AUT Child and Youth Health Research Cluster

Faculty of Health & Environmental Sciences Research Roadshow

Members: Julie Blamires, Annette Dickinson, Mandie Foster, Michael Neufeld, Jagamaya Shrestha-Ranjit, Paul Ripley, Kim Arrowsmith, Margaret Jones, Sally Britnell, Shayne Rasmussen, Tineke Water, Ann Hodren, Susan Platt, Katrina Coleman, Sarah Williams, Meg Smith, Nikki Anderson, Jacqui Lawless, Simon Leadley, Chiedza Hokoza, Elisabeth Coyne, Virginia Jones, Chris Moir, Smita Keshoor, Irene Zeng, Brie Fenton, Amy Kercher, Sonja Goedeke, Ying Wang, Liesje Donkin, Fiona Brooks, Lindsay Smith and Karin Plummer.

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Presenters: Arrowsmith, K; Blamires, J; Connell, T; Foster, M.

Child Invisibility and Childhood Obesity Policy

In a qualitative case study, data from four childhood obesity policies and six policy contributors were analysed for the presence of a child's voice in New Zealand childhood obesity policy.

The results showed that children were mostly *invisible* in childhood obesity policy. *Adult voice* dominated policy and children were considered to be *incompatible* to policy about childhood obesity.

Children rarely contributed to policy because they were not involved aside from one *tokenistic* effort. One significant finding was that adults preferred to advocate for children in the form of *whanau voice* across all forms of policy.

According to the United Nation Convention on the Rights of Children, children should be present in childhood obesity policy however ethical and commercial barriers prevent children's participation.

Arrowsmith, K; Blamires, J; Dickinson, A. (2022)

An Integrative Review of the Experiences and Perspectives of Children and Young People Living with Juvenile Onset Systemic Lupus Erythematosus (jSLE).

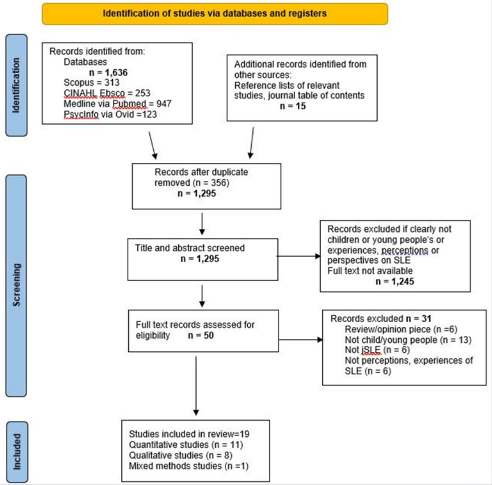
Julie Blamires, Mandie Foster, Annette Dickinson, Sara Napier

Background: Juvenile onset Systemic lupus erythematosus (jSLE) is a multi-system autoimmune disease that impacts on the daily life of children and young people. It is more aggressive than in adults, with greater disease activity, rates of organ involvement and higher mortality rates.

Purpose : To describe the experiences and perspectives of children and young people living with jSLE

Methods: An integrative review guided by the five steps described by Whittemore and Knafl was conducted. Literature was identified using Scopus, CINAHL, Medline via PubMed and PsycInfo via Ovid databases.

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow chart


Identification of studies via databases and registers

Identification

Records identified from:
Databases
n = 1,636
Scopus = 313
CINAHL Ebsco = 253
Medline via Pubmed = 947
PsycInfo via Ovid =123

Additional records identified from other sources:
Reference lists of relevant studies, journal table of contents
n = 15

Screening

Records after duplicate removed (n = 356)
n = 1,295

Title and abstract screened
n = 1,295

Records excluded if clearly not children or young people's or experiences, perceptions or perspectives on SLE
Full text not available
n = 1,245

Full text records assessed for eligibility **n = 50**

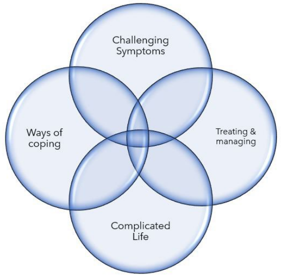
Records excluded **n = 31**
Review/opinion piece (n =6)
Not child/young people (n = 13)
Not jSLE (n = 6)
Not perceptions, experiences of SLE (n = 6)

Included

Studies included in review=19
Quantitative studies (n = 11)
Qualitative studies (n = 8)
Mixed methods studies (n =1)

Analysis & Synthesis: Following Whittemore and Knafl's framework all data from the nineteen full text articles extracted and summarised in a data extraction table. This process of breaking down and extracting information from each source of data enabled the authors to understand what was was known about children and young people's experience of SLE and set the stage for additional data analysis. An inductive thematic analysis was used. 25. Two authors independently identified initial codes. Three authors discussed the patterns in the data, grouping the codes into broad theme and sub-themes. All authors agreed on four main themes that encompassed the data

Results: Nineteen studies involving more than 1400 participants were included. Four themes were identified: challenging symptoms (including subthemes of disruptions and challenges, keeping up appearances, unpredictability, and tired and sad), medicines and side effects (dreaded steroids, conflicted feelings, medication adherence), ways of coping (family, friends and groups, relationships with health providers and maintaining positivity), and complicated life (school, sports and social, giving things up and quality of life).



Key themes representing young people's experience of living with SLE

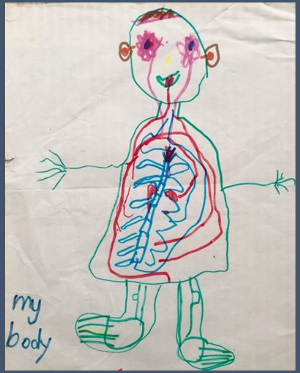
Discussion: The burden of SLE on the daily life of young people is complicated, challenging and stressful. The symptoms of fatigue, anxiety and depression impact on not only quality of life but on day to day emotional and psychosocial wellbeing. Challenges included medication side effects and disruptions to normal life. Participants also described a sense of invisibility of their disease and thus a lack of empathy at times from both parents and health professionals.

Julie Blamires Current Collaborations & Projects

What do I know and who do I tell.

The purpose of this art based study is to look at how children from New Zealand, Australia and the United Kingdom:

•Understand their condition and its management (medicines and/or treatments)
Learnt about their condition
•Decide who they will tell and why they choose those people.
•Feel when they have told someone else
•Think are the most important things about their condition to tell someone



Living with Chronic cough and bronchiectasis during COVID 19 Pandemic (qualitative research study joint project with CMDHB)

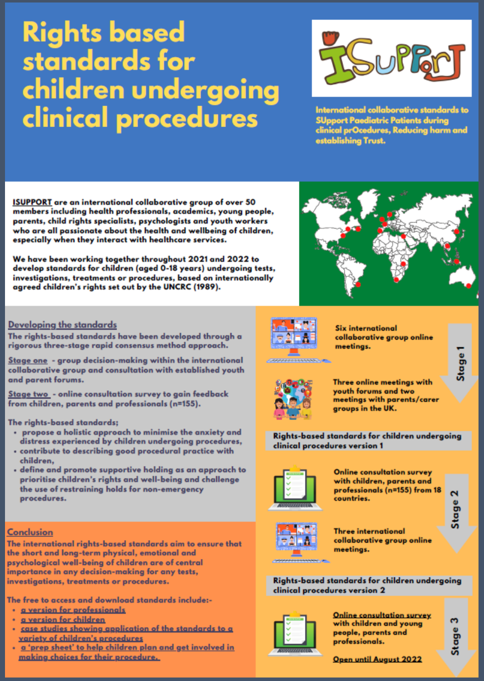
Integrative literature reviews underway:

- Australasian protocols and guidelines on the prevention and management of OM in children receiving oncology treatment
- Experiences and perceptions of siblings of child/YP with chronic illness or disability.
- Causative Factors of Compassion Fatigue in Nurses Working in Aged Care and Palliative Care Facilities

Experiences and perspectives of children, young people and their whānau living with and managing Systemic Lupus Erythematosus in NZ

Aims: To explore the experiences and perspectives of children, young people and their whānau living with and managing systemic lupus erythematosis(SLE).

Methodology: Interpretive Descriptive (ID) and the primary data sources will be indepth semi-structured family group interviews.



Rights based standards for children undergoing clinical procedures

ISUPPORT

International collaborative standards to SUpport Paediatric Patients during clinical prOcedures, Reducing harm and establishing Trust.

ISUPPORT are an international collaborative group of over 50 members including health professionals, academics, young people, parents, child rights specialists, psychologists and youth workers who are all passionate about the health and wellbeing of children, especially when they interact with healthcare services.

We have been working together throughout 2021 and 2022 to develop standards for children (aged 0-18 years) undergoing tests, investigations, treatments or procedures, based on internationally agreed children's rights set out by the UNCRC (1989).

Developing the standards
The rights-based standards have been developed through a rigorous three-stage rapid consensus method approach.

Stage one - group decision-making within the international collaborative group and consultation with established youth and parent forums.

Stage two - online consultation survey to gain feedback from children, parents and professionals (n=155).

The rights-based standards;
- propose a holistic approach to minimise the anxiety and distress experienced by children undergoing procedures,
- contribute to describing good procedural practice with children,
- define and promote supportive holding as an approach to prioritise children's rights and well-being and challenge the use of restraining holds for non-emergency procedures.

Conclusion
The international rights-based standards aim to ensure that the short and long-term physical, emotional and psychological well-being of children are of central importance in any decision-making for any tests, investigations, treatments or procedures.

The free to access and download standards include:-
- a version for professionals
- a version for children
- case studies showing application of the standards to a variety of children's procedures
- a 'prep sheet' to help children plan and get involved in making choices for their procedure.

Stage 1
Six international collaborative group online meetings.
Three online meetings with youth forums and two meetings with parents/carer groups in the UK.

Rights-based standards for children undergoing clinical procedures version 1

Stage 2
Online consultation survey with children, parents and professionals (n=155) from 18 countries.
Three international collaborative group online meetings.

Rights-based standards for children undergoing clinical procedures version 2

Stage 3
Online consultation survey with children and young people, parents and professionals.

Open until August 2022

Other projects:

- **The Long-Term Impact of COVID-19 on Nursing**: An e-Panel Discussion from the International Network for Child and Family Centred Care (International Network for Child and Family Centred Care (INCFCC).
- **Defining Child and Family Centred Care approach**: a concept analysis (joint project AUT and Edith Cowan University)
- **The nursing health history**: A conversation with a purpose. A discursive article.
- **Child invisibility in Aotearoa New Zealand** childhood obesity policy: A qualitative case study
- The **impact of policies and legislation on the structure and delivery of support services for children with cerebral palsy** and their families in New Zealand (Scholarly Paper: Professional Perspective)
- **Children and youth's participation in decision making within health care organisations**. Survey of managers and leaders within health care services in New Zealand

Sibling’s Experiences of Living with a Sibling who has a Chronic Illness

Purpose: This integrative review will explore what is known about a sibling’s experience of living with a sibling who has a chronic illness and will identify the gaps in the literature.

Methods: An integrative review guided by the five steps described by Whittemore and Knafl was conducted. Literature was identified using Scopus, CINAHL, Medline via PubMed and PsycInfo via Ovid databases.

Inclusion criteria: Published peer-reviewed empirical research in English from 2012 to 2022 focused on sibling’s experience (3yrs to 24yrs) of living with a sibling who has a chronic illness.

Exclusion criteria: Published peer-reviewed empirical research that does not meet the inclusion criteria or research undertaken within a PICU or on an acute illness or on death and dying.

The literature search has been completed and divided into quantitative/mixed and qualitative articles. The researchers aim to publish two articles and report the findings at conferences.

An international collaborative research project between Auckland University of Technology and Edith Cowan University, School of Nursing and Midwifery.

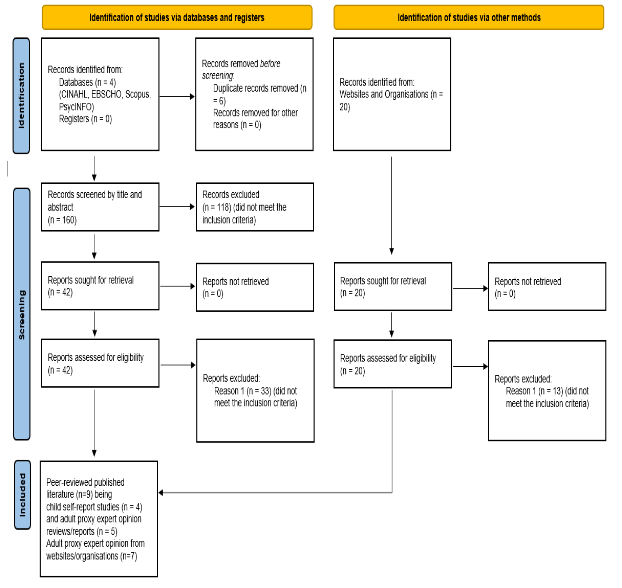
Tanya Connell

Children and Young People’s Participation in Decision Making within Health Care Organisations
An Integrative Review

Foster, M., Moir, C., Jones, V., Shrestha-Ranjit, J., Blamires, J., Fenton, B., Dickinson, A. (2022)

Background:This integrative review examined child self-reported peer-reviewed manuscripts and published guidelines, policy, reviews, expert opinion and legislation to explore how New Zealand CYP participate in discussions and decision-making processes within health care settings and what are the barriers and benefits to such participation.

Methods: Four child self-reported peer-reviewed manuscripts and twelve expert opinion documents were retrieved from four electronic databases (CINAHL, EBSCO, Scopus and PsycINFO) including academic, government and institutional websites.



Records identified from:
Databases (n = 4)
(CINAHL, EBSCHO, Scopus, PsycINFO)
Registers (n = 0)

Records removed *before screening*:
Duplicate records removed (n = 6)
Records removed for other reasons (n = 0)

Records identified from:
Websites and Organisations (n = 20)

Records screened by title and abstract
(n = 160)

Records excluded
(n = 118) (did not meet the inclusion criteria)

Reports sought for retrieval
(n = 42)

Reports not retrieved
(n = 0)

Reports sought for retrieval
(n = 20)

Reports not retrieved
(n = 0)

Reports assessed for eligibility
(n = 42)

Reports excluded:
Reason 1 (n = 33) (did not meet the inclusion criteria)

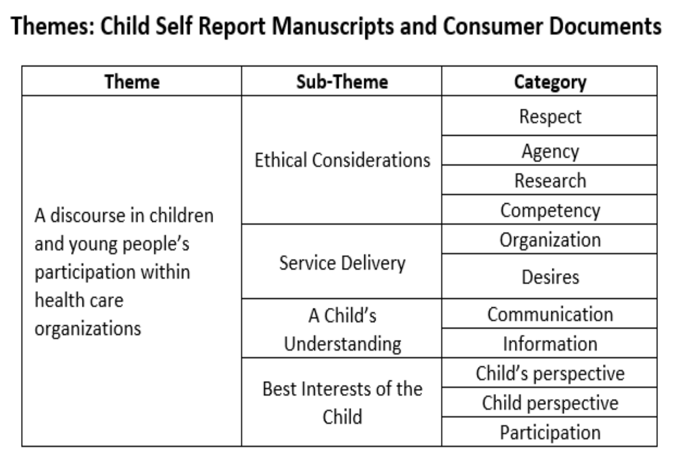
Reports assessed for eligibility
(n = 20)

Reports excluded:
Reason 1 (n = 13) (did not meet the inclusion criteria)

Peer-reviewed published literature (n=9) being child self-report studies (n = 4) and adult proxy expert opinion reviews/reports (n = 5)
Adult proxy expert opinion from websites/organisations (n=7)

Inductive content thematic analysis generated one theme (a discourse in CYP participation within health care organisations), four sub-themes (ethical considerations, service delivery, a child’s understanding, best interest of the child), 11 categories and 93 codes from 202 findings.

It is evident within this review that there is a discourse between what expert opinion are stating is required to promote CYP’s participation in discussions and decision-making processes within health care settings and what is occurring in practice. In essence including CYP’s participation in discussions and decision-making processes within health care settings requires a contextually embedded multi-tiered lens approach with careful attention to critical reasoning and situational knowledge.



Themes: Child Self Report Manuscripts and Consumer Documents

Theme	Sub-Theme	Category
A discourse in children and young people’s participation within health care organizations	Ethical Considerations	Respect
		Agency
		Research
		Competency
	Service Delivery	Organization
		Desires
	A Child’s Understanding	Communication
		Information
	Best Interests of the Child	Child’s perspective
		Child perspective
		Participation

Mandie Foster Current Collaborations & Projects

Present Projects

- Key Stakeholders' Perceptions of Children and Youth's Participation in Decision Making within Health Care Organisations
- Development of an International Child Research Checklist: Delphi Study
- Co-Design of Teaching and Learning Resources with Families and Nursing Students in Australia and New Zealand
- Nurses' Attitudes toward the Importance of Families and Perceived Outcomes of Family Involvement in Nursing Care
- Staff's experiences of their child's best interests during hospitalization

International Research Collaboration

- The Long-Term Impact of COVID-19 on Nursing: An e-Panel Discussion from the International Network for Child and Family Centred Care
- Impact of Antibiotic Allergy Labelling on Clinical Outcomes and Compliance of Drug Allergy Reporting for Children and Young People in Australia

Burak Bora
10 years old
Turkey

Level of restriction: Strict. Home schooling; not allowed to leave the family house and play with friends.

" We can stay safe by obeying rules."

Foster, M. et al. (2021). Seeing lockdown through the eyes of children from around the world: Reflecting on a children's artwork project. *Nursing Praxis in Aotearoa New Zealand, 37*(3)

Click on the picture to view the NCQ YouTube Video

Integrative Literature Reviews Underway:

- Fathers' Experiences of Caring for a Child with a Chronic Illness: A Meta-Synthesis of Quantitative Research
- Fathers' Experiences of Caring for a Child with a Chronic Illness: A Meta-Synthesis of Qualitative Research
- Risk and Protective Factors of Self harm and Suicidality in Adolescents: An Umbrella Review
- The Impact of COVID-19 Vaccine on Children and Young People: An Integrative Review
- Hand in Hand: A Systematic Review on the Impact of Antibiotic Allergy Labels and Delabeling Practices
- The Focus of COVID-19 Research for Nurses Providing Care for Children and Young People: A Scoping Review
- Child and Family Centred Care: A Concept Analysis

Needs of Children Questionnaire Projects

- Staff Experiences in using the Needs of Children Questionnaire at Liverpool Hospital
- Implementation of NCQ in HKH Crown Princess Victoria's Children's and Youth Hospital in Linkoping
- Psychometric testing of the NCQ in Sweden
- Psychometric testing of the NCW in Turkey

JAN
Leading Global Nursing Research
RESEARCH METHODOLOGY: INSTRUMENT DEVELOPMENT
Open Access

Development and validation of the needs of children questionnaire: An instrument to measure children's self-reported needs in hospital

儿童需求调查问卷的编制与验证:测量儿童自述住院需求的量表
Mandie Foster PhD, PG Dip/Cert, RN, Lisa Whitehead BSc (Hons) (Lond), MA (Liverpool), PhD (Liverpool), RN, Diana Arabiat PhD, MN, RN

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