Clinical Excellence Queensland

Child and Family Centred Care

Evidence-based principles for the care of critically unwell children





Child and Family Centred Care: Evidence-based principles for the statewide delivery of health services to critically unwell children

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Executive Summary

When a child or young person is critically unwell, it can be a highly distressing experience for both the patient and family. It has the potential to result in significant physical and psychological morbidity, particularly in vulnerable population groups. The way in which healthcare is delivered to critically unwell children, as well as their parents'/carers' perceptions of this care, can influence the family's capacity to cope and adjust, which plays a key role in the child's longer-term recovery outcomes.

This paper was developed based on diagnostics and solution design to promote Child and Family Centred Care (CFCC) for critically ill children and young people across their patient care journey. In this document, Child and Family Centred Care is defined as:

"A philosophical approach and a set of principles to guide the planning, delivery, evaluation and continuous improvement of healthcare that is grounded in active partnership between healthcare providers, children and families, at a level that reflects the child's competence and of the family's choosing."

The Child and Family Centred Care principles for the care of critically ill children and young people are as follows:

- **Respect and dignity**: Healthcare providers listen to, respect and respond to children's and families' values, perspectives, choices, cultural background, developmental stage, capabilities, skills and expertise, such that their knowledge, priorities and beliefs are considered integral to the planning and delivery of care.
- **Meaningful partnerships**: Meaningful partnerships are achieved when care planning and delivery considers the day-to-day ways of living for children and families, as well as the norms, values and beliefs of various cultures and geographical regions, in order to support the needs, strengths, values, and abilities of all. It requires collaboration at all levels of healthcare from direct patient care to professional development, service design and implementation, organisational-wide and health service policy.
- **Communication and information sharing**: This principle involves sharing information with families on an ongoing basis and in ways they find useful and affirms and fosters their participation in care and decision-making. Communication and exchange of information should be open, timely, honest, objective and accessible for their age and health literacy level.
- Empowerment, flexibility and choice: Health care providers should adopt a holistic approach to care that identifies and builds on the unique strengths and individuality of each child, family and community. It should also empower each child and family to discover their own strengths and build confidence in their own autonomy to make choices and decisions about their own health as well as their child's health
- Equity-oriented care: This principle embraces the unique practices and strengths of different cultures that support families. This is particularly important for families that identify as Aboriginal and/or Torres Strait Islander, and those from culturally and linguistically diverse backgrounds including migrants and refugees.

It also acknowledged that some families may face additional challenges to accessing healthcare for their children due to social marginalisation, anticipated stigma, institutionalised racism, and previous negative interactions. Equity-oriented healthcare focuses on directing resources to those with the greatest need and offers care that is inclusive and responsive to the socio-cultural contexts.

There is robust evidence to demonstrate the benefits of a genuine partnered approach to paediatric healthcare, whereby the child and family's needs are centred and their participation in decision-making and care planning is not only supported but embraced. CFCC has been associated with improved health outcomes as well as increased competence of children and young people to manage their own health, and overall family coping. It acknowledges the unique attitudes, culture, values and knowledge held by different individuals and harnesses the expertise of children and families in their own care. In this way it empowers them to be active agents in their care within the hospital and longer term when they return home.

This document is a deliverable of the Queensland Paediatric Critical Care Pathway (QPCCP) project, which aims to establish a coordinated and streamlined approach to the provision of effective, efficient, consistent and safe care for any critically unwell child and young people in Queensland. Following a statewide, multidisciplinary, cross Hospital and Health Service (HHS) solution co-design workshop in April 2019 with key stakeholders across Queensland and New Sales Wales, a set of overarching solutions were proposed to address the issues facing children and young people at risk of critical illness. The workshop had broad representation across HHSs, facility size, disciplines and specialities – administrators, consumers and providers who reviewed data and themes from diagnostics. The solutions were endorsed by the QPCCP Steering Committee (SC) and shared with Health Service Chief Executives (HSCE). One of the solutions was to "Adopt principles underpinning best practice child & family centred care – informing solutions". The CFCC principles were identified to underpin and inform other solutions from the QPCCP project.

Following the extensive literature review this document was co-designed in consultation with a range of medical, nursing, allied health Aboriginal and/or Torres Strait Islander healthcare workers and consumer representatives from across the state that have expertise and experience of delivering healthcare to children and young people. Input was sought from healthcare professionals across different settings including: tertiary, regional and remote facilities; and range of areas (Emergency Department (ED), ward, critical care/ Intensive Care Unit (ICU), retrieval service providers).

The paper provides practical mechanisms to embed the principles at a practice level as well as an organisational and policy level, to ensure that CFCC is embedded across all hospital and health services that provide care for children and young people. This document is supplemented by a CFCC poster designed for healthcare professionals as visual aid of the CFCC principles (Appendix A).

Key recommendations

It is recommended that Hospital and Health Services work with consumers and clinicians to identify opportunities to:

- 1. embed the CFCC principles in clinical care and supporting policy and procedures.
- 2. assess the implementation of CFCC and identify areas for improvement.
- 3. engage consumers and carers as partners in implementation, evaluation and improvement activities relating to the delivery of CFCC in Queensland.

1 Introduction

Critical illness in children is a life changing event for the child and their kin—their parents, siblings, carers, partners, peers, and wider family network. Medical advances have resulted in increasing numbers of children and young people surviving critical illness, such as serious physical injury, cardiorespiratory disease and sepsis¹. Despite increased survival rates, critical illness is, by definition, life-threatening and exposes children and their families to extreme stressors. For the critically unwell child or young person, these may include:

- highly invasive procedures
- separation from family
- dislocation from community and culture
- aeromedical retrieval
- altered levels of consciousness
- elevations in light and noise levels
- significant sleep deprivation
- multiple strangers providing sophisticated caretaking procedures
- and exposure to other critically ill and dying children and young people.²

When a child or young person is critically unwell, there is an instant role change for parents, from being responsible for the safeguarding, protecting and caring for their child, to being dependent on the clinical team to save their child's life.¹ At the same time, due to their increased care needs, when caring for a critically unwell child or young person, parents often perform more complex care duties, similar to those carried out by health professional.³ These parental role changes are accompanied by numerous additional stressors including: witnessing their child frightened and in pain; confronting physical changes in their child; being required to make frequent, difficult decisions often with limited information on which to base them; and interacting with numerous specialty clinicians while simultaneously balancing existing commitments in their home life, such as work and other dependants.¹

There is a well-established relationship between exposure to extreme stressors in a vulnerable population and physical and psychological morbidity.^{2, 4} As such, paediatric critical illness can present serious threats to the long-term health and wellbeing of not only the child but also the family.^{2, 4} Childhood critical illness has been shown to have a negative impact on most caregivers' physical and mental health, as well as financial status, social interactions, family dynamics and general wellbeing.^{1, 3}

In turn, the manner in which the family adjusts to, and copes with, a child's illness can substantially influence the child's longer-term health outcomes following critical illness or injury.

The provision of health services to children and young people is a key indicator of the performance of a health system. However, delivering health care services that meet the needs of children, young people and their families remains one of the fundamental challenges faced by health care systems world-wide.⁵ When HHSs, health professionals, patients, families and carers work in genuine partnership, the quality and safety of healthcare rises, medical errors and costs decrease, provider satisfaction increases and patient care experience improves.⁶⁻⁸ Active child and family participation in care planning and delivery is well recognised as essential for optimising a child's health, meeting a child's developmental and emotional needs, and increasing the safety and quality of paediatric critical care.⁹ Children who participate in their own care may experience less pain and discomfort than children who are not involved.¹⁰ Unfortunately, families of critically unwell children report multiple unmet needs regarding information and health professional collaboration, with 'partnership' at times tokenistic and occurring on an ad hoc basis rather than as key component of planned care.^{11, 12} In Australia, the Garling Report found that children's rights and interests in healthcare are often given secondary consideration, and are subservient to systemic and institutionalised interests.¹³ This is mirrored by the findings of other reports internationally, which have observed inadequacies at every point in children's chain of care, from referral to diagnosis, surgery and intensive care.^{14, 15}

In order to improve the quality of health services for critically unwell children and young people, their needs and best interests must be at the centre of health professional principles and intentions, and at the centre of health professional practice.^{16, 17} Child and Family Centred Care is a patient centred approach that orients children to a central position within healthcare and recognises family involvement as instrumental to the child's care.¹⁸ It is acknowledged to be the gold standard in the provision of patient centred and integrated care to infants, children and young people.^{15, 19}

1.1 The need for Child and Family Centred Care

A child and family centred approach to the provision of care to critically unwell and deteriorating children and young people is not only best practice but is also strongly supported by international, national, and state-based charters, frameworks and strategies.

The Convention on the Rights of the Child (ratified by Australia in 1990) acknowledges the importance of child and family centredness in care delivery and explicitly states children's right to express their concerns; convey their perspectives; do things themselves if they can; and make decisions or be involved in decision-making about matters that are about them or that impact them.²⁰ It further acknowledges that the family is the natural environment for the nurturing and care of children and young people.

The Charter on the Rights of Children and Young People in Healthcare Services in Australia, aimed at ensuring that the care provided to children and young people is appropriate and acceptable, is underpinned by three key principles.²¹

First, the primary consideration should be the child's best interests; second, all children are to be listened to and taken seriously; and third, the family is recognised as the fundamental decision-making unit in a child's life.²¹

The Australian Safety and Quality Framework for Health Care identifies patient-focused care as the first of three dimensions required for a safe and high-quality health system, reflecting a growing recognition of the importance of placing the child at the centre of their healthcare experience.²² Under Standard One, Clinical Governance, of the National Safety and Quality Health Service (NSQHS) Standards, effective governance in health service organisations that provide care for children ensures that healthcare is child and family focused and meets children's physical, mental and psychosocial needs.²³ Standard Two, Partnering with Consumers, requires active partnership between consumers, clinicians and health service organisations.²³ Partnering with children and young people as well as their families requires different approaches than to partnering solely with adults for a variety of reasons including: children are more dependent than adults, children have varied developmental needs, and there is greater variability in children's capacity to be involved in partnership.²⁴ The requirement for genuine partnership and respect is also embedded in the six actions of the NSQHS Standards that focus specifically on meeting the needs of Aboriginal and/or Torres Strait Islander people.

A child and family centred approach is reflected in the guiding principles of the Department of Health Queensland's *Statewide Plan for Children and Young People's Health Services to 2026.*²⁵ Under this plan, all entities providing public sector health services to children have committed to placing children, young people and their families and carers at the centre of health service delivery. This commitment extends to working collaboratively with children, young people, and their families both in the redesign and provision of healthcare to achieve the required systemic change.

1.2 Queensland Paediatric Critical Care Pathway Project

The aim of the QPCCP project is to establish a coordinated and streamlined approach to the provision of effective, efficient, consistent, and safe care for any critically unwell child and young person anywhere in Queensland. The QPCCP project was initiated and is driven by senior paediatric critical care medical, nursing and allied health clinicians from across the state and was endorsed by the Queensland Paediatric Quality Council (QPQC), Queensland Clinical Senate (QCS), Queensland Child and Youth Clinical Network (QCYCN), Statewide Intensive Care Clinical Network (SICCN), and the Directors of Paediatrics. The project has been approved and funded through Clinical Excellence Queensland, Department of Health (DoH). The QPCCP project utilises a clinical service redesign methodology, engaging clinicians and consumers in co-design throughout each phase. The diagnostic phase of the project involved extensive quantitative and qualitative data collection and analysis to ascertain what is working well, what is not working well, and suggestions for improvement in relation to the provision of critical care services to infants, children and young people in Queensland. Whilst staff endeavour to provide the best possible care for children within their capacity and capability, there are several systemic and structural limitations that often make this challenging.

Recurring themes and issues that were identified during the diagnostic phase include:

- Children and young people exposed to stressful environments due to circumstance mostly outside the control of staff (e.g. inappropriate behaviour in mixed emergency departments).
- Limited and inadequate communication concerning retrievals (e.g. unexpected changes in the mode of retrieval and destination).
- Limited family orientation to new facilities following retrieval or transfer.
- Limited child- and youth-friendly spaces in non-paediatric specific facilities.
- Financial burden for the family and extensive time spent away from other family members including siblings, due to distance between the receiving facility and home.
- Inconsistent continuity of care for paediatric patients.
- Inadequate information provided to families about diagnosis, prognosis and care, and inadequate involvement in the decision-making process.
- Inadequate provisions for local palliative care and/or repatriation of deceased children, particularly in remote and Aboriginal and/or Torres Strait Islander communities.

These issues indicate that care provided to infants, children and young people across the critical care continuum is not always child and family centred. Families reported that they want:

- Access to care locally.
- Support and continuity of care.
- Informed discussions, including active participation in the decision-making process.
- Education regarding their child's diagnosis, prognosis and care needs.
- Time to be considered an influential factor in clinical decision-making.

Following a multidisciplinary solution design workshop with key stakeholders across Queensland and New South Wales, the QPCCP project established a set of overarching solutions to address the aforementioned issues for children and young people. A need for clinical governance was identified as a key priority to engender a culture of CFCC in the provision of care for infants, children, and young people.

1.3 Purpose and scope

The purpose of this document is to define and establish overarching, evidence-based principles for CFCC, and to provide recommendations for practice in specific critical care contexts (e.g. emergency departments, intensive care, retrievals and transfers) to support HHSs to care for critically unwell, deteriorating, or at risk of deteriorating, children and young people in the best and safest way possible.

This document underpins and informs other outcomes stemming from the QPCCP Project, including the development and implementation of Paediatric Close Observation Units, paediatric critical care multidisciplinary telehealth consultations, and the Paediatric Critical Care Advice and Retrievals Action Group.

While the focus of this document is CFCC, as it applies to critically unwell, deteriorating or at-risk children, the principles could equally be applied to all infants, children and young people receiving health services.

The development of this principles document was an iterative process. This document has been created with consideration of the common elements and patterns for CFCC identified in a comprehensive literature review. It was then refined to align with the experiences, expertise and scientific knowledge of consumers and clinicians.

It is expected this paper, alongside the CFCC poster, will be useful resources for nurses, medical practitioners, allied health practitioners, Aboriginal and/or Torres Strait Islander healthcare workers, and other members of the interprofessional healthcare team to enhance the quality of their partnerships with children and families accessing care, ultimately improving clinical outcomes and the child and family's experience of healthcare through the use of evidence-based CFCC practices.

1.3.1 Definitions

Child: throughout this document, the term 'child' or 'children' is generally used to include all newborn infants, babies, children and young people up to the age of 18 years. Definitions of childhood vary, and age limits are arbitrary. For the purpose of this document, the United Nations Convention on the Rights of the Child was used to define the age cut off, at 18 years. This definition also accords with the definition in key pieces of Queensland legislation that relate to the rights and wellbeing of children.²⁰

The responsibility for caring for a critically unwell child involves a partnership between health providers, the child and the family. For young children, decisions about care and treatment are usually made by the parents, who are recognised as the fundamental decision-makers in the child's life. The Charter on the Rights of Children and Young People in Healthcare Services in Australia also emphasises participation by children and young people, consideration of their views, and where possible involvement in decision-making processes.²¹ When a child's age or ability prevents them from understanding and actively contributing to the decision-making process, they are entitled to information and involvement as is appropriate for their age, ability to understand, and psychological state, including information about the decision and rationale for the decision.

Young person: throughout this document the term 'young person' is used to identify a distinct subgroup with specific needs that set this population apart from both younger children and adults. Young people may authorise medical treatment when they are old enough and mature enough to decide for themselves, provided they are capable of understanding what is proposed and why, and of expressing their own wishes. 'Gillick competency' is the legal term referring to a child, adolescent or young person's ability to understand and provide consent. In Queensland, an adolescent of 15 years or above would normally be expected to have sufficient maturity, intelligence and understanding to consent to medical examination and treatment for minor or routine procedures. However, decision-making competence does not simply arrive with puberty; it depends on the maturity and cognitive ability of the individual and the seriousness of the treatment decision to be made.

An adolescent experiencing a more complicated condition or critical illness may therefore require support to make informed decisions about care and treatment, as Gillick competence requires that the child fully understands both the condition and the proposed treatment options.

They should also have the ability to weigh risk and benefit, and to consider long term factors such as the effects on family life and on schooling.²⁶ Provision of effective healthcare services during adolescence involves acknowledgement of the breadth and intensity of biopsychosocial development during this period, and identification of the needs that set this population apart from children and adults.²⁷ The provision of developmentally appropriate healthcare over this important period of development is a key issue impacting upon young people's biomedical outcomes^{28, 29}; adherence to therapy^{27, 30}; satisfaction with healthcare provision³¹; engagement with healthcare services^{26, 32}; self-care practices³³; and their achievement as self-reliant, independent and productive members of society.³⁴

Family: The term is used to describe a range of social relations; 'family' should be interpreted broadly to include those who are closest to the child in knowledge, care, and affection. It includes parents, siblings, grandparents, aunts, uncles, cousins, friends, kin, elders and carers. It also includes guardianship arrangements.²⁴ In this context, the family may be biologically related or unrelated to the child. They are individuals who provide support, and with whom the child has a significant relationship. A family may also include the representative/s who are physically present with the child and others who are absent but actively involved in the child's custody or care.³⁵

2 Child and Family Centred Care (CFCC)

For many years family centred care (FCC) has been the benchmark of quality for paediatric practice. However, a substantial flaw within the framing and implementation of FCC is that focus is predominantly on partnership between health professionals and parents, without sufficient consideration of the child. This can result in a failure to adequately and appropriately engage children and young people in their healthcare.¹⁵ Consequently, there is an emergent drive to focus more firmly on children's rights and ability to be fully engaged in their healthcare.

CFCC is a philosophy of healthcare which integrates and extends the ideas of both patient centred and family centred care to account for children's agency and human rights to participate in healthcare decisions as a key and active member of the partnership with health professionals. It acknowledges that children's competence and participation will vary over time and be influenced by factors such as environment, culture, health literacy and previous interactions with healthcare providers.^{6, 15, 16, 36} CFCC involves shifting away from disease-oriented medicine where the patient is a passive subject of intervention, towards patient-oriented medicine where the child and family are actively involved in the care process.¹⁹

All CFCC models recognise that the concept of childhood is inseparable from the concept of family. Families have primary responsibility for nurturance, promoting their child's wellbeing, and play an integral role in providing care to children and young people with health conditions.^{3, 15, 18, 37} As such, families are seen as instrumental members of the care team, who provide emotional and physical support to the patient before, during and after a healthcare encounter.³

Within this view, the child and the family participate actively in the decision-making, planning and provision of their child's care to the extent they choose.^{6, 9, 11, 14, 16, 38}

CFCC is culturally sensitive, which builds a trusting environment through supporting relationships that value and recognise the importance of family traditions, beliefs and management styles as healthcare providers collaborate.³⁷ CFCC therefore describes the optimal healthcare as experienced by children, young people and their families.

3 Definition of Child and Family Centred Care

There is currently no universally accepted definition of CFCC or its constituent elements. However, all definitions centre around the notion of placing the child and family at the centre of care. The definition used in this document is drawn from a range of published definitions and broadly aligns with, while expanding upon, existing Children's Health Queensland (CHQ) definitions of FCC.^{3, 11, 14, 37-39}

Definition:

Child and Family Centred Care (CFCC) is a philosophical approach and a set of principles to guide the planning, delivery, evaluation and continuous improvement of healthcare that is grounded in active partnership between healthcare providers, children and families, at a level that reflects the child's competence and of the family's choosing.

4 Benefits of Child and Family Centred Care

Research has highlighted the following benefits of family centred care:^{8, 9, 40-43}

- Better health outcomes for critically unwell children and young people.
- Increased competence of children and young people to better manage their own healthcare independently.
- Increased engagement in treatment resulting in more effective treatments.
- Improved healthcare decision-making based on better information and collaboration between professionals and families.
- Improved 'buy-in' and follow-through when care plan is developed with the family.
- Reduced parental stress and anxiety.
- Greater parental confidence, satisfaction, and family empowerment.
- More efficient and effective use of a healthcare professional's time and healthcare resources.
- Improved communication between healthcare professionals.
- Opportunities for healthcare professionals to learn from families about the actual workings, positives and challenges of the healthcare service and system.
- Significantly increased child, family, and staff satisfaction ratings.

5 Principles of Child and Family Centred Care

The guiding principles identified below reflect a synthesis of the literature which identifies the key components of CFCC that are universal across paediatric illness populations and care contexts. Examples of CFCC in practice are also provided.

5.1 Respect and dignity

Healthcare providers listen to, respect and respond to children's and families' values, perspectives, choices, cultural background, skills and expertise, such that their knowledge, priorities and beliefs are considered integral to the planning and delivery of care.^{9, 11, 14, 36, 39, 44} The concept of respect and dignity includes recognition of the wide variety in the structure of families, the role different family members may play in a child's life, their backgrounds, and cultures. It also recognises that all family members are affected when a child is critically ill, respects different methods of coping, and acknowledges that in providing care, health professionals need to consider the effects of the child's illness and hospitalisation on the family unit.¹ Understanding families' needs and priorities contribute to realistic and better-defined outcomes and is important to enhance families' abilities to support the care plan and optimise health outcomes.^{3, 45}

In practice – Healthcare professionals	Example
Build rapport to develop a sense of trust	 Involve social worker, Indigenous Hospital Liaison Officer, or other healthcare professional with an existing relationship.
Learn and understand their beliefs, preferences, priorities, needs, concerns and their abilities to provide care	 Prompts in admission forms and care planning documentation. Record this information in the patient file and note if they change. Have regular conversations as part of care planning or ward rounds.
Create time and a safe space to hold respectful conversations	 Social workers can facilitate conversations between the patient, family and healthcare team. Social workers often have greater capacity to provide education at the health literacy level of the patient and family.
Create opportunities for the family to feel valued and included	 If the family is unable to be physically present, find alternate mechanisms e.g. Online Telehealth platform, Teams, phone conference. Provide details for the carers/family to contact the treating team. Give the family the option in advanced to be involved in conversations.

5.1.1 Respect and dignity in practice

Ensure the patient, family and other important people can participate in conversations about care	•	Early identification of possible language barriers, cultural barriers, health literacy, and sociodemographic factors e.g. Prompt in admission process. Early involvement of social worker, Indigenous Health Liaison Officer, and/or interpreter.
Understand who the important people are in the patient's life	•	Understand who the child's carers are, what the kinship structures are, who the most appropriate person is to discuss the child's care, and how best to communicate with those people.
Acknowledge the different and unique needs of family members	•	Recognise that each family member may have a different level of health literacy and individual ways of coping.

5.2 Meaningful partnerships

The term partnership is embedded both implicitly and explicitly in all current understandings and definitions of CFCC.^{1, 3, 11, 14, 44, 46, 47} Indeed, CFCC is internationally recognised as care that is grounded in some form of joint partnership between children and young people, families and members of the interprofessional healthcare team. However, meaningful partnership involves a more robust notion of child and family inclusion than parental consent to treatment; allowing parents to stay with a hospitalised child: or episodic instances of partnering with various team members.⁴⁶ Rather, the concept of meaningful partnerships has been described as "the active process whereby practitioners walk the talk" of CFCC.⁴⁸ Partnerships include interdependent interactions and supportive collaborations between all parties. As required by NSQHS Standards—Standard Two, Partnering with Consumers, children and their families are partners in their healthcare decision-making, with clinicians encouraging them to participate in care planning, decision-making and delivery at a level that reflects both the child's competence and the child's and family's choosing.^{44, 48} Genuinely meaningful partnership is achieved when care planning considers the day-to-day ways of living for children and families, as well as the norms, values and beliefs of various cultures and geographical regions, in order to meet the needs, strengths, values, and abilities of all.^{3, 11, 48} Developing meaningful partnerships requires collaboration with children, young people and families at all levels of healthcare, not only at the level of direct patient care, but also in professional education, program and policy development, service design and delivery, and evaluation, at the institutional (i.e. HHS) and organisational (i.e. DoH) level.^{14, 44}

5.2.1 Meaningful partnerships in practice

In practice – Healthcare professionals	Example
Recognise the important role of clinicians in establishing and maintaining partnerships	 Clarifying mutual expectations of partnership and enhancing their understanding of environmental influences on the child and their family.

Shared decision-making and care planning	 Clinicians and patients make decisions together using the best available evidence and share ownership for those decisions. Provide decision guides to help children and families weigh the benefits and risks of treatment choices as they relate to their individual values (e.g. the Ottawa Personal Decision Guide). Facilitate involvement in care e.g. giving children and families a meaningful role on rounds, having children and families share their concerns first during medical discussions, and thanking patients and families for their contributions. Define overall goals of care (including decisions regarding limiting or withdrawing life-prolonging interventions). Connected case management is inclusive of all treating teams. In some instances, connected care may include the connected care for a parent/ carer, for example continuity of postnatal care of the mother when her newborn is critically ill and is transferred for care under a paediatric team.).
Recognise that the concept of partnership may be interpreted differently based on a family's cultural or geographical background	 Avoid assumptions about what 'good partnership' looks like different families. Identify and understand different knowledge systems, this is particularly important for Aboriginal and/or Torres Strait Islander families that hold, share and process knowledge in unique ways.
Understand that partnerships between children, families and healthcare team members may change over	 Create opportunities to understand the child and family's perception of 'partnership' and 'collaboration'. The course of the relationship and models of care should allow for this fluidity.

Facilitate the child and family's involvement in care

- Educate and support the patient to do simple self-care tasks and manage aspects of their care that they are comfortable with and capable of.
- Encourage parents to be present during invasive procedures to reduce pain in child undergoing the procedure and accelerate the recovery process.
- Explain to the parent what will happen during the procedure; suggesting ways in which they can assist and support; asking them what they think would help; and how they think their child will go.
- Check in on parents/carers after invasive procedures and debrief if it was particularly distressing for them.
- Offer open presence at the bedside (defined as no or minimal restrictions on presence at the bedside) or flexible presence that meets their needs.
- Offered parents/carers the option to be taught how to assist with care to improve confidence and competence in their caregiving role.
- If an infant, child or young person is being transferred, keep the carer and child together where possible e.g. Newborn baby and mother.
- If the carer is unable to accompany, keep the carer and family informed.

HHS and organisational strategies to support partnerships	Example
Identifying and addressing institutional- level barriers to families engaging in meaningful partnerships	 Provide subsidised parking for families of hospitalised children. Providing a care coordinator as a single point of contact in order to maintain consistency and overcome the 'revolving door' of healthcare workers, where families don't know who to approach. Development of positive, open approaches to towards visiting and access to sleeping in close proximity to the child to reduce child anxiety and increase family member roles as partners in care.
Ensure staff have the right skillset	• Education in parent–professional communication, negotiation skills, family dynamics, conflict resolution and the provision of other types of social support.

Creating a physical environment that meet the needs of children and families.	•	Advocate and support consumer input, drawing on their lived experiences to inform ways in which clinical settings can be tailored to promote feelings of safety, security, and conducive to the involvement of family in the child's care.
Ensure children, young people and families are meaningful partners in care at all levels of the organisation	•	Including both children, young people, families and kin in the development and evaluation of facility design, with adequate representation and diversity of experiences.

5.3 Communication and information sharing

Patients and families must be equipped to participate in health care discussions in order to engage in meaningful partnerships. This principle involves sharing information with families on an ongoing basis and in ways they find useful and affirms and fosters their participation in care and decision-making. It also involves conscious valuing and actively seeking the information held by families as the expert in their child's care, values and preferences.^{14, 18, 36, 47} Communication and exchange of information should be open, timely, honest, objective and accessible (i.e. at an appropriate level considering the child's and family's health literacy).^{3, 14} Education is a necessary component of communication and information sharing in the provision of effective CFCC for the child, family and healthcare professionals, approached from the perspective of mutual learning about the disease and treatment.³

5.3.1 Communication and information sharing in practice

In practice – commencement of healthcare	Example
Provide orientation information	 Communication to the patient and family what they can except before they arrive at the facility and suggest essential things to bring.
	 Age-appropriate leaflet/brochure/booklet to family and the child about the clinical setting (including facilities and family support available) and the facility's commitment to CFCC.

In practice – throughout care	Example
Build rapport with families establish a sense of trust between	 Facilitation of conversations by social worker of Indigenous Hospital Liaison Officer. Be reliable and follow through with commitments e.g. call at the time you commit to or communicate if plans have changed.

Understand the child and family's level of health literacy and delivering information accordingly	 Work with the family to find out their understanding of the medical situation and reassure them that it is not a test. Use various strategies to promote health literacy e.g. use "teach backs" and "show backs," in which children or family members restate information provided by clinicians or demonstrate newly taught skills to increase understanding, decrease confusion, and correct any misunderstanding or misperception. Explain what care is being given and why (including the most routine procedures) in terms that are understandable to the child (where possible) and family e.g. use informational pamphlets and videos. Avoid making assumptions about what children/families know or want to know, discuss their goals together and identify what information they are looking for.
Identify and support social, developmental, and cultural factors that may impact communication	 Address patient and family communication needs promptly e.g. an interpreter for individuals whose preferred language is not English; who have sensory or communication impairments; or Indigenous health worker involvement to ensure culturally safe care for Aboriginal and/or Torres Strait Islander families. Provide information in terms and formats (including pictures) children and family members can understand.
Involve parents or other designated family members in care discussions	 Making sure they are available for multidisciplinary rounds to discuss concerns, the health care plan, and progress, and encourage them to participate. Family members should be asked about the best means to reach them since many families find it difficult to be present in the ICU on a regular basis and may nonetheless wish to receive information about the child's clinical care and status and to participate in shared decision-making. Schedule meetings in advanced and inform the family to give them enough time to organise their attendance for important procedures/conversations. Provide children and families with the right tools to express their needs, concerns, preferences e.g. relevant medical terminology, link them with the right services.

The treating team should be transparent with the child and family where appropriate	 Clinicians should routinely discuss key domains of prognosis with children and family e.g. risks of short- and long-term mortality, ventilator dependence, functional impairment and cognitive impairment. Clinicians should provide clear and complete information regarding the range of medically appropriate treatment options, including the risks and benefits of each option. Clinicians should avoid the use of medical jargon and explain the meaning of important terms when communication with families.
Tailor engagement setting and style to suit the child and family	 Offer different engagement forums for example: Smaller one-on-one conversation vs. larger meeting with multidisciplinary team. At the bedside vs. in a private consult room. With the child vs. without the child. Using technology/resources to support the conversation versus no technology enhancements. Phone, videoconference, email or face-to-face conversation. Opportunities for the child and/or family to contribute agenda items in care planning. Offer follow-up/ debrief. Sit down conversation versus hallway.

In practice – transfer of care	Example
The transfer of a patient to a different care setting should be accompanied by prompt relevant and accurate communication about the episode	 Including details of active clinical problems and plans for ongoing management. Give the child and/or family the opportunity to add any information that may be important or was missed.
Orientate the family to new wards/facilities	 In all settings the clinical team should be introduced, naming the team leader, explaining the role of clinal team members and expressing commitment to delivering care that is child and family centred, even in mixed settings. The family should be encouraged to tell the team something about the child's personal history along with any pertinent medical details in order for the clinical team to become familiar with the child as a person.

Communicate back to family/community at home	•	If a family has been transferred out of their local area, it is important to communicate back to the local community.
Care closer to home	•	Where possible and clinically safe, transfer the patient back to their local or a closer facility.

HHS and organisational strategies	Example
Training	 Cultural competency training to support communication with Aboriginal and Torres Strait Islander patients and families e.g. Cultural Practice Program Health practitioners (clinicians, nurses, allied health staff) should receive training in family centred communication, and how to facilitate and support family members in shared decision-making as an integral element of critical care training.
Align organisational priorities with CFCC	Embed the provision of CFCC within strategic priorities to ensure adequate organisational buy-in and leadership.
Foster family engagement	 Specific practices to enhance family engagement and communication should be implemented and evaluated as part of quality improvement projects.

5.4 Empowerment, flexibility and choices

Healthcare providers should adopt a holistic approach to care that identifies and builds on the unique strengths and individuality of each child and young person, family and community (even in difficult and challenging situations). It should also empowers each child and family to discover their own strengths and build confidence in their own autonomy to make choices and decisions about their own health as well as their child's health.^{3, 6, 14, 45} This includes providing formal and informal support for children, young people and their families to enable their full partnership in care and shared decision-making at a level of their choosing, prior to (where possible), during and after hospitalisation.^{14, 45} Supporting and facilitating flexibility including a range of clinically appropriate choices that are in the child's best interest (informed) for the child and family, ensures that services are tailored to the needs, beliefs and cultural values of each family. Achieving this necessitates flexibility in organisational policies, procedures and practices.^{6, 36}

5.4.1	Empowerment ,	flexibility	and choices	s in practice
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In practice –	Example
healthcare professionals	
Support the mental health and psychosocial wellbeing of family, carers and kin	 Recognise that families are often psychologically stressed and can have difficulties coping during a child's critical illness. Identifying the social, emotional and financial impact of the illness on the child and the family. Assessment of the child and family's support needs, recognising that desired outcomes of care plans are flexible and not necessarily. absolute, and adapting care to the context of the family background Encouraging and facilitating family-to-family support and networking; between families who may be experiencing similar challenges.
Flexibility and adaptability	 The preferred level of involvement of different carers and family members may change over time. Acknowledge that the right choice for an individual and family may be less conventional, and less streamlined for the medical team. In discussing the goals of care and treatment decisions, clinicians and family should be encouraged to actively deliberate back and forth about the pros and cons of the various diagnostic and therapeutic options. The thoughts and concerns of the family as well as those of the healthcare team members should be shared and discussed openly. As deliberations proceed clinicians should offer to provide a recommendation that is based on an understanding both of the medical facts and of the child's and family's values, and should explain the rationale that underlies the recommendation and participate actively in decision-making.
Options	 Clinicians should inform the family of all of the options available to them, provide opportunities to discuss their preferences and the treating teams recommendations, and provide them with accurate and sufficient information to help them make decisions, whilst also noting that this may not be possible in time-critical situations or when the decision made by the family is not in the best interests of the child. Different families may reasonably make different choices depending on what matters most to them.
Respect the unique needs of different carers/family carers	 Recognise that different family members may prefer different levels of disclosure and discussion.

5.5 Equity-oriented care

Equity-oriented care recognises the remarkable strength that lies at the heart of Aboriginal and/ or Torres Strait Islander cultures. With the oldest living cultures in the world, they have demonstrated resilience and adaptability over thousands of years. There is a growing body of evidence that suggests that channelling this culture could contribute to improved health and wellbeing.⁴⁹ Cultural strengths can be enabled through traditional cultural practice, kinship ties, connection to land and country, art, song and ceremony, dance, healing, spirituality, empowerment, ancestry, belonging and self-determination.⁴⁹

Children are seen as equal members of the community, and thus the responsibility for the child is shared among family and broader kin, including health care decisions. The strong ties to community are a vital source of comfort and support, and the health of each individual contributes to the wellbeing of their community as a whole. Elders are highly respected members and important to family and community functioning. Spirituality helps families cope with challenges and assists with connectedness and support of individuals. Communities surviving and thriving in the face of adversity have strength in spirit and display resilience that can be harnessed to serve as protective factors against poor health outcomes.

A strengths-based discourse is also useful for culturally and linguistically diverse families. When healthcare professionals understand a family's culture and its strengths, they respectfully integrate these strengths into care to enhance health outcomes and foster the child's and family's sense of identity, culture, and agency.

There is increasing recognition that CFCC discourses tend to reflect and reproduce Euro-western values and assumptions about participation, principally from the perspectives of middle-class healthcare professionals located in predominantly urban settings.³⁶ Consequently, CFCC has only been minimally explored in the context of families and children whose health and healthcare is likely to be compromised by multifaceted social and structural factors including institutional racism, material deprivation, and historically entrenched power imbalances.¹⁸ Populations that are particularly vulnerable include:

- Children and young people in lone parent families led by women
- Children and young people in state care
- Aboriginal and/or Torres Strait Islander Children and young people
- Children and young people in families that experience stigma and other social marginalisation.

These families may face additional challenges and barriers to navigating the healthcare system. They may be reluctant to access healthcare for their children due to parental concerns related to social marginalisation, anticipated stigma and institutional racism, and previous negative interactions within healthcare providers. When carers feel disempowered, judged, or traumatised in healthcare encounters, they may choose to minimise their family's contact with health care service, which can impact on inequitable outcomes and care levels.

Children and families that have been exposed to traumatic experiences may respond to clinical environments with attitudes and behaviours that may be deemed 'difficult' due to their distress and feelings of insecurity.^{2, 50} This creates further disparities in the provision of the care and can have significant impacts on development due to the prolonged activation of the body's stress response system when it is frequently re-triggered.⁵¹

Specifically for Aboriginal and/or Torres Strait Islander families, the collective trauma associated with the Stolen Generations and contemporary child protection system, creates significant barriers to families feeling safe to engage with child health and related services ⁵². This highlights that addressing health inequalities and healthcare inequities is therefore inseparable from engaging with and supporting the well-being of the family as a whole.

It must be acknowledged that further work is required to understand what CFCC means for Aboriginal and/or Torres Strait Islander children, families, and communities. HHSs are encouraged to work with local Aboriginal and/or Torres Strait Islander communities to identify and appreciate the ways in which healthcare providers can tailor care to be CFCC for their region. CFCC inherently recognises that a one-size fits all approach is not appropriate and emphasizes that care must be tailored to accommodate and respond to the unique needs, knowledge, practices, beliefs, and family structures for each patient. All healthcare professionals should employ best practice regarding culturally safe care for Aboriginal and Torres Strait Islander patients and families, as outlined in the *Aboriginal and Torres Strait Islander patient care guideline*.

Socially responsive and inclusive healthcare can mitigate the impact of childhood adversity across the life course. Research has shown that people living in marginalising conditions who receive equity-oriented care experience improved health outcomes over time. Equity-oriented healthcare (also termed inequity-responsive care) is about directing adequate resources to those with the greatest needs.³⁶ Equity-oriented health care incorporates three key dimensions:

- 1. Trauma and violence informed care,
- 2. Culturally safe care, and
- 3. Contextually tailored care.^{36, 53}

Taken together, these three dimensions of equity-oriented care are central to providing equitable access to CFCC that is inclusive and responsive to the social contexts and complexities of families and children's lives (refer to Figure 1). Culturally safe and trauma informed care have also been recognised as essential components of (NSQHS) Standard Five, Comprehensive Care, in the provision of care for children and young people.²⁴

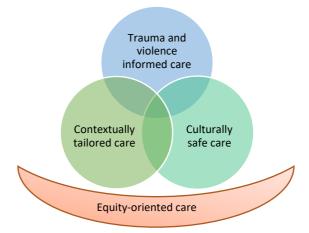


Figure 1: Key dimensions of equity-oriented care

Trauma and violence informed care involves healthcare provision which recognises that people impacted by social inequity often experience multiple forms of violence and experience challenges accessing the supports needed to improve their physical and emotional safety^{36, 53, 54}, and aims to mitigate the potential harms and traumatising effects of seeking healthcare by creating safe and trusting environments.⁵⁵

Cultural safety for Aboriginal and/or Torres Strait Islander people involves creating an inclusive environment which affirms their culturally identity, physical and emotional safety, and mutual respect. It is about recognising that Aboriginal and/or Torres Strait Islander people have a holistic view of health that is not adequately met by the biomedical model of healthcare.⁵⁶ Aboriginal and/or Torres Strait Islander people have collective experiences and memory of culturally unsafe service provision, including abuse, institutional racism and cultural insensitivity in accessing healthcare.⁵⁴ Aboriginal and/or Torres Strait Islander children, young people, families and communities are more likely to access services that are culturally safe and experience better outcomes in such services.

Cultural safety goes beyond the Cultural Practice Program to more explicitly address inequitable power relations, institutionalised, interpersonal racism and other forms of discrimination, and aims to shift attention away from "cultural differences" as the source of the problem, and onto the culture of healthcare as the site for transformation.^{36, 53} This includes improving the way health services engage with Aboriginal and/or Torres Strait Islander families as well as families who have culturally and linguistically diverse backgrounds; recognising the impact of intergenerational trauma, and respecting cultural diversity.

Contextually tailored care expands the notion of patient centred care to include services that are explicitly tailored to the populations served and to local contexts. This involves understanding the broader social, political and historical contexts within which children and families live, work, and grow. Tailoring practices, organisational policies and clinical guidelines to optimally address the most pressing needs of local populations.⁵⁷

5.5.1 Equity-oriented care in practice

In practice – Culturally safe care	Example
Right to self- determination	 Identify and embed the wide range of views held by Aboriginal and Torres Strait Islander children families about their goals for self-determination and how to achieve them in the context of critical care. Healthcare professionals should promote Aboriginal and/or Torres Strait Islander children's and their community's right to self-determination, and work in genuine partnership with the child, their family and their community to ensure their culture has been central in the decision-making process.

Respectful and affirming of culture	 Relationships that are respectful of culture should have clear and interactive communication to enable shared understandings of Aboriginal and/or Torres Strait Islander world views, adhere to cultural protocols, and respect Aboriginal and/or Torres Strait Islander knowledge structures and ways of knowing. Inclusion of relevant support services e.g. Indigenous Liaison Service, Indigenous Nurse Navigator. Adapting engagement strategies to suit the patient and family eg. factoring in time for broader family consultation, accessing larger spaces to support extended family engagement, understanding who the decision makers are within the family, understanding cultural protocols of the family engaged. Respect customary practices before, during and after passing of the child. These practices may be sacred and may not be widely discussed outside of the community. It may be appropriate to involve the Indigenous Hospital Liaison Officer to facilitate these proceedings.
Support and reassurance	 At times, families need guidance and acceptance about care/comfort. e.g. in family meetings when discussing end-of-life care, allow families to make decisions about when to cease. In some instances, easier for the treating team to move forward and not leaving the family with the decision about when to stop.

In practice - Culturally and linguistically diverse families	Example
Time and resources	 Time and resources should be invested to ensure that relationships are effective and sustainable. This includes early identification of the family's level of health literacy and comprehension, and need for support services as appropriate e.g. Interpreter.
Diverse world views	 For children and families from culturally and linguistically diverse backgrounds, health workers should consider the cultural perspectives and beliefs of the child and their family when involving them in decision-making processes.

In practice - Trauma and violence informed care	Example
Time and resources	 Time and resources should be invested to ensure that relationships are effective and sustainable, this includes early identification of the family's level of health literacy and comprehension and provide support services as appropriate e.g. Interpreter.
Physical environments	 Taking the time to understand and acknowledge how traumatic experiences can have serious outcomes that can manifest in different physical, psychological and behavioural ways. Acknowledging how clinical environments can have a range of triggers, can be traumatising in themselves, and contribute to retraumatising. Create safe spaces within the facility for patients and families that seek to provide respect, inclusion, comfort and emotional security e.g. sensory modulation, non-clinical spaces, peer-led support.
Emotional and psychological safety	 Work to build a culture of trust between the treating team to empower the patient and family feel safe to express their needs and desires openly.

HHS and organisational strategies	Example
Training	 Provide training to staff on trauma and violence informed care, culturally competency and cultural safety.
Monitor and evaluation	 Establish mechanisms to monitor and evaluate the application of trauma and violence informed care, as well as culturally safe care.
Policy and procedure	 Ensure trauma-informed and culturally safe care is embedded into organisational policy and procedure.

6 Facility and organisational level recommendations for CFCC

As discussed above, CFCC extends beyond the individual relationships and interactions between healthcare professionals, children, and families. At a health service (HHS) and organisational (DoH) level, support is required to assist health services to be more child and family centred by considering CFCC in program policy and service development. Where possible, strategic priorities of HHSs should align with CFCC principles to foster implementation.

Change champions, including administrative staff, researchers, clinical leaders and patient/family champions throughout hospital and health services will help to promote a culture of CFCC. It is recommended that each HHS have dedicated and transparent policies and procedures to legitimise and support families' contributions to the care of their family member. This can be achieved through existing consumer networks in alignment with National Safety and Quality Health Service (NSQHS) Standard 2: Partnering with Consumers. Leadership teams within HHSs can demonstrate their commitment to CFCC by understanding the principles and their application, setting, and measuring against established targets, and providing adequate resources and support. There is benefit when staff and healthcare professionals have a shared understanding of CFCC, which is assisted by enabling access to relevant education and training, and tools. Finally, co-assessment, involving partnering with children and families in monitoring and evaluating the quality of CFCC occurring at both the patient and system level is an important part of quality improvement and patient safety.

Section 1.1 of the paper, the need for Child and Family Centred Care, demonstrates that international, national, and state-based charters, frameworks and strategies already set the precedent for CFCC as best practice. However, the implementation of the principles and their subsequent evaluation are lacking. To provide CFCC and continually strengthen practices, it is important to measure, monitor and report against robust evaluation frameworks. Ongoing evaluation of CFCC should include feedback from children (at an age and developmentally appropriate level) parents and family members, through consultation activities such as interviews, surveys and focus groups.

7 Consultation regarding best practice principles for CFCC

QPCCP Working Group two adopted a co-design methodology with a consumer representative coleading the work with two clinicians with support from the QPCCP Project Team. The Working Group two members provided input and expertise to facilitate the development of this paper, please see Appendix B for membership. Other stakeholders consulted and made valuable contributions to the paper are outlined in Appendix C.

8 Conclusion

This document is intended to guide and inform healthcare professionals in providing Child and family Centred Care to critically unwell paediatric patients across Queensland. The CFCC principles underpin a culture of care that is collaborative in nature and has a holistic lens on healthcare. Patients and their families have shared opportunities in decision-making, with the child's desires and needs being foregrounded.

The impetus to integrate Child and Family Centred Care principles is apparent in the benefits conferred to children and young people who are critically unwell. CFCC has been associated with improved clinical outcomes and psychosocial wellbeing of the child through tailored their care that is responsive to their needs and preferences. It is also important for reducing stress of the family members by empowering them to meaningfully engage in decision-making and the child's care. Ultimately communication between the treating team, patient, and carers is improved, which facilitates streamlined, timely, appropriate and safer care children and young people.^{8, 9, 40-43}

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Appendices Appendix A: CFCC Poster



Appendix B: Working Group 2 Membership

Position	Unit/Ward/Team/Branch	HHS/Division
Social Worker, PICU*	Townsville Hospital	Townsville HHS
Speech Pathology Team Leader,	Queensland Children's	Children's Health
Inpatients*	Hospital	Queensland HHS
Consumer*	Caboolture	Metro North HHS
Assistant Director, Nutrition & Food Services (Paediatrics)	Gold Coast University Hospital	Gold Coast HHS
CNC, Children's ED	Gold Coast University Hospital	Gold Coast HHS
Principal Program Manager	QPCCP Project	Clinical Excellence QLD
Paediatric Nurse Educator, Education & Research	Rockhampton Base Hospital	Central QLD HHS
SMO, Oncology	Queensland Children's Hospital	Children's Health Queensland HHS
Executive Director Allied Health CHQ Family centred care (FCCC) committee	Queensland Children's Hospital	Children's Health Queensland HHS
Director, Social Work	Queensland Children's Hospital	Children's Health Queensland HHS
Indigenous Workforce Coordinator	Office of Indigenous Health	North West HHS
IHLO, PICU	Townsville Hospital	Townsville HHS
Nurse Educator, Generalist	Atherton Hospital	Cairns and Hinterland HHS
Staff Specialist, ICU	Mackay Base Hospital	Mackay HHS
Acting NUM, Connected Care Program	Queensland Children's Hospital	Children's Health Queensland HHS
Consultant Paediatrician	Caboolture Hospital	Metro North HHS
Consultant Paediatrician	Caboolture Hospital	Metro North HHS
SMO, PICU	Queensland Children's Hospital	Children's Health Queensland HHS
*Co-leads of the working group		

Appendix C: Stakeholder consultation

Division/ Network/ Committee	Contribution	
QPCCP Steering Committee		
Aboriginal and Torres Strait Islander Health Division		
 Queensland Child and Youth Clinical Network: Clinicians' Collaborative Aboriginal and Torres Strait Islander Health Worker – Maternal, Child & Youth Health Network 	These stakeholders were involved in the consultation process and were provided with opportunities to review and endorse the paper.	
Statewide Maternity and Neonatal Clinical Network		