Lecturer/ Digital Health Education and Workforce Development lead (Nursing)	Department of Nursing/ School of Health Sciences/ Faculty of Medicine, Dentistry and Health Sciences
2	Prof Denise Harrison	Professor	Department of Nursing/ School of Health Sciences/ Faculty of Medicine, Dentistry and Health Sciences
3	Dr Mark Merolli	Senior Lecturer & Research Fellow	Department of Physiotherapy/ School of Health Sciences/ Faculty of Medicine, Dentistry and Health Sciences
4	Ms Nicole Pope	PhD student	Department of Nursing/ School of Health Sciences/ Faculty of Medicine, Dentistry and Health Sciences
5	-	-	-
6	-	-	-
7	-	-	-
8	-	-	-
9	-	-	-

Toronto - Please provide details of Toronto researchers involved in the project.

To be eligible, a proposal must include at least 2 researchers from each partner university (the co-PI counts as one) and must be led by, or include in a significant role, ECRs (as defined by their institution of employment).

	Title & Full Name	Position	Dept/Faculty/School
1	Dr Jennifer Stinson	Professor – Status	Lawrence S. Bloomberg Faculty of Nursing
2	Dr Chitra Lalloo	Assistant Professor (Status)	Institute of Health Policy, Management and Evaluation, University of Toronto
3	Dr Quynh Pham	Scientific Director/ Assistant Professor (status)	Centre for Digital Therapeutics, Institute of Health Policy, Management and Evaluation, University of Toronto
4	Prof Fiona Campbell	Professor of Anesthesia	Department of Anesthesiology and Pain Medicine, University of Toronto
5	-	-	-
6	-	-	-
7	-	-	-
8	-	-	-
9	-	-	-

Supporting Documents

Please upload the following supporting documents. Abbreviated CVs (max 2 pages) of all lead collaborators (Co-Is) with selected list of publications UoM: Support letter from Line Manager/ or Head of Department/Research Domain UniMelb: All applicants are required to enter the application into the Themis Submissions Workbench and have approved by their Head of Department by the deadline.

- File: 2 Page CV_Jen_Stinson_2023.pdf
- File: Sophie Jones CV_May 2023_2pages.pdf
- File: Dowding short CV May 23 (002).pdf
- File: Dowding letter of support May23.pdf

Declaration & Approval

Declaration

We declare that the statements made and information given in this application are to the best of our knowledge, true, complete, and correct. We have read and fully understand the Guidelines for Applicants. We understand that the personal data provided in this form will be used by the relevant committees and authorised personnel responsible for handling applications for the award.

Confirm

Notification of Outcome

From: Researcher Development Schemes
To: dawn.dowding@manchester.ac.uk; Sophie Jones; jennifer.stinson@sickkids.ca
Cc: luketx.li@utoronto.ca; Kevin Rowley; Alicja Sobecka; international partnerships; Researcher Development Schemes; Mark Gregory; Anton Donohoe-Marques
Subject: the Manchester-Melbourne-Toronto Research Fund Notification
Date: Friday, 11 August 2023 1:37:34 PM
Attachments: MMT Research Fund Guidelines 2023 (1).pdf

Dear Prof Dowding, Dr Jones, Dr Stinson,

Thank you for your application for the Manchester-Melbourne-Toronto Research Fund.

We are pleased to inform you that your project titled "Standards for reporting and auditing children's pain in EHRs" has been selected for funding.

The funding amounts are as follows:

- Manchester funding: GBP £ 8860
- Melbourne funding: AUD $ 14960
- Toronto funding: CAD $ 13860

Please refer to the attached guidelines for important information on Reporting and Publications requirements, as well as details about Change of Investigator and Extensions.

You will receive additional information regarding the transfer and administration of funds shortly from each respective institute.

Kindly reply to this email to confirm your acceptance of the award.

Once again, congratulations on your achievement, and we wish you great success with your research project!

Best wishes,

Manchester-Melbourne-Toronto Research Fund Selection Committee

The University of Melbourne, the University of Manchester and the University of Toronto

Professor Justin Zobel, Pro Vice-Chancellor, Graduate & International Research The University of Melbourne	Professor Stephen Flint, Associate Vice-President, Internationalisation The University of Manchester	Professor Alex Mihailidis, Associate Vice-President, International Partnerships The University of Toronto

Appendix N
Graduate Researcher Development Grants

Application

Faculty of Medicine, Dentistry and Health Sciences
Graduate Researcher Development Grants for 2022

Applications

Applications are sought for grants of up to $25,000 to support projects, within the area of graduate researcher development, to be undertaken within twelve months of funding being awarded.

Applications are welcomed from current graduate researchers and academic staff (in fixed term or continuing appointments) of the MDHS Faculty. Graduate researcher led projects are encouraged however, it must be in collaboration with an academic staff member. Honorary academic staff are eligible to lead an application where their primary research affiliation is the MDHS Faculty.

The grants will be funded by the MDHS Faculty and will be awarded to projects that stand to demonstrably advance development for graduate researchers. Priority will be given to projects that advance graduate researcher development in ways that align with or complement the objectives and priorities of the Faculty, and from teams of applicants drawn from different Schools and Departments.

Where an application proposes to design, develop and pilot a graduate researcher development offering, this may take the form of seminars, workshops, programs, webinars, or podcasts, but is not limited to these formats. Offerings should take into account the unpredictability of working arrangements occasioned by the COVID-19 pandemic (for example, by including options for online participation).

Projects should be delivered within twelve months of funding being awarded. However, within that parameter the length of individual projects is not fixed, so as to allow flexibility to suit the proposed project. Please include and justify the proposed timing of the project in the application.

Applications should outline ways in which the applicant or applicants will work closely with graduate researcher cohorts to ensure that projects are responsive to cohort needs, interests and preferences.

Please send your application and any questions to rwhitsed@unimelb.edu.au. Applications are due on 30 April 2022.

FACULTY OF MEDICINE, DENTISTRY AND HEALTH SCIENCES

RESEARCHER DEVELOPMENT GRANT APPLICATION FORM 2022

Name and current position of applicant(s):

- A/Prof Catherine Granger, Director of Graduate Research, School of Health Sciences & Associate Professor in Department of Physiotherapy
- Professor Alicia Spittle, Associate Dean Research, Faculty of Medicine, Dentistry and Health Sciences & Professor in Department of Physiotherapy
- Dr Lyndal Hickey, "Diversity and Inclusion Hub" School of Health Sciences Hub Champion & Teaching and Research Fellow in Department of Social Work
- Dr Stephen McKeever, "Healthy Start to Life Hub" School of Health Sciences Hub Champion; Early and Mid-Career Academic Association Representative, School of Health Sciences; & Lecturer in Department of Nursing
- Dr Selina Parry, "Optimising Health and Wellbeing Hub" School of Health Sciences Hub Champion & Teaching and Research Senior Lecturer in Department of Physiotherapy
- A/Prof Sarah Wise, Graduate Research Coordinator & Associate Professor in Department of Social Work
- Dr Kate Hayward, Graduate Research Coordinator & Senior Research Fellow in Department of Physiotherapy
- Professor Kim Bennell, Graduate Research Coordinator & Professor in Department of Physiotherapy
- Ms Nicole Pope, PhD Candidate, Department of Nursing
- Ms Georgina Whish-Wilson, PhD Candidate, Department of Physiotherapy
- Mr Peter Blight, Academic Programs Coordinator (Research), School of Health Sciences

Project Title: Inspiring diversity in career pathways for clinician graduate researchers

Brief Description (no more than 500 words) of the proposed researcher development offering (please explain here: (a) how the budget and length of project are justified in light of project aims; (b) how the project aims align with or complement the objectives and priorities of the MDHS Faculty; and (c) how you intend to engage graduate researchers.

This project centres on career preparedness and development of clinician graduate researchers (GRs). It aims to facilitate GRs to actively plan career options early in their candidature, inspire and educate them about diverse career pathways, and create a network of GRs and alumni across various industries.

Alignment with Faculty: A MDHS Review of Graduate Research top recommendation was that Faculty should allocate resources to career readiness programs. The review documented that GRs felt there was no clarity on transitions from PhD to employment and felt unsupported when looking for career pathways. In addition, it was recognised that the support required for clinicians doing PhDs is different and that support should be tailored. This project addresses these recommendations. It also aligns with MDHS values, especially collaboration, diversity, and inclusion.

GRs: This initiative arose out of Q&A event A/Prof Granger held with the MSHS GRs in 2021. We brainstormed ideas for new initiatives to improve GR experience and raised the concept of a GR

careers program. Our team includes two PhD candidates; they have been and will be involved in all aspects of the project including seminars, evaluation, and dissemination (co-author) of results.

This 10-month offering includes:

1) Career showcase:
    - Q+A seminars "Ask me anything" held monthly
    - Purpose: to provide GRs an opportunity to ask guests questions about their career, i.e., pathway, challenges, advice, lessons learnt.
    - Guest: One speaker per event. Guests will be diverse (i.e., gender, culture, sexuality, age), ideally a PhD alumnus of MDHS & from an allied health or nursing clinical background. A variety of careers will be showcased including Hospital CEO/ Chief Allied Health Officer, Department of Health, Private Practice, and Industry.
    - Participants: For this pilot, all GRs from MSHS will be invited regardless of whether they have a clinical background. Clinician GRs will be strongly encouraged to attend. A variety of different times and delivery formats will be offered to be inclusive of different work patterns.
    - Host: Co-chaired by a GR and academic staff member.
    - Venue: Dual Delivery.
2) Building your CV:
    - Seminar focused on building a competitive CV for jobs post-graduation.
    - Meeting with panel of experienced academics for CV review and advice.
3) Alumni mentoring careers program:
    - A sub-group of confirmed GRs will enter a formal mentoring program with an alumnus of MDHS. Mentees will be matched with a mentor in an industry that is closely related to their desired career pathway.

Evaluation: The primary outcome is GRs' experience of the program measured using focus groups and surveys. All GRs in MSHS (N=141) will be invited to complete the survey. Focus groups conducted with a sub-group. Ethics will be sought. Results will be disseminated within faculty, industry (including prospective clinician GRs), and as a journal publication.

Budget and length: 10-month program and 2-month evaluation. If successful, the vision is for a yearly rolling program running March-December. $25,000 will contribute to research assistant salaries (assist with organisation/coordination of program and evaluation), catering, and vouchers (guests and focus groups).

Notification of Outcome

THE UNIVERSITY OF MELBOURNE

Nicole Pope <nppop@student.unimelb.edu.au>

FW: MDHS Graduate Research Development Grants - Outcome

7 messages

Catherine Granger <catherine.granger@unimelb.edu.au> Mon, Jun 27, 2022 at 9:43 AM
To: Lyndal Hickey <hickeyl@unimelb.edu.au>, Peter Blight <pblight@unimelb.edu.au>, Sarah Wise <sarah.wise@unimelb.edu.au>, Kim Bennell <k.bennell@unimelb.edu.au>, Kate Hayward <kate.hayward@unimelb.edu.au>, Stephen McKeever <mckeever@unimelb.edu.au>, Selina Parry <selina.parry@unimelb.edu.au>, Georgina Whish-Wilson <gwhishwilson@student.unimelb.edu.au>, Nicole Pope <nicole.pope@student.unimelb.edu.au>, MDHS Associate Dean Research <MDHS-ADResearch@unimelb.edu.au>
Cc: Bruce Thompson <b.thompson@unimelb.edu.au>, Denise Harrison <deniseh@unimelb.edu.au>, Patricia Murray <p.murray@unimelb.edu.au>

Dear CIs

Thank you for your contribution to this grant application.

I am delighted to share the news that we were successful in being awarded $20,000 for our project 'Inspiring diversity in career pathways for clinician graduate researchers'.

We have until the end of the year to use the funds. I will be in touch again very shortly to set up a meeting to plan the project, evaluation (including ethics applications) and recruitment of an RA to work on the project.

Thanks

Catherine

Associate Professor Catherine Granger FACP PhD BPhysio(Hons) GCUT

Dame Kate Campbell Fellow | Physiotherapy | Faculty of Medicine, Dentistry & Health Sciences

Director of Graduate Research | Melbourne School of Health Sciences

Physiotherapy Research Lead | The Royal Melbourne Hospital

Level 7, Alan Gilbert Building, 161 Barry Street

The University of Melbourne, Victoria 3010 Australia

P: +61 3 8344 8126 **M:** +61 439 854 672 **E:** catherine.granger@unimelb.edu.au

Pronouns: She/her

From: Rebecca Whitsed <rwhitsed@unimelb.edu.au>
Sent: Friday, 24 June 2022 1:49 PM
To: Catherine Granger <catherine.granger@unimelb.edu.au>
Cc: MDHS Associate Dean Graduate Research <mdhs-adgr@unimelb.edu.au>
Subject: MDHS Graduate Research Development Grants - Outcome

Dear Catherine et al.,

Congratulations on your successful application to the MDHS Graduate Research Development Grant scheme for your project 'Inspiring diversity in career pathways for clinician graduate researchers!'

Below is a summary of the conditions of the award, reporting requirements and information we require from you to arrange the transfer of funds.

Award Conditions

- Projects must be completed and funds expended by 31 December 2022. If you require an extension, please contact us to discuss.
- Funds must be expended as per the budget detailed in the submitted EOI (attached). If there are any changes to the planned expenditure of the funds, please contact us to discuss.
- Project outputs (i.e. events, workshops, resources) are to be promoted on the Biomedical and Health Sciences PhD Program Canvas site (where applicable), we will work with you to enable this as well as utilise our existing comms channels to assist in promotion/communication. Please keep us in the loop as your project develops so we can provide support and don't hesitate to reach out if we can assist in any other way more generally.

Reporting

- Initial funding meeting to be held with Associate Dean Graduate Research and awardees to further discuss the project.
- Mid Report – due 3 months into the project.
- Final Report – due at the completion of the project.
- A template document for both reports will be provided to all awardees with confirmed due dates for reporting once funds have been transferred.
- Presentation to be made to the Faculty Graduate Research Experience and Wellbeing Subcommittee (FGREWSC) in early 2023.

Required Information for Funds Transfer

- The total award amount of $20,000 will be transferred to you by the CFO Group. We understand in some cases this may not be the amount you requested in your proposal however, in balancing the budget we wanted to support as many worthwhile initiatives as possible.

- Please complete the below and provide a complete account string for the account in which the funds will be deposited:

Company	Budget Unit	Cost Centre	Project	LPC	Activity	Location

Congratulations again and we look forward to working with you!

Kind regards,

Rebecca

Rebecca Whitsed (she/her) | **PhD Programs & Project Coordinator**

Learning and Teaching Unit | Faculty of Medicine, Dentistry and Health Sciences

Level 1, Brownless Biomedical Library

The University of Melbourne, VIC 3010 Australia

T: (03) 8344 5679 **M:** 0428 131 380 **E:** rwhitsed@unimelb.edu.au

unimelb.edu.au | facebook.com/melbuni | twitter.com/unimelb

Please note: I am working from home.

We acknowledge the Traditional Owners of the land on which we work, and pay our respects to the Elders, past and present.

Appendix O
Study One Email Invitation

THE UNIVERSITY OF MELBOURNE

Nicole Pope <nppop@student.unimelb.edu.au>

Seeking Research Participants: The PARTNERSHIP Study
12 messages

Nicole Pope <nicole.pope@student.unimelb.edu.au> Thu, Nov 18, 2021 at 8:58 AM
To: PEDIATRIC-PAIN@lists.dal.ca

Dear colleagues,

Our team of clinicians and researchers are conducting a project exploring how electronic medical/health records (EMRs/EHRs) are designed and used to facilitate best pain care for hospitalised children.

This research is called: The PARTNERSHIP Study: ExPloring recommendAtions and pRacTice usiNg EmRS to Help kids In Pain.

We need your expertise! We would like to interview you about your experiences as clinical pain experts using EMR/EHRs to care for hospitalised children with pain.

We will first ask you to complete a brief (5-10min) survey to capture demographic details. This will be followed by a (virtual) interview, which will take about 60 minutes.

More information about the project and our team can be found in the attached information sheet.

This research is funded by grants from the University of Melbourne, Australia (Melbourne Research Scholarship, Be Sweet to Babies Studentship and The Vera Scantlebury Brown Scholarship) This study has been approved by the University of Melbourne Health Research Ethics Board (HREC REF: 2021-22171-23430-6).

Please contact me or email Prof. Denise Harrison,

deniseh@unimelb.edu.au, the Responsible Researcher if you would be interested in participating in this study. We would be happy to provide you with more information.

Sincerely,

Nicky

Nicole Pope | (RN, MPhil) | PhD Student
Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

The University of Melbourne, Victoria 3010 Australia

m: +61 400 981 610 | **e:** Nicole.Pope@student.unimelb.edu.au
Twitter: @NickyPope16 | ORCID: 0000-0001-7617-8778

I acknowledge the Traditional Owners of the land on which I work, and pay my respects to the Elders, past and present.

Appendix P
Study One Participant Information Sheet

PARTNERSHIP Study
ExPloring recommendAtions and pRacTice usiNg
EMRS to Help kids In Pain

THE UNIVERSITY OF MELBOURNE

Plain Language Statement

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

Prof. Denise Harrison (Responsible Researcher)	Tel: +61 (3) 9035803	deniseh@unimelb.edu.au
Ms Nicole Pope (PhD Student)	Tel: +61 400 981 610	Nicole.pope@student.unimelb.edu.au
Dr. Dianne Crellin (Associate Researcher)	Tel: +61(3) 3844 4947	dcrellin@unimelb.edu.au
A/Prof. Greta Palmer (Associate Researcher)	Tel: +61 (3) 93454753	greta.palmer@rch.org.au
Prof. Mike South (Associate Researcher)	Tel: +61 (3) 9345 5182	mike.South@rch.org.au

Introduction

Thank you for your interest in participating in this research project. The following information about the project is provided so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This research is the first part of a larger study looking into how electronic medical records (EMRs), sometimes called electronic health records (EHRs), are used to care for children in hospitals who have pain. This part of the research project hopes to learn more about what clinical pain experts, like you, think are important features and functions of EMRs/EHRs used in your hospitals to provide best pain care to children.

What will I be asked to do?

Should you agree to participate, you will be asked to complete a brief online survey (5-10mins). You will then be asked to take part in a virtual (online) interview using the Zoom videoconferencing platform. It would be helpful to see each other during this conversation so it would be ideal to have your camera turned on during the interview. But you can choose to have your camera off if you wish. The interview should take approximately 1 hour (60min) to complete and will be audio-visually recorded. It will

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

be essential to have access to a secure internet connection and a quiet space for these interviews. If there are technical difficulties or if you prefer not to use Zoom, the interview can be done over the telephone. A summary of your results can be shared with you to ensure that the researcher accurately captured our interview. Final study results can also be shared with you if you would like. If you agree to participate in this study, you will be asked to sign electronic consent which will be obtained at the beginning of the online survey. You will be given a copy of this Participant Information Sheet and the Consent form to keep.

What are the possible benefits?

This will be the first study to explore clinical pain experts' views on using EMRs/EHRs to provide the best pain care to children in hospitals. The results may benefit all people involved in caring for children in hospital, and importantly, children and families themselves. Learning about the features and functions of EMRs/EHRs that allow for best pain care may help other children's hospitals better use EMRs/EHRs when caring for children. We may also learn how EMRs/EHRs can be enhanced to improve care for children with pain. Finally, we will also learn about how EMR/EHR data can be used for future research and hospital quality improvement activities.

What are the possible risks?

This is a negligible risk research project. There is no foreseeable risk of harm or discomfort associated with your participation in this project. The Zoom interviews help to save time (i.e., travel time) and expense. The interviews will be scheduled at a time that is convenient for you.

Do I have to take part?

No. Participation is entirely voluntary. You can withdraw at any time. If you wish to withdraw during the online interview, you can simply exit the meeting without explanation. All information that you have provided, including the interview recordings, can also be withdrawn and will not be used for the research project if you wish. Any associations you have with the University of Melbourne, health services or researchers will not be affected if you choose not to participate

Will I hear about the results of this project?

A summary of early results of this research project will be shared with you if you would like to read the results and confirm that they align with the information you shared at the time of the online interview. A summary of the final results of this study will be shared with you and at research conferences and forums, and published in an academic, peer-reviewed journal.

Ethics ID Number: 2021-22171-23430-6 Plain Language Statement: V3 02/09/2021

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

What will happen to information about me?

The information we collect from the brief survey and the interviews will be securely recorded, and these recordings and your information will be totally confidential and stored securely on the University of Melbourne's server in password-protected files. Only the research team will have access to this data. Your name, or any other personal information, will not be used at any stage, including when results are published and shared. All data will be retained for five years following publication. All data will be deleted following this period.

Is there any potential conflict of interest?

There are no potential conflicts of interest associated with this research project.

Who is funding this project?

Nicole Pope (PhD Student) is the recipient of the Melbourne Research Scholarship, the Be Sweet to Babies Studentship, and the Vera Scantlebury Brown Scholarship. These funding sources are supporting the full program of research.

Where can I get further information?

If you would like more information about the project, don't hesitate to get in touch with the researchers whose names and contact details are provided at the top of this document.

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne (HREC REF: 2021-22171-23430-6). If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team and/or the name or ethics ID number of the research project.

Appendix Q
Study One Participant Consent Form

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

Consent Form

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

Responsible Researcher: Professor Denise Harrison

Additional Researchers: Nicole Pope (Research student), Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor)

Name of Participant: _____

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that the purpose of this research is to understand how Electronic Medical Records systems (EMRs) can facilitate best pain management practices for hospitalised children and their families.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I will be required to offer my thoughts and ideas of about what features and functions of EMRs allow best pain care practices for hospitalised children and their families.
6. I understand that my interviews will be audio and/or videotaped.
7. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
8. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
9. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
10. I understand that given the small number of participants involved in the study, it may not be possible to guarantee my anonymity.
11. I understand that after I sign and return this consent form, it will be retained by the researcher.

Participant Signature: Date:

Ethics ID Number: 22171 Project Start Date: 30/09/2021 Version: V1

Appendix R
Study One Questionnaire

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

REDCap Questions

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

Survey Information for participants

As a clinical pain expert working in a hospital with an advanced electronic medical/health record (EMR/EHR) system you have been invited to participate in this study, which seeks to learn about how EMR/EHRs are used to provide pain care to hospitalised children. (please see plain language statement linked below)

There are two parts to this study; the first is this brief online survey, the second is virtual (online) interview, details of which will be confirmed with you.

In this survey, we ask questions about the EMR/EHR used in your hospital, including features and functions of the EMR/EHR related to pain care for children. There will also be some questions related to your involvement in tailoring the EMR/EHR for your hospital

Please answer all questions. If you are unsure of any details, please select the response that most closely applies to you.

The survey will take approximately 5 -10 minutes to complete. Your answers will be saved at the completion of the survey.

Consent Form

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences
Responsible Researcher: Professor Denise Harrison
Additional Researchers: Nicole Pope (Research student), Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor)

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement (attached) to keep.
2. I understand that the purpose of this research is to understand how Electronic Medical/Health Records systems (EMRs/EHRs) can facilitate best pain management practices for hospitalised children and their families.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I will be required to offer my thoughts and ideas of about what features and functions of EMRs allow best pain care practices for hospitalised children and their families.
6. I understand that my interviews will be audio and/or videotaped.

Ethics ID Number: 22171 Script and Interview Guide: V3 02/09/2021

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

7. I understand that my participation is voluntary, and if I do not wish to take part, I am under no obligation to do so. I am also free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
8. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
9. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
10. I understand that given the small number of participants involved in the study, it may not be possible to guarantee my anonymity.
11. I understand that after I sign and return this consent form, it will be electronically retained by the researcher.

Yes, I have read and understood the information and would like to proceed

No, I do not want to complete the survey

Survey Questions

What is your professional group?

Nursing

Medical

Allied Health (e.g., OT, PT, Resp Therapist)

Other – Please specify

I have worked in this profession for (years):

What is your specialty?

What hospital do you work at? (please specify below):

What is your department/division?

What EMR/EHR System does your hospital use?
EPIC
Cerner
CareCloud
Athenahealth
GE Centricity
eClinicalWorks
nextgen
Allscripts

Ethics ID Number: 22171 Script and Interview Guide: V3 02/09/2021

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Praxis
Meditech
Medhost
Netsmart Technologies
UH Medical records

Other: (Please specify below)

How long has the EMR system been implemented at your hospital?

0-5 years

6- 10 years

11 – 15 years

16-20 years

More than 20 years

Unsure

Was it possible to tailor the EMR system to suit your organisation?

Yes

No

Unsure

Were EMR system functions tailored to address pain care?

No

Unsure

Yes

Were you involved in tailoring EMR system functions for pain care?

No

Yes

If yes, how so? (Please specify below)

Not applicable

How is data entered into the EMR? (Select all that apply)

Fixed computer

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Portable computer

Handheld device

An integrated patient portal system

Integrated equipment (Please specify the type of equipment, i.e., a monitor)

Who can enter data into the EMR (Select all that apply)

Clinicians

Parents

Children (patients)

Who can enter pain-related data into the EMR? (Select all that apply)

Clinicians

Parents

Children (patients)

What pain assessment tools are integrated into the EMR? (Select all that apply)

Faces Leg Activity Cry Consolability (FLACC)

Wong-Baker FACES pain rating scale

Faces Pain Scale-Revised (FPS-R)

Visual Analog Scale (VAS)

Colour Analog Scale (CAS)

Numerical Rating Scale (NRS)

Neonatal Pain Assessment Tool (PAT tool)

Neonatal Infant Pain Scale (NIPS)

Premature Infant Pain Profile (PIPP)

Premature Infant Pain Profile-Revised (PIPP-R)

Other (Please specify below)

Ethics ID Number: 22171 Script and Interview Guide: V3 02/09/2021

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

What sorts of pain interventions are recorded in the EMR? (Select all that apply)

Medications

Physical measures (i.e., Comfort positioning, breastfeeding)

Psychological measures (i.e., Cognitive Behavioural Therapy)

Would you like to receive a copy of the preliminary findings gathered from the interview?

Yes

No

If YES, would you be willing to offer feedback on these findings to ensure their accuracy?

Yes

No

Do you have any other comments about your hospital's EMR system?

Ethics ID Number: 22171

Script and Interview Guide: V3 02/09/2021

Appendix S
Study One Interview Guide

Script and Interview Guide

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

Date and time of interview:
Duration:

Script

Hi, my name is Nicky Pope. I am a Ph.D. student at the University of Melbourne, Australia. I am also a paediatric nurse.

I wanted to start by saying thank you for taking the time to participate in this study. As mentioned in the information you received, this study is the first of larger research project aimed at exploring how EMRs are used to facilitate best pain management for hospitalised children.

I thought it might be helpful to start with a background. As clinicians, we know that children in hospitals undergo several painful procedures each day and that almost all children will experience pain while they are in hospital. We also know that despite synthesised evidence and recommendations on best pain care, children's pain is undertreated in children's hospitals worldwide. The reasons behind this are complex. It is generally thought that EMRs have the potential to help improve the way clinicians provide care. EMRs can make care more efficient, reduce errors, standardise care, and even enhance assessing and managing children's pain. EMRs have been implemented in the US/Canada since the early 2000s; however, Australian paediatric hospitals have only begun using EMRs in the last six years.

Given your expertise on children's pain, and that you work in a hospital with an advanced EMR, and your experience using EMRs, we have a lot to learn from you about the functions, and features of EMRs that support best pain care practices for children.

I expect that this interview will take approximately 60mins. If at any time you wish to withdraw from the interview, please feel free to do so. You can 'leave' the meeting. If you are experiencing technical difficulties, we can always revert to telephone interviews. My phone number is available on the information sheet, but I will also put it in the chat.

As you know, I will record this interview for data analysis. Please also remember to refrain from disclosing any personal or identifiable information related to patients, families, or colleagues. Do you still consent to have this interview recorded? Ok- I am going to go ahead and press record now.

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START RECORDING- PUT PHONE NUMBER IN CHAT

I want to confirm that the interview is now being recorded. Thanks again for offering your time and sharing your expertise about how EMRs can be used to facilitate best pain care for children.

If I can confirm a few details

Participant Name:

Hospital:

Department/Role:

Thank you. Ok, I want to try and understand a bit about how clinicians in your organisation record and access clinical data regarding the assessment and management of children's pain and this might vary for different disciplines, so can I ask you to focus on how a nurse/doctor might engage with the EMR?

	Interview script	Key Topics (not direct questions)	
Access	Ok. Perhaps we could start by you telling me about how pain-related data is recorded in the EMR	Can information be added at the patient's bedside?	
		Does the EMR integrate with other systems to capture pain data, e.g., are other things integrated such as monitors	
		Can children or families enter their own pain data into the EMR directing using an interface?	
Assessment	Thank you for that information. I would now like to focus on pain assessment. Can you tell me about how clinicians use EMR to undertake a pain assessment and enter pain assessment data?	What pain data can be entered into the EMR?	
		How are pain assessment tools accessed in the EMR?	
		Are there any prompts or reminders to guide clinicians to undertake a pain assessment using a pain assessment tool? Can you describe how these work?	
		Do you think prompts help guide clinicians to undertake a pain assessment and guide interventions	
		Can pain assessment be documented in any other way besides using a tool?	
	We know that sometimes capturing other aspects of pain in pain assessment, beyond the physical symptoms, can be difficult. Can you tell me a little about how/if clinicians can enter psychosocial aspects of pain, such as anxiety, stress, fear – in the EMR?	How does the EMR allow for biopsychosocial assessment of pain, are there prompts to remind staff to consider these aspects of pain assessment?	

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	Given your experience using EMRs, do you think that the EMR could be optimised in any way to enhance the way clinicians assess children's pain?	What might improve the way clinicians access pain assessment tools?	
		What might improve the frequency of pain assessment?	
		What might improve the way clinicians assess other aspects of pain beyond physical symptoms?	
Interventions	Thanks for the information on pain assessment. I want to move the focus to pain interventions now. Can you tell me about how clinicians use the EMR in ordering and providing interventions for pain?	Are there prompts and reminders to guide clinicians in the prescription of pharmacological interventions? Can you describe how this works?	
		Are there prompts and reminders to guide clinicians in prescribing non-pharmacological interventions (Physical and Psychological interventions)? Can you describe how these work?	
		Are there prompts and reminders to guide clinicians to offer/provide/administer pharmacological AND non-pharmacological interventions? Can you describe how these work?	
	We know that sometimes children miss out on non-pharmacological interventions. Do you have any suggestions on how an EMR might help clinicians to consider non-pharmacological measures?	What might improve the way clinicians provide pain intervention?	
		What might help clinicians to consider using non-pharmacological measures	
Re-assessment	Thank you. I am now moving on to the re-evaluation of pain. Would you mind telling me about how clinicians use the EMR to undertake a re-evaluation of pain, whether this is following an intervention or as part of ongoing care?	Are there prompts to guide re-assessment of pain following intervention? Can you describe how these work?	
		What might improve the re-assessment of pain following intervention?	
Decision support	We have spoken a bit about the decision support functions of your hospital's EMR concerning pain assessment and interventions. Can you think of any other clinical decision support functions of your hospital's EMR that help clinicians provide pain care to children and drive improvement in care?	How are Clinical Practice guidelines embedded in the EMR?	
		Are any other decision supports embedded into the EMR?	
Collaborativ	Ok. Thank you. I want to move on to learn about how children and families are involved in their pain care in your hospital, with a	How does your EMR allow patients and families to be involved in pain assessment, intervention decisions, and re-assessment? How might the EMR system be optimized to meet clinical and consumer needs?	

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	particular focus how the EMR or related system. Can children and families use the EMR or a portal to be involved in their pain care?	How might the EMR system be optimized to enable collaborative decision-making between HCP and families better?	
Use of data	I would like to now move on to the use of EMR pain data. Can you tell me how/if the pain data entered in the EMR is used for any quality improvement activities?	How do you use EMR pain-related data?	
		Is EMR data used in quality improvement – if so, how?	
EMR impact	Thank you. So, nearing the end of my questions, now. I want to learn about how you think EMRs have impacted pain care practices in your hospital?	What impact do you think EMR has had on pain practices?	
		How do you see the future of EMRs in pain care for hospitalised children	
		Can you think of any barriers relevant to your hospital that impact how clinicians use EMRs to manage pain?	

Thank you. Well, that concludes my questioning. Before we end the interview, did you have any questions or comments you wish to make?

Thank you once again for offering your time and expertise. I greatly appreciate you sharing your thoughts today. If you have not got anything further you would like to add, and I will stop the recording now

STOP RECORDING

Colleague recommendation (for snowballing recruitment):

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Appendix T
Study One Human Research Ethics Committee Approval

Office of Research Ethics and Integrity

Human Ethics Application Approval

ATTENTION: PROF Denise Harrison

154 - Nursing
140 - Medicine, Dentistry and Health Sciences
The University of Melbourne

Research Application

Reference Number:	2021-22171-23430-6
Project Title:	Exploring international pain expert recommendations regarding the use of Electronic Medical Record Systems to optimise pain management for hospitalised children

Dear PROF Denise Harrison,

Thank you for your response to queries raised by LNR 4C at a meeting held on 15 October 2021 .

The Committee agreed to **approve** the application on the basis that it meets the requirements of the National Statement on Ethical Conduct in Human Research (2007, Updated 2018). Please see overleaf, *Summary Details for the Approved Human Ethics Project* and *Conditions of Approval*. It is your responsibility to ensure that all people associated with the Project are made aware of what has been approved.

Desk-based elements of your project and face-to-face research can commence now, as can data collection that can be conducted online or via telephone, subject to necessary approvals or amendments to ethics applications.

Please consult the COVID-19 website for research guidance, FAQ and updates. https://staff.unimelb.edu.au/covid-19-response/research-activity

If you have any queries on these matters, or require additional information, please contact me using the details below. Please quote the ethics ID number and the title of the Project in any future correspondence.

Yours sincerely,

MRS Marianela Delgado-Henriquez

Research Ethics Officer

Human Ethics Team
Office of Research Ethics and Integrity | Research, Innovation & Commercialisation
Level 5, Alan Gilbert Building, 161 Barry Street, Carlton
The University of Melbourne, Victoria 3010, Australia
T: (03) 8344 4387 E: mdelgado@unimelb.edu.au

Summary Details for the Approved Human Ethics Project

Project Title:	Exploring international pain expert recommendations regarding the use of Electronic Medical Record Systems to optimise pain management for hospitalised children
Reference Number:	2021-22171-23430-6
Approval Date:	09/11/2021
Expiry Date:	09/11/2021
Responsible Human Ethics Committee	LNR 4C
Project Supervisor	PROF Denise Harrison
Other Investigators	Mrs Nicole Pope, DR Greta Palmer, PROF Michael South, DR Dianne Crellin
External Investigators	Ms. Ligyana Candido

Documents table:

Document Type	File Name	Date	Version
Recruitment materials	21_09_13_Study 1 Twitter Promotion	20/09/2021	v1
Recruitment materials	21_09_13_Recruitment Email	20/09/2021	v1
Other	PARTNERSHIP_Study__ExPloring_recommendAtions_and_pRacTice_usiNg_EmRS_to_Help_kids_In_Pain (1)	20/09/2021	v3
Interview questions and/or themes	21_09_13_Study 1 Script and Interview Guide	20/09/2021	v3
Questionnaire(s) and/or survey instrument(s)	21_09_13_Study 1 REDCap questions	20/09/2021	v2
Recruitment materials	28_09_13_Study 1_ PLS_V4	28/09/2021	v4
Consent form	21_09_28_Study 1 Consent_V2	28/09/2021	v2

Conditions of Approval:

Research projects are normally approved to the anniversary date of the approval. Projects may be renewed yearly for up to a total of three years upon receipt of a satisfactory annual report. If a project is to continue beyond three years, two optional extensions of one year each (3+1+1) will need to be applied for. Anything beyond 5 years will need a new application to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

1. **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.
2. **Variation to Project:** Any subsequent variations to the Project must be notified formally to the Committee for consideration and approval before they are implemented. If the Committee considers that the proposed changes are significant, you may be required to submit a new application.
3. **Incidents or adverse events:** Researchers must report immediately to the Committee anything that could affect the ethical acceptability of the project, including adverse effects on participants or unforeseen events. Failure to do so may result in suspension or cancellation of approval.
4. **Monitoring:** All projects are subject to monitoring at any time by the Committee.
5. **Annual Report:** An annual report must be submitted each year on the anniversary of project approval, and at the conclusion of the project. Ethics approval will lapse if an annual report is not submitted.
6. **Auditing:** All projects are subject to audit by members of the Committee.

Appendix U
Project Data Management Plan

PARTNERSHIP Study: ExPloring recommendAtions and pRacTice usiNg EmRS to Help kids In Pain - Managing Data @Melbourne

1. Getting Started

Faculty / Department

- Faculty of Medicine, Dentistry and Health Sciences

Project Start Date

05/11/2021

Project End Date

03/08/2023

2. Developing your DMP (about your data)

What kinds of data will you collect, create or reuse?

Online survey data will be collected using the secure REDcap software while qualitative audiovisual interview data will be collected via the secure Zoom software. NVivo software will be used to manage qualitative interview transcripts data.
Survey questions will capture demographic detail including age, clinical role, hospital and detail related to the hospital electronic medical record system. Audio-visual semi-structured interviews questions will capture detail related the participants experiences using electronic medical records systems to assessment and manage children's pain. The invitation to participate will be distributed via the Pediatric Pain Mailing List (PPML). This electronic mailing list has been established for more than 25 years and brings together a community of paedaitrc pain clinicians from around the world to share clinical experiences and seek advice. Clinicians self-subscribe to this mailing list and can unsubscribe at any time. The PPML has also been used to recruit research participants for a variety of studies.

It is expected to have around a 20-30% response rate. Qualtrics research data management software hosted by the University of Melbourne will be used to organise survey data responses. Interviews interviews will be audio-recorded using the Zoom recording function and stored securely on the University of Melbourne's server in password protected files.

What file formats will the data be in?

Syntax (.sas), CSV (.csv) and SPSS files will be created to read, format and analyse REDCap survey data.
Digital audio visual data files generated (qualitative interviews) will be in MPEG-4 (.mp4) format and any audio data files generated will be in MPEG-3 (.mp3) format. MPEG-4 and MPEG-3 are international Standards Organization (ISO) specifications and these formats are readable by most media players. Interview transcripts will be generated as textual file formats (.docx).

3. Ethics and Legal Issues

How will you manage any ethical issues?

This project will involve interviewing approximately 20 people. University of Melbourne Ethics approval has been sought. Informed consent will be sought from participants. All data will be anonymised.

How will you manage copyright and Intellectual Property Right (IPR) issues?

No intellectual property will be generated by the project. IP assignment is not required.

4. Organising, Storing and Backing-up your Data

How will you store and backup your data during the project?

Data will be stored on the University departmental share drive, which is backed up by University IT. While in the field, data will be stored on a University of Melbourne owned laptop as well as an external drive. Field data will be transferred to the departmental share drive as soon as possible.

How will you manage access and security?

The data is of a sensitive nature and needs to be protected. The data will be stored on the University of Melbourne departmental share drive, which is restricted to members of the project team with affiliations at the University of Melbourne and requires authentication. The external hard drive will be kept in a locked filling cabinet in the principle researcher's office. Only members of the project team with affiliations at the University of Melbourne will have access to this.

5. Documenting and Describing your Data

What documentation and metadata will accompany the data?

Digital administrative records (i.e., licenses and permissions, consents, information sheets) and other research related electronic documents (i.e., research plan, publications) will be stored securely on University of Melbourne departmental share drive, which is restricted to members of the project team with affiliations at the University of Melbourne and requires authentication. All electronic files will be named in accordance with the pre-determine naming convention and stored in a hierarchical directory structure.

How will the consistency and quality of the data be controlled?

Systematic records of the research will also be maintained. All members of the research team are familiar with the pre-determined data naming and filing convention, which ensures that data files are easier to locate, retrieve and distinguish.

6. Sharing and Preserving your Data

How will you share your data?

This study will not generate publicly available datasets.

Are there any restrictions on data sharing required?

Not applicable

Appendix V
Study Two Advertising Flyers

Are you a parent or primary carer of a child who has had any pain during this admission to hospital?

You are eligible to take part in our

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

Help us learn about:

How kids and families in hospital can use our electronic medical record technology to be involved in their pain care.

How will you help?

You will answer some questions which will take about 45 minutes. This will happen while your child is in hospital.

What we learn from this study may help kids and families be better involved in pain care while in hospital.

THANK YOU!

Want to participate?

Please call, text, or email Nicole Pope

Ph: 0400 981 610 nicole.pope@student.unimelb.edu.au

This study has been approved by RCH Human Research Ethics Committee. Approval number (XXX)

1

V2 15/03/2022

Appendix W
Study Two Participant Information and Consent Forms

Adolescent Information Statement/Consent Form

Study Number:	83902
Research Study Title	Understanding primary caregiver and adolescent perspectives on their role using digital technology for pain care
Full Name of Project:	The PARTNERSHIP Study: Exploring Recommendations and Practice using Electronic Medical Record Systems to Help Kids In Pain
Responsible Researcher:	Nicole Pope
Additional Researcher(s)	Prof. Denise Harrison (lead supervisor) , Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor) Sophie Jones (Researcher)
Version Number:	V 1.0 **Version Date:** 25th January 2022

1. What is this research study about?

Children in hospital often have pain, even though hospital staff try to minimize it.
This study is looking into how it might be possible for children and their families to report their pain using computer system, like a patient portal. Patient portals can let patients and families read parts of their hospital health information and even enter their own information. You might know about the My RCH Portal already. Hospitals in other countries have used these kinds of computer systems for a while, but haven't looked into how these systems could be used for children in hospital who have pain.

2. Who is running the research study?

This study is being done at RCH. The research team (named above) includes nurses and doctor who have all worked in children's hospitals and have done research involving children.

3. Who is funding this research study?
This study is not funded.

4. Why am I being asked to be in this study?

We are asking you to be in this study because you are a patient at RCH and have had pain.

5. What will I be asked to do?

We will ask you first to complete a short (5 minute) online survey and then take part in an interview which will take about 45 minutes. The interview will happen while you are in hospital, in a quiet place, and at a time that does not interrupt hospital care.

How will this help me or other children in the future?

This will be the first study to learn about how children would like to use a patient portal while in hospital to help care for children with pain. This project will not directly help you now, but we hope that the project will help other children with pain in the future. It could do this by helping hospitals design patient portals in a way that helps patients and families be involved in decisions about pain care.

6. What are the risks and/or inconveniences?

The time that you spend on this research project may inconvenience you., so we will make sure the interview is at a time that suits you.

We don't think that this study will hurt you, but if you are worried by any of the questions, you do not need to answer them.

If you feel upset during the interview you can take a break or stop the interview if you want to. You can choose not be in this study at any time.

7. Do I have to be in this study?

No. You do not have to be in this study. It is up to you whether you take part. You can talk to your parents about whether this study is right for you. If you change your mind after you start the study, talk to your parents. You can leave the study anytime and you do not need to tell us why you want to stop being in the study. If you leave the study, the hospital staff will still look after you the best way that they can.

8. What will be done to make sure my information is confidential?

The information collected from you will be anonymous.

We will keep a paper copy of the consent form in a locked filing cabinet, and only the research team members will have access.

Your information, such as your name will not be collected in the online survey. We will make a recording of the interview. This is so we can concentrate on listening to what you have to say rather than being distracted by taking notes. We will use a digital voice recorder to record the interview. The recording will be transferred to password-protected files stored electronically on computers.

After the interview, we will transcribe the recording. This means we will make a full written copy of the recording. The research team will do this. Any identifying information, including your name, will be removed, meaning this information is also de-identified. After we have finished with the recording, we will delete it because this is the law. The full written copy of the recording will be stored electronically on secure, password protected files on computers.

Storage of information

We may keep the research project data for 25 years. The data will be securely stored at the Royal Children's Hospital

9. Will I get to see the results of this study when it is finished?

We will send your parent an email with the study's main findings. The summary will be the results of the whole group of study participants, not just your individual results.

10. **Who do I contact if I have questions about the study?**

If you have any questions, you can talk to us, the study team. You can call the study nurses or you can ask your parents to talk to us.

Prof. Denise Harrison Phone: (03) 9035 8034 deniseh@unimelb.edu.au

Ms Nicole Pope Phone: 0400 981 610 nicole.pope@student.unimelb.edu.au

You can contact the Director of Research Operations at The Royal Children's Hospital if you:

- have any concerns or complaints about the project
- are worried about your rights as a research participant
- would like to speak to someone independent of the project.

The Director can be contacted by telephone on (03) 9345 5044.

Consent Form

Study Number: 83902

Research Project Title: The PARTNERSHIP Study: Exploring Recommendations and Practice using Electronic Medical Record Systems to Help Kids In Pain

Version Number: V 1.0 **Version Date:** 25 January 2022

- I have read this information statement and I understand its contents.
- I understand what I have to do to be involved in this project.
- I understand the risks I could face being part in this project.
- I voluntarily consent to take part in this research project.
- I have had been able to ask questions about the project and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee. I understand that the project is required to be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Information Statement and Consent Form.

Adolescent Name	Adolescent Signature	Date
Parent/Guardian Name	Parent/Guardian Signature	Date

Declaration by researcher: I have explained the project to the participant who has signed above. I believe that they understand the purpose, extent and possible risks of their involvement in this project.

Research Team Member Name	Research Team Member Signature	Date

Parent/Guardian Information Statement/Consent Form

Study Number:	83902
Research Study Title	Understanding primary caregiver and adolescent perspectives on their role using digital technology for pain care
Full Name of Project:	The PARTNERSHIP Study: Exploring Recommendations and Practice using Electronic Medical Record Systems to Help Kids In Pain
Responsible Researcher:	Nicole Pope
Additional Researcher(s)	Prof. Denise Harrison (lead supervisor) , Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor) Sophie Jones (Researcher)
Version Number: V 2.0	**Version Date:** 15th March 2022

Thank you for taking the time to read this **Parent/Guardian Information Statement and Consent Form**. We would like to invite you and your child to participate in a research study that is explained below. This document is **5 pages long.** Please make sure you have all the pages.

What is this Information Statement?

These pages tell you about the research study. It explains to you clearly and openly all the steps and procedures of the study. The information is to help you to decide whether you and your child would like to take part in the study. Please read this information statement carefully.

It is your choice whether you and/or your child takes part in the research project. If you decide you do not want your child to be involved, it will not affect the treatment and care your child gets at The Royal Children's Hospital. Before you decide to take part, you can ask us any questions about the research study.

If you would like to take part in the study or if you would like your child to take part, please sign the consent form at the end of this
information statement. By signing the consent form, you are telling us that you:

- understand what you have read
- have had a chance to ask questions and received satisfactory answers
- consent to you and/or your child taking part in the study

We will give you a copy of this information statement and the consent form to keep.

1. What is this research study about?

Children in hospital do commonly experience pain, even though so much effort is made to minimise that. This study is looking into how patient reporting their experience of pain via a portal in the electronic medical record might be used to improve pain management further.

Over the last six years, Australian children's hospitals have begun using computer-based systems to record medical information instead of paper-based records. Many of these computer systems include ways for patients and or their families to read parts of the medical record and even enter their own information. Research from international hospitals shows that using computers can improve the quality and safety of care, patient engagement in care, and outcomes for patients and families. But not much is known about how we can make the best use of these systems to care for hospitalised children who have pain.

This study is part of a larger research project looking into how hospital electronic systems, such as electronic medical record systems, are used to care for children in hospital who have pain. The study hopes to learn more about if and how children and parents would like to use an electronic (or computer-based) system, such as a patient portal (i.e., My RCH Portal) while in hospital to help treat your/your child's pain, in a way that matters to you and your child.

2. Who is running the research study?

This research project will take place at the Royal Children's Hospital. It is being undertaken as part of a PhD project at the University of Melbourne. The research team (named above) includes nurses, doctors, and researchers at the Royal Children's Hospital and the University of Melbourne. They are expert clinicians who are all involved in pain care in different areas of the hospital. They have all conducted research focusing on improving pain management for babies and children.

3. Who is funding this research study?
This study is not funded.

4. Why am I and my child being asked to be in this study?

We are asking you and/or your child to take part in this study because your child is being treated at the Royal Children's Hospital for a painful condition.

5. What will my child and I be asked to do?

We will ask you first to complete a short (5 minute) online survey and then take part in an interview which will take about 45 minutes. The interview will take place while you/your child are in hospital in a quiet place within the hospital at a time that suits you and does not interrupt hospital care.

What are the possible benefits for me and other people in the future?

This will be the first study to learn about how children and families would like to use a patient portal while in hospital to help care for children with pain. This project will not directly benefit your child. However, we hope that the project will benefit other children with pain in the future. It could do this by helping hospitals design patient portals in a way that helps patients and families be involved in decisions about pain care.

6. What are the potential risks and/or inconveniences?

The time that you and your child spend on this research project may inconvenience you both. Therefore, the interview will be scheduled at a convenient time for you and your child.

We don't think that participating will cause you or your child any harm or discomfort. We have tried to ensure that the survey questions are respectful and appropriate. However, if you or your child are worried by any of the questions, you do not need to answer them.

If you or your child become upset during the interview, you/your child can take a break or withdraw from the interview. We can arrange for you/your child to get free counseling. This will be provided by someone who is not part of the research team. You may also decide to withdraw yourself/your child from the project.

7. Do we (myself and my child) have to take part?

No. It is your choice whether you and your child take part in this research project.
You do not have to agree. If you consent and change your mind, you can still withdraw yourself/your child from the study. You do not need to tell us why you or your child want to stop being in the study.

Whatever your decision, it will not affect any treatment or care your child gets or your family's relationship with the Royal Children's Hospital.

8. What will be done to make sure my child's information is confidential?

The information collected from you and your child will be anonymous.

We will keep a paper copy of the consent form in a locked filing cabinet, and only the research team members will have access.

No identifiable information (i.e., yours/your child's name, address etc.) will be collected in the online survey. We will make a digital audio recording of the interview. This is so we can concentrate on listening to what you and your child have to say rather than being distracted by taking notes. We will use a digital voice recording device to record the interview. The recording will be transferred to password-protected files stored electronically on a secure internal server.

After the interview, we will transcribe the recording. This means we will make a full written copy of the recording. The research team will do this. Any identifying information, including your/your child's name, will be removed during transcription, meaning this information is also de-identified. After we have finished with the recording, we will completely destroy it as required by law. De-identified transcripts will be transferred to password-protected files stored electronically on a secure internal server.

9. Storage of information
We may keep the research project data for 25 years. The data will be securely stored at the Royal Children's Hospital

10. Will we be informed of the results when the research study is finished?

We will send you a letter summarising the study's main findings. The summary will be the results of the whole group of study participants, not just your child's individual results.

11. Who do I contact if I need more information about the study?

If you would like more information about the study or if you need to speak to a member of the research team, please contact:

Prof. Denise Harrison Phone: (03) 9035 8034 deniseh@unimelb.edu.au

Ms Nicole Pope Phone: 0400 981 610 nicole.pope@student.unimelb.edu.au

You can contact the Director of Research Operations at The Royal Children's Hospital if you:

- have any concerns or complaints about the project
- are worried about your rights as a research participant
- would like to speak to someone independent of the project.

The Director can be contacted by telephone on (03) 9345 5044.

Consent Form

Study Number: 83902

Research Project Title: The PARTNERSHIP Study: Exploring Recommendations and Practice using Electronic Medical Record Systems to Help Kids In Pain

Version Number: V 1.0 **Version Date:** 25 January 2022

- I have read this information statement and I understand its contents.
- I understand what I have to do to be involved in this project.
- I understand the risks I could face being part in this project.
- I voluntarily consent to take part in this research project.
- I have had been able to ask questions about the project and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee. I understand that the project is required to be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Information Statement and Consent Form.

Adolescent Name	Adolescent Signature	Date
Parent/Guardian Name	Parent/Guardian Signature	Date

Declaration by researcher: I have explained the project to the participant who has signed above. I believe that they understand the purpose, extent and possible risks of their involvement in this project.

Research Team Member Name	Research Team Member Signature	Date

Appendix X
Study Two Questionnaire

Demographic survey items

Questions	Options
Part 1. About you	
You are:	The primary caregiver of a child at RCH An adolescent (aged 12 or older) at RCH
(For PCGs) What is your relationship to the patient at RCH	Mother Father Other relative
What is your age?	(Free text)
(For PCGs) What is your child's age?	(Free text)
What is your primary language	English Other: Please specify
Reason for hospital visit	Acute illness Known disease Surgery/trauma Other
Inpatient hospital unit	Butterfly Cockatoo Dolphin Koala Kookaburra Kelpie Platypus Possum Rosella
Part 2: Portal use and computer experience	
Do you currently use the RCH MyChart portal?	Yes No
What is your general level of computer experience	Less experienced (e.g., browse the web, check email, or less) Somewhat experienced (e.g., edit photos, use a spreadsheet) Very experienced (e.g., create web-page, write computer programs or more)

Appendix Y
Study Two Interview Guide

Demographic survey items

Questions	Options
Part 1. About you	
You are:	The primary caregiver of a child at RCH An adolescent (aged 12 or older) at RCH
(For PCGs) What is your relationship to the patient at RCH	Mother Father Other relative
What is your age?	(Free text)
(For PCGs) What is your child's age?	(Free text)
What is your primary language	English Other: Please specify
Reason for hospital visit	Acute illness Known disease Surgery/trauma Other
Inpatient hospital unit	Butterfly Cockatoo Dolphin Koala Kookaburra Kelpie Platypus Possum Rosella
Part 2: Portal use and computer experience	
Do you currently use the RCH MyChart portal?	Yes No
What is your general level of computer experience	Less experienced (e.g., browse the web, check email, or less) Somewhat experienced (e.g., edit photos, use a spreadsheet) Very experienced (e.g., create web-page, write computer programs or more)

Script and interview guide

Thank you for taking the time to meet with me today. My name is Nicky Pope. I am a registered nurse and a PhD student at the University of Melbourne.

As mentioned in the information you received, this research study is one of a larger research project looking into how hospital electronic system, such as EMRs and patient portals are used to care for children in hospital who have pain. You might have seen the nurses and doctors using these systems while you have been in hospital. You might also have heard of or are already using the RCH MyChart.

This is important because we know that children in hospital experience pain daily. This might be due to the reasons they came into hospital, or from other procedures, like needles, that are needed as part of their care. Research has shown us that EMRs, and patient portal systems can improve hospital care. Patient portal systems can help patients and families be more involved in their/their child's care and better communicate hospital staff, It is important to learn about how these systems can be designed and used to help children in hospital with pain.

Families at RCH can already use the (outpatient) MyChart patient portal to look at things like medications and appointments. RCH is now planning to use a similar patient portal system, called MyChart Bedside, that patients and families can use while in hospital.

Given your recent experience in hospital and that you/your child experienced pain while you were here, we would like to learn more about how you/your child would like to use the MyChart Bedside to help with your/your child's pain care while in hospital.

I expect that this interview will take 60 minutes. Being involved in this study is completely your choice. If at any time during the interview you don't want to continue with the interview, please let me know and we can stop. I will be using this digital voice recorder to record the interview to pay attention to what you are saying, rather than taking notes. Once we finish the interview, I will transcribe the audio recording, and then delete it. None of your/your child's personal details, such as names, will be used when I transcribe the interview. Instead of using your name, we can use a pseudonym that you can choose.

Do you still consent to have this interview recorded?

START RECORDING

Thank you. I want to confirm that the interview is now being recorded. Thanks again for your time in sharing your thoughts about how we could use the inpatient portal system, MyChart Bedside, to help kids in hospital who have pain. Ok, I will start with my questions.

Broad question	Follow-up question(s)
1. What do you think about having an electronic system, such as a patient portal, so you can be involved in your/your child's pain care while in hospital?	Do you currently use the My RCH portal? If so, what do you find most helpful/least useful about this patient portal?
2. What do you think about using an electronic system, such as a patient portal, to track and report your pain symptoms while in hospital?	What type of information about your/your child's pain symptoms would be most important for you to communicate to the medical/nursing teams?
3. What do you think about an electronic system, having functions to remind you/ your child to track and report your pain symptoms?	How might this function work? Examples include a notification to assess pain, drop down boxes with options to categorise pain
4. How could an electronic system, such as an inpatient portal, help you to track and report things to help you when you have pain?	What type of information about things that help you when you have pain would be most important for you to track and report?
5. Can you think of any functions of the electronic system that might be useful to remind you to track and report things to help when you have pain?	How might this function work? Pop-ups/prompts for tips about how to manage pain
6. How might you like to communicate with hospital staff using the electronic system?	
7. If a portal was available with information for parents, what do you want to know about managing your child's pain whilst in hospital?	What type of resources/information would you find useful to have in a pain management toolbox
8. What would motivate you or prevent you from using an electronic system, such as an inpatient portal to help with your/your child's pain care in while hospital?	
9. If were to you use a patient portal to report and track your child's pain, what is the most important aspect of this process for you?	

Appendix Z
Study Two Human Research Ethics Committee Approval

ETHICS APPROVAL & GOVERNANCE AUTHORISATION

The Royal Children's Hospital Melbourne

09 June 2022

Mrs Nicole Pope
Department of Nursing
University of Melbourne

Dear Mrs Pope

Project Title: Partnership study: Study 2: Understanding primary caregiver and adolescent perspectives on using an inpatient portal for pain management

---

HREC Reference Number: **HREC/83902/RCHM-2022**
RCH HREC Reference Number: **83902**

I am pleased to advise that the above project has received **ethical approval** from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The project has also received **governance authorisation at the Melbourne Children's Campus** (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: **09 June 2022**
**Please note the HREC are no longer issuing pre-determined approval periods. Ethical approval is now ongoing, subject to the submission of an annual report on the anniversary of HREC approval.*

Approved Documents:
The following documents have been reviewed and approved:

Document	Version	Date
Research Protocol	2.0	17 March 2022
Mature Minor information statement and consent form	2.0	26 March 2022
Adolescent advertisement flyer/poster	2.0	15 March 2022
Parent/Guardian information and consent form	2.0	15 March 2022
Primary caregiver advertisement flyer/poster	2.0	15 March 2022
Questionnaire	1.0	25 January 2022
Script and Interview Guide	1.0	25 January 2022

Conditions of Ethics Approval:

- You are required to submit to the HREC:
  - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Safety monitoring and reporting in clinical trials involving therapeutic goods November 2016*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves exposure of persons to ionising radiation, you must ensure that your research is carried out in accordance with the Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) Code of Practice for the 'Exposure of Humans to Ionizing Radiation for Research Purposes (2005)' (Radiation Protection series Publication No.8)
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.
- Comply with the following privacy of patient information statement:
  - Accessing identified patient information from health services other than your own for research purposes is not permitted. Precinct polices regarding appropriate access MUST be followed. Identified patient information must ONLY EVER be accessed after governance authorisation or quality assurance (QA) approval from the appropriate health service.

Yours sincerely,

Retracted

Adrienne Mackey
Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au

Office of Research Ethics and Integrity

Human Ethics Registration Acknowledged

ATTENTION: PROF Denise Harrison

The University of Melbourne

Research Application

Reference Number: 2022-24382-29523-2
Project Title: Understanding primary caregiver and adolescent perspectives using an inpatient portal for pain management

Dear PROF Denise Harrison,

Thank you for submitting your Human Ethics Registration. It has been acknowledged. Please see overleaf, **Summary Details for the Registration and Conditions of Registration**.

Please do not hesitate to contact me if you have any queries.

Yours sincerely,

MR Robert Reid

Research Ethics Officer

Research Ethics Officer
Office of Research Ethics and Integrity
Research, Innovation & Commercialisation
Level 5, Alan Gilbert Building, 161 Barry Street, Carlton
The University of Melbourne, Victoria 3010 Australia
E: robert.reid@unimelb.edu.au

Summary Details for the Human Ethics Registration

Title:	Understanding primary caregiver and adolescent perspectives using an inpatient portal for pain management
Ethics ID:	2022-24382-29523-2
Approval Date:	21/06/2022
Expiry Date:	21/06/2025
Responsible Human Ethics Committee	STEMM 1
Project Supervisor	PROF Denise Harrison

Documents table:

Document Type	File Name	Date	Version
Application	Script and interview guide	25/01/2022	v1
Application	Script and interview guide	25/01/2022	v1
Application	Participant information and consent forms	15/03/2022	v2
Application	28_02_2022 Advertising Flyer_Poster_Adolescent	15/03/2022	v2
Application	28_02_2022_Advertising Flyer_Poster_Primary Caregiver	15/03/2022	v2
Other	22_02_28_PROTOCOL_RCH ETHICS_Study 2	17/03/2022	2

Application	Mature Minor information and consent forms	26/03/2022	v2
Application	83092 Ethics and Governance 09.06.2022	09/06/2022	v1

Conditions of Registration:

Please note that the following conditions apply to your registration. Failure to abide by these conditions may result in suspension or discontinuation of registration and/or disciplinary action.

1. The Royal Children's Hospital Melbourne HREC is the responsible Human Ethics Committee for this research.
2. The Royal Children's Hospital Melbourne HREC approval must be current for the life of the approval.
3. You are required to keep the University of Melbourne informed of any subsequent amendments you have made to the project and any such changes must be approved by the Royal Children's Hospital Melbourne HREC. For registrations only, amendments can be notified to the University by way of the annual report.
4. You are required to submit an annual report to the University of Melbourne Human Ethics Committee at the registration anniversary date or at the conclusion of the project if it continues for less than that time. Requests for annual reports will be sent out via Infonetica ERM.

Appendix AA
Study Three Survey Questionnaire

PARTNERSHIP Project: National Clinician Survey

Start of Block: SECTION 1: Information and Consent

SECTION 1: INFORMATION AND CONSENT
This section provides information about the study and seeks your consent to participate.

Plain Language Statement

Project: The PARTNERSHIP Study: ExPloring recommendAtions and pRacTice usiNG EmRS to Help kids In Pain

Responsible Researcher: Ms. Nicole Pope
Department of Nursing, School of Health Sciences, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne
Tel: 0400 981 610
Email: nicole.pope@student.unimelb.edu.au

Research team members:
Professor Denise Harrison (Research Supervisor)
Dr Dianne Crellin (Associate Researcher)
A/Professor Greta Palmer (Associate Researcher)
Professor Mike South (Associate Researcher)
Ms Janelle Keyser (Associate Researcher)

Introduction
Thank you for your interest in participating in this research project. The following information about the project is provided so that you can decide if you would like to take part in this research.
Please take the time to read this information. You may ask questions about anything you don't understand or want to know more about. Your participation is voluntary.
If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about? T
This research is part of a larger study looking into how electronic medical records (EMRs) are used to care for children in hospitals who have pain. This part of the research project hopes to learn more about how clinicians working in Australian paediatric hospitals currently use or want to use EMRs to provide pain care to children.

What will I be asked to do?
Should you agree to participate, you will be invited to complete an online survey (10-15 minutes) about how you currently use your hospital EMR system in providing pain care to children, and how you might like to use the EMR in the future in enabling pain care.

What are the possible benefits?
You will not benefit directly in the short term from participating. However, the information you provide may lead to future improvements in EMR designs to support clinicians in delivering pain care for children. This will ultimately help to improve treatment of pain in hospitalised children.

What are the possible risks?
There are no foreseeable risks associated with your participation in this project.

Do I have to take part?
Participation is voluntary. If you do not wish to take part, you do not have to. If you decide to participate and submit your responses, but later change your mind, information you have already provided in the survey will be included in our analysis.

However, the responses you provide will not be identifiable. Researchers and employers will not be able to identify who responds to the survey so your decision whether to participate will not be known.

Any associations you have with the University of Melbourne, health services, or researchers will not be affected if you choose not to participate.

Will I hear about the results of this project?
We will share the findings of this research via a summary of the survey results that will be disseminated to clinicians at your hospital. We will also share the results of the research through journal publications, conference presentations, and via professional associations.

What will happen to information about me?
You are not required to provide any personal details in the survey. Your participation and the responses are anonymous. We intend to protect the confidentiality of your information within the limits of the law.

The information you provide will be treated as confidential and will be stored electronically and held under password protection at The University of Melbourne.

The information you provide will be accessible only to the principal investigator, Ms Pope and the project supervisor, Professor Harrison who will be working on data analysis.
The other researchers will only have access to pooled results and not the individual survey records. Per research code requirements, we will store the information collected for 5 years after releasing any publications of this research project.

We may reuse the data we collect in this study for future research in the same general area of research as this project. The data we collect in this project, and any future reuse of this data, will always be published as summary statistics, so your individual responses will never be identifiable or reported separately.

If you decide to include potentially identifying comments in the survey, we will not include any potentially personally identifiable details if these comments are published.

Is there any potential conflict of interest?
There are no potential conflicts of interest associated with this research project.

Who is funding this project?
Nicole Pope (PhD Candidate) is the recipient of the Melbourne Research Scholarship, the Be Sweet to Babies Studentship, and the Vera Scantlebury Brown Scholarship. These funding sources support the full program of research, which includes this study.

Where can I get further information?
If you would like more information about the project, don't hesitate to get in touch with the researchers whose names and contact details are provided at the top of this document.

Who can I contact if I have any concerns about the project?
This project has human research ethics approval from The University of Melbourne (HREC REF:).

If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010.
Tel: +61 8344 1376 or
Email: research-integrity@unimelb.edu.au.

All complaints will be treated confidentially. In any correspondence, please provide the name of the research team and/or the name or ethics ID number of the research project.

If you wish to keep a copy of this Plain Language Statement, you can download it as a PDF via the link below

Page Break

CONSENT

Project Supervisor: Professor Denise Harrison
T: 03 9035 8034
E: deniseh@unimelb.edu.au

Principal Investigator: Nicole Pope (PhD Candidate)
T: 0400 981 610
E: Nicole.pope@student.unimelb.edu.au

Additional Researchers: Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor), Ms Janelle Keyser (Associate researcher)

1. I consent to participate in this project, the details of which have been explained to me, and I have access to digital copy of the written plain language statement to keep.

2. I understand that the purpose of this research is to examine how clinicians use Electronic Medical Records systems (EMRs) when caring for hospitalised children with pain.

3. I understand that my participation in this project is for research purposes only.

4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.

5. In this project I consent to completing an online survey about my perceptions and experiences using EMRs in children's pain care.

6. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.

7. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.

8. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the project supervisor and the principal investigator

9. I understand that by checking the box below and responding to the survey, I consent to participate in this research.

Do you consent to participate in this survey?

- o Yes, I consent to participate in the survey (1)
- o No, I do not consent to participate in the survey (2)

Skip To: End of Survey If Do you consent to participate in this survey? = No, I do not consent to participate in the survey

End of Block: SECTION 1: Information and Consent

Start of Block: SECTION 2: The following questions are about how you use your hospitals EMR to assess and treat children's pain, including how families and children are involved in this process

SECTION 2: PAIN ASSESSMENT AND INTERVENTIONS

The following questions are about how you use your hospital EMR to assess and treat children's pain, including how families and children are involved in this process.

Where do you record pain assessment scores in the EMR? (Select all that apply)

- o I use the EMR pain assessment fields to record pain scores (i.e. smart form or flow sheets) (1)
- o I use free text fields to record pain scores (2)
- o I record pain scores as additional notes within other vital signs in flow sheets (3)
- o Other: (please describe) (4) _____

What pain assessment tools are integrated into your hospital EMR? (Select all that apply)

- Colour Analog Scale (CAS) (1)
- Comfort B (2)
- Faces Leg Activity Cry Consolability (FLACC) (3)
- Revised Faces Legs Activity Cry Consolability (rFLACC) (4)
- Faces Pain Scale-Revised (FPS-R) (5)
- Functional Activity Score (FAS) (6)
- Neonatal Pain, Agitation, Sedation Scale (N-PASS) (7)
- Neonatal Pain Assessment Tool (PAT tool) (8)
- Modified Pain Assessment Tool (mPAT) (9)
- Numerical Rating Scale (NRS) (0-10) (10)
- Premature Infant Pain Profile (PIPP) (11)
- Premature Infant Pain Profile Revised (PIPP-R) (12)
- Visual Analog Scale (VAS) (13)
- Wong-Baker FACES pain rating scale (14)
- Not applicable/there are no pain assessment tools in the EMR (15)
- Other (Please describe below) (16)

_____

Please rate your level of agreement with the following statements about using pain assessment tools integrated into the EMR

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)	Not applicable (8)
The EMR pain assessment tools are easy to access (1)	○	○	○	○	○	○	○	○
The EMR pain assessment tools have improved how often I undertake a pain assessment compared to when we did not use an EMR (2)	○	○	○	○	○	○	○	○
The EMR pain assessment tools are set up in a way that helps me to engage children and families in pain assessment (3)	○	○	○	○	○	○	○	○

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Please use the following space if you would like to elaborate on any of your above responses, or provide additional detail about the EMR pain assessment tools

_____

Besides pain scores, do you use the EMR to record any other aspects of pain assessment (i.e. psychosocial and functional consequences)?

- o No, I only record pain score (1)
- o Yes, I record other aspects of pain assessment (please describe) (2)

_____

Display This Question:

If Besides pain scores, do you use the EMR to record any other aspects of pain assessment (i.e. psyc... = Yes, I record other aspects of pain assessment (please describe)

Please indicate **where in the EMR** you record **other aspects** (i.e., psychological and functional consequences) of pain assessment (Select all that apply)

- o Nursing/medical notes (1)
- o In the EMR pain assessment field (i.e. smart forms or flowsheets) (2)
- o In the EMR vital signs assessment field (3)
- o Other (Please describe) (4)

_____

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Please rate your level of agreement with the following statements about using the EMR when undertaking pain assessments

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)	Not applicable (8)
The EMR is designed in a way that drives me to assess and record detailed pain assessment that includes aspects beyond pain scores alone (i.e. psychosocial and functional consequences) (1)	○	○	○	○	○	○	○	○
The EMR is designed in a way that has improved how often I undertake more detailed pain assessments, beyond pain scores alone, compared to when we did not use an EMR (2)	○	○	○	○	○	○	○	○
The EMR is designed in a way that helps me to involve children and families in undertaking detailed pain assessments, beyond pain scores alone, compared to when we did not use an EMR (3)	○	○	○	○	○	○	○	○

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Please use the following space if you would like to elaborate on any of your above responses or provide additional detail using EMRs to undertake detailed pain assessments beyond pain scores alone.

_____

Are there any prompts or alerts in your EMR that remind you to undertake a pain assessment?

- o No (1)
- o Yes (Please describe) (2) _____

Display This Question:

If Are there any prompts or alerts in your EMR that remind you to undertake a pain assessment? = Yes (Please describe)

How useful are these prompts or alerts to guide you to undertake a pain assessment?

	Extremely useless (1)	Moderately useless (2)	Slightly useless (3)	Neither useful nor useless (4)	Slightly useful (5)	Moderately useful (6)	Extremely useful (7)
Prompts or alerts are: (1)	○	○	○	○	○	○	○

Please use the following space if you would like to elaborate on any of your above responses or provide additional detail about EMR prompts and reminders for pain assessment

_____

Page Break

What sorts of pain interventions do you record in the EMR? (Select all that apply)

- Pharmacological (i.e., medications including sucrose) (1)
- Physical (i.e., Comfort positioning, breastfeeding, skin to skin contact, heat/ice packs etc.) (2)
- Psychological (i.e. Distraction such as games, music, movies, iPad, TV, reading etc) (3)
- Interdisciplinary referrals (i.e., occupational therapy, play therapy, music therapy, life specialist, pain team etc.) (4)
- Other: (Please describe) (5) _____
- I don't record pain interventions in the EMR (6)

Please indicate where you record **pharmacological** pain interventions in the EMR (Select all the apply)

- The electronic medication administration record (eMAR/MAR) (1)
- The nursing/medical notes (2)
- Other (Please describe) (3) _____

How often do you record **pharmacological** pain interventions in the EMR?

	Always (1)	Often (2)	Sometimes (3)	Rarely (4)	Never (5)
Recording of pharmacological interventions (1)	○	○	○	○	○

Please indicate where you record **physical** and **psychological** pain interventions in the EMR (Select all that apply)

- The nursing/medical notes (1)
- The EMR pain assessment/treatment field (2)
- The EMR vital signs field (3)
- Other (Please describe) (4)
- I do not record physical or psychological interventions (5)

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How often do you record **physical** and/or **psychological** pain interventions in the EMR?

	Always (1)	Often (2)	Sometimes (3)	Rarely (4)	Never (5)
EMR recording of physical and/or psychological interventions (1)	○	○	○	○	○

Please rate your level of agreement with the following statements about using the EMR for pain intervention/treatment practices

	Strongly agree (1)	Agree (2)	Somewhat agree (3)	Neither agree nor disagree (4)	Somewhat disagree (5)	Disagree (6)	Strongly disagree (7)	Not applicable (8)
Using the EMR supports me to initiate and document PHARMACOLOGICAL pain interventions (i.e., medications including sucrose) (1)	○	○	○	○	○	○	○	○
Using the EMR supports me to initiate and document PHYSICAL interventions for pain (i.e., Comfort positioning, breastfeeding, skin to skin contact, heat/ice packs etc.) (2)	○	○	○	○	○	○	○	○
Using the EMR supports me to initiate and document psychological interventions for pain (i.e. Distraction such as games, music, movies, iPad, TV, reading etc.) (3)	○	○	○	○	○	○	○	○
Using the EMR has improved how I treat pain in children compared to when we did not use an EMR (4)	○	○	○	○	○	○	○	○
Using the EMR has improved how I involve children and families in treating children's pain compared to when we did not use an EMR (5)	○	○	○	○	○	○	○	○

Please use the following space if you would like to elaborate on any of your above responses or provide additional detail how the EMR design support clinicians to initiate and record

Page 13 of 18

interventions for pain.

_____

Are there any prompts or alerts in your EMR that remind you to initiate pain interventions?

- ○ No (1)
- ○ Yes, but only MAR prompts for medications (2)
- ○ Yes, MAR prompts for medications AND other prompts for other pain interventions (Please describe) (3) _____

Display This Question:

If Are there any prompts or alerts in your EMR that remind you to initiate pain interventions? = Yes, but only MAR prompts for medications

And Are there any prompts or alerts in your EMR that remind you to initiate pain interventions? = Yes, MAR prompts for medications AND other prompts for other pain interventions (Please describe)

How useful are these prompts or alerts to guide you to initiate pain interventions?

	Extremely useless (1)	Moderately useless (2)	Slightly useless (3)	Neither useful nor useless (4)	Slightly useful (5)	Moderately useful (6)	Extremely useful (7)
Prompts or alerts are: (1)	○	○	○	○	○	○	○

Please use the following space if you would like to elaborate on any of your above responses or provide additional detail about EMR prompts and reminders for pain interventions

_____

To what extent do you feel that using the EMR has supported you in **documenting** pain care

	Completely (1)	Largely (2)	Moderately (3)	Slightly (4)	Not at all (5)	Not applicable (6)
The EMR design supports my documentation of pain (1)	○	○	○	○	○	○

To what extent do you feel that using the EMR has supported you in **providing** pain care

	Completely (1)	Largely (2)	Moderately (3)	Slightly (4)	Not at all (5)	Not applicable (6)
The EMR design supports me providing pain care (1)	○	○	○	○	○	○

Page Break

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How do you feel EMR designs could better support clinicians in providing pain care to children and families?

_____

How do you feel EMR designs could better support children and families to be engaged in their pain care?

_____

Do you have any other ideas about the use of digital technology for hospitalised children's pain care?

_____

Is there anything else you would like to share about your experience using EMRs to care for hospitalised children with pain?

_____

End of Block: SECTION 2: The following questions are about how you use your hospitals EMR to assess and treat children's pain, including how families and children are involved in this process

Start of Block: SECTION 3: ABOUT YOU: The following questions are about you and the demographic groups you are part of. This information will be helpful for our understanding of who uses EMRs.

SECTION 3: ABOUT YOU

The following questions are about you and the demographic groups you are part of. This information will be helpful for our understanding of who uses EMRs

Which of the following best describes your role?

- Paediatrician (1)
- Anesthetist (2)
- Registered Nurse (3)
- Registered Midwife (6)
- Neonatologist (7)
- Nurse Practitioner (4)
- Other: Please state (5) _____

Q82 Which state or territory are you based in?

- Victoria (1)
- New South Wales (2)
- South Australia (3)
- Queensland (4)
- Northern Territory (5)
- Australian Capital Territory (6)
- Western Australia (7)
- Tasmania (8)

How many years have you been a registered healthcare professional?

- Less than 1 year (1)
- 1-5 years (2)
- 5-10 years (3)
- 10-20 years (4)
- More than 20 years (5)

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How many years have you worked in the neonatal/paediatric/adolescent field?

- Less than 1 year (1)
- 1-5 years (2)
- 5-10 years (3)
- 10-20 years (4)
- More than 20 years (5)

What EMR does your hospital use (Select all that apply)

- EPIC (1)
- CERNER (ieMAR) (2)
- MetaVision (3)
- Other (Please state) (4) _____

How long have you been using your hospital's EMR?

_____

End of Block: SECTION 3: ABOUT YOU: The following questions are about you and the demographic groups you are part of. This information will be helpful for our understanding of who uses EMRs.

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Appendix BB
Study Three Participant Information Sheet

PARTNERSHIP Study
ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

THE UNIVERSITY OF MELBOURNE

Plain Language Statement

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

Prof. Denise Harrison (Research Supervisor)	Tel: +61 (3) 9035803	deniseh@unimelb.edu.au
Ms Nicole Pope (PhD Student)	Tel: +61 400 981 610	Nicole.pope@student.unimelb.edu.au
Dr. Dianne Crellin (Associate Researcher)	Tel: +61(3) 3844 4947	dcrellin@unimelb.edu.au
A/Prof. Greta Palmer (Associate Researcher)	Tel: +61 (3) 93454753	greta.palmer@rch.org.au
Prof. Mike South (Associate Researcher)	Tel: +61 (3) 9345 5182	mike.South@rch.org.au
Ms Janelle Keyser (Associate Researcher)		Janelle.Keyser@health.qld.gov.au

Introduction

Thank you for your interest in participating in this research project. The following information about the project is provided so that you can decide if you would like to take part in this research.

Please take the time to read this information. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This research is part of a larger study looking into how electronic medical records (EMRs) are used to care for children in hospitals who have pain. This part of the research project hopes to learn more about how clinicians working in Australian paediatric hospitals currently use or want to use EMRs to provide pain care to children.

What will I be asked to do?

Should you agree to participate, you will be invited to complete a brief online survey (10-15 minutes) about how you currently use your hospital EMR system in providing pain care to children, and how you might like to use the EMR in the future in enabling pain care.

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

What are the possible benefits?

You will not benefit directly in the short term from participating. However, the information you provide may lead to future improvements in EMR designs to support clinicians in delivering pain care for children. This will ultimately help to improve treatment of pain in hospitalised children.

What are the possible risks?

There are no foreseeable risks associated with your participation in this project.

Do I have to take part?

Participation is voluntary. If you do not wish to take part, you do not have to.

If you decide to participate and submit your responses, but later change your mind, information you have already provided in the survey will be included in our analysis. However, the responses you provide will not be identifiable.

Researchers and employers will not be able to identify who responds to the survey so your decision whether to participate will not be known. Any associations you have with the University of Melbourne, health services, or researchers will not be affected if you choose not to participate.

Will I hear about the results of this project?

We will share the findings of this research via a summary of the survey results that will be disseminated to clinicians at your hospital.

We will also share the results of the research through journal publications, conference presentations, and via professional associations.

What will happen to information about me?

You are not required to provide any personal details in the survey. Your participation and the responses are anonymous.

We intend to protect the confidentiality of your information within the limits of the law.

The information you provide will be treated as confidential and will be stored electronically and held under password protection at The University of Melbourne. The information you provide will be accessible only to the principal investigator, Ms Pope and the project supervisor, Professor Harrison who will be

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

working on data analysis. The other researchers will only have access to pooled results and not the individual survey records. Per research code requirements, we will store the information collected for 5 years after releasing any publications of this research project.

We may reuse the data we collect in this study for future research in the same general area of research as this project.

The data we collect in this project, and any future reuse of this data, will always be published as summary statistics, so your individual responses will never be identifiable or reported separately. If you decide to include potentially identifying comments in the survey, we will not include any potentially personally identifiable details if these comments are published.

Is there any potential conflict of interest?

There are no potential conflicts of interest associated with this research project.

Who is funding this project?

Nicole Pope (PhD Candidate) is the recipient of the Melbourne Research Scholarship, the Be Sweet to Babies Studentship, and the Vera Scantlebury Brown Scholarship. These funding sources support the full program of research, which includes this study.

Where can I get further information?

If you would like more information about the project, don't hesitate to get in touch with the researchers whose names and contact details are provided at the top of this document.

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne (HREC REF: 2022-23409-30913-3). If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence, please provide the name of the research team and/or the name or ethics ID number of the research project.

Appendix CC
Study Three Consent Form

Consent Form

Department of Nursing, Melbourne School of Health Sciences | Faculty Medicine, Dentistry and Health Sciences

PARTNERSHIP Study

ExPloring recommendAtions and pRacTice usiNg EMRS to Help kids In Pain

Project Supervisor: Professor Denise Harrison T: 03 9035 8034 E: deniseh@unimelb.edu.au
Principal Investigator: Nicole Pope (PhD Candidate) T: 0400 981 610
Nicole.pope@student.unimelb.edu.au

Additional Researchers: Dr Dianne Crellin (Supervisor), Associate Prof. Greta Palma (Supervisor), Prof. Mike South (Supervisor), Ms Janelle Keyser (Associate researcher)

Name of Participant: _____

1. I consent to participate in this project, the details of which have been explained to me, and I have access to digital copy of the written plain language statement to keep.
2. I understand that the purpose of this research is to examine how clinicians use Electronic Medical Records systems (EMRs) when caring for hospitalised children with pain.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. In this project I consent to completing an online survey about my perceptions and experiences using EMRs in children's pain care.
6. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
7. I understand that the data from this research will be stored at the University of Melbourne and will be destroyed after 5 years.
8. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the project supervisor and the principal investigator
9. I understand that by checking the box below and responding to the survey, I consent to participate in this research.

Ethics ID Number: 2022-23409-30913-3 Project Start Date: 22/06/2022Version: V1

Appendix DD
Study Three Human Research Ethics Committee Approval

Office of Research Ethics and Integrity

Human Ethics Application Approval

08/11/2022

ATTENTION: PROF Denise Harrison

154 - Nursing
140 - Medicine, Dentistry and Health Sciences
The University of Melbourne

Reference Number: 2022-23409-33735-4
Project Title: Exploring Australian Clinicians' Perspectives using Electronic Medical Records systems to Care for Hospitalised Children with Pain

Dear PROF Denise Harrison,

Your application for amendment to your project has been considered by an Executive Committee. You have been given approval to proceed with the project in line with the amendments on the basis that it meets the requirements of the National Statement on Ethical Conduct in Human Research (2007, Updated 2018).

Any original conditions attached to your project remain applicable. It is your responsibility to ensure that all people associated with the project are made aware of what has been approved.

Please contact us via the Correspondence tab if you have any questions or if you require further assistance.

Kind regards,

DR Megan Huynh

Research Ethics Officer

Human Ethics Team
Office of Research Ethics and Integrity | Research, Innovation & Commercialisation
Level 5, Alan Gilbert Building, 161 Barry Street, Carlton
The University of Melbourne, Victoria 3010, Australia
T: (03) 8344 2015

E: megan.huynh@unimelb.edu.au

Summary Details for the Approved Human Ethics Project:

Project Title:	Exploring Australian Clinicians' Perspectives using Electronic Medical Records systems to Care for Hospitalised Children with Pain
Reference Number:	2022-23409-33735-4
Approval Date:	17/08/2022
Expiry Date:	17/08/2025
Responsible Human Ethics Committee	LNR 4A
Project Supervisor	PROF Denise Harrison
Other Investigators	Mrs Nicole Pope, DR Greta Palmer, PROF Michael South, DR Dianne Crellin
External Investigators	Ms Janelle Keyser

Documents Table:

Document Type	File Name	Date	Version
Other	PARTNERSHIP_Study__ExPloring_recommendAtions_and_pRacTice_usiNg_EmRS_to_Help_kids_In_Pain		
Consent	PARTNERSHIP Study 3_ Consent Form V2	08/07/2022	v1

form		
Recruitment materials	PARTNERSHIP Study 3_ PLS_V2	08/07/2022 v1
Recruitment materials	Survey Promotion_eposter	08/07/2022 v1
Recruitment materials	PARTNERSHIP_Study_3_National_Survey_of_Clinicians	08/07/2022 v1
Other external approvals	Letter of Support - Exploring _ospitalised Children with Pain	08/07/2022 v1
Other external approvals	Letter of support for Nicole Pope signed by Nadia Badawi	08/07/2022 v1
Other external approvals	CHQ Letter of Support HREC No. 23409	08/07/2022 v1
Recruitment materials	Recruitment email	14/07/2022 v1
Other external approvals	Letter of Support_Draft_CIIW	26/07/2022 v1
Other	Ethics response	26/07/2022 v1
Other	NPOPE_PROTOCOL_ETHICS_Study 3	20/10/2022 v2

Conditions of Approval:

Research projects are normally approved to the anniversary date of the approval. Projects may be renewed yearly for up to a total of three years upon receipt of a satisfactory annual report. If a project is to continue beyond three years, two optional extensions of one year each (3+1+1) will need to be applied for. Anything beyond 5 years will need a new application to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

1. **Limit of Approval:** Approval is limited strictly to the research as submitted in your Project application.
2. **Variation to Project:** Any subsequent variations to the Project must be notified formally to the Committee for consideration and approval before they are implemented. If the Committee considers that the proposed changes are significant, you may be required to submit a new application.
3. **Incidents or adverse events:** Researchers must report immediately to the Committee anything that could affect the ethical acceptability of the project, including adverse effects on participants or unforeseen events. Failure to do so may result in suspension or cancellation of approval.
4. **Monitoring:** All projects are subject to monitoring at any time by the Committee.
5. **Annual Report:** An annual report must be submitted each year on the anniversary of project approval, and at the conclusion of the project. Ethics approval will lapse if an annual report is not submitted.
6. **Auditing:** All projects are subject to audit by members of the Committee.