

TITLE

COMPLEX AND ESSENTIAL PEDIATRIC MEDICAL PROCESS**SCOPE**

Provincial

DOCUMENT

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NOTE: The first appearance of terms in bold in the body of this document (except titles) are defined terms – please refer to the Definitions section.

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OBJECTIVES

- To identify a process for bringing together Alberta Health Services (AHS) and Children's Services (CS) when either system is concerned about the complex medical situation, urgent need(s), care and/or safety of a **child**.
 - Refer to the AHS and CS jointly developed *Complex Pediatric Medical Situations Involving CS Process* (see *Appendix A*).
- To provide direction to **health care professionals** when the medical decisions for a child that are made by their **guardian(s)** are in conflict with the health care team and may potentially place the child at risk.
 - If the child is determined to be a **mature minor**, then they are considered to be acting as their own decision-maker (refer to the AHS *Consent to Treatment/Procedure(s) Minor / Mature Minors Procedure*).
 - Refer to the AHS and CS jointly developed *Essential Pediatric Medical Needs Conflict Prevention and Resolution Process* (see *Appendix B*).
- To emphasize collaboration and support between Physicians, the child, guardian(s), **family, health care providers**, AHS, regional CS, and when applicable, Delegated First Nation Agencies (DFNAs).
- To recognize that family may be essential in supporting the child and welcome their involvement based on the wishes of the guardian(s) and/or child (as appropriate).
 - It is the responsibility of health care providers to extend involvement to family as determined by the guardian(s) and/or child (as appropriate).

PRINCIPLES

Addressing the best interests of the child through a philosophical lens of reducing **harm** through collaboration between AHS, CS, the guardian(s), and the child (to the extent appropriate), is seen as the most appropriate approach for complex and essential pediatric medical decision-making. This guideline recognizes that the involvement of legal processes in medical decision-making regarding children is the least favourable option when trying to ensure their safety and well-being.

AHS and CS endorse the principles of timely and effective collaboration that follows the principles of Patient and Family Centred Care. Reasonable means shall be taken by health care providers to reach consensus, including taking into consideration as appropriate, the views of the child, guardian(s), family, Physicians, and other available and relevant supports.

APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

ELEMENTS

1. Points of Emphasis

- 1.1 This guideline supports two (2) collaborative processes developed jointly by AHS, CS and DFNA.
- 1.2 Health care professionals are expected to refer to and follow the *Complex Pediatric Medical Situations Involving CS Process* (see *Appendix A*) for situations of concern related to:
 - a) care of the child;
 - b) decisions that appear to be detrimental to the health or safety of the child; and/or
 - c) an immediate or urgent need that has to be addressed.
- 1.3 Health care professionals are expected to refer to and follow the *Essential Pediatric Medical Needs Conflict Prevention and Resolution Process* (see *Appendix B*) when there is conflict regarding medical decision-making between the guardian(s), and/or child (if appropriate) and the health care team that may potentially place the child at risk to:
 - a) not receive essential medical services; or
 - b) receive non-beneficial or potentially harmful treatments that are not clinically indicated.

- (i) For situations involving potentially end-of-life treatment withdrawals and/or if the child is being cared for in an Intensive Care Unit (ICU) environment, health care providers shall follow the AHS *Dispute Prevention and Resolution in Critical Care Settings* Policy and Procedure, and the AHS *Advanced Care Planning and Goals of Care Designation* Policy and Procedure.
- 1.4 For the purposes of this guideline, the attending pediatric Physician is to be considered the **most responsible health practitioner (MRHP)**.
- 1.5 The MRHP in consultation with AHS Social Work (where available) shall clarify the identity of the guardian(s) and if the guardian(s) would like others to be involved in discussions with the MRHP and AHS about the child. This is to ensure appropriate collaboration and communication occurs between AHS, CS, and the guardian(s), child and family (when applicable), and needed supports are in place for the guardian(s), child and family (refer to educational resources on Insite such as the *Legal Status Decision Making Chart*).
 - a) If there is a legal agreement or an order that informs care and/or decision making, a copy shall be placed in the **health record**. Examples include the following:
 - (i) Permanent Guardianship Agreement;
 - (ii) Temporary Guardianship Order;
 - (iii) Permanent Guardianship Order; and
 - (iv) Joint Guardianship (generally with foster parents).

2. Complex Pediatric Medical Situations Involving CS Process

- 2.1 When a concern in Section 1.3 above is identified by a health care provider, they shall notify the MRHP. The MRHP shall consult with AHS Social Work (where available) to involve CS and potentially initiate the *Complex Pediatric Medical Situations Involving CS Process* (see *Appendix A*). If AHS Social Work is not available, the MRHP may initiate this process.
 - a) This process may also be initiated by a member of the CS team.
- 2.2 The AHS Social Worker or designate, when available, shall collaborate and communicate with CS and the MRHP, and may consult with the discipline lead.
- 2.3 If the case meets clinical judgement criteria as determined by AHS and CS, the *Complex Pediatric Medical Situations Involving CS Process* shall be initiated as outlined in *Appendix A*.

3. Essential Pediatric Medical Needs Conflict Prevention and Resolution Process

- 3.1 When a situation in Section 1.4 is identified, the MRHP shall initiate the *Essential Pediatric Medical Needs Conflict Prevention and Resolution Process* (see *Appendix B*).
- a) If blood products are involved, the AHS *Pediatric Blood / Blood Product Algorithm* is to be used in conjunction with this process (refer to *Appendix C*).
- 3.2 The MRHP shall review the risks and benefits of the recommended treatment options, including those that are believed to be essential medical needs, with the guardian(s), child and family (when applicable) in order to address any concerns and to try to resolve conflict and build consensus so that agreement for the medical treatment/procedure can be obtained.
- 3.3 The MRHP shall ensure a health care team member is identified as a liaison to provide consistent communication over time between the guardian(s), child, family (when applicable) and the health care team during longer hospital stays or when frequent Physician turnover is likely.
- 3.4 When preventing or addressing conflict with the guardian(s), child, family, and the health care team, the MRHP should also re-evaluate the following:
- a) Alternate decision-makers: Whether the decision-maker (mature minor, guardian(s), or other) is appropriately identified and whether there is consensus amongst decision-makers if there is more than one with equal authority (refer to the AHS *Consent to Treatment/Procedure(s) Minors / Mature Minors Procedure*);
- b) The guardian(s) or mature minor's capacity for decision-making; and
- c) Voice of the child: Providing an opportunity for any child, even though not assessed as a mature minor, to express their opinion on matters affecting them to the extent they are able is important. When a child has the cognitive and emotional maturity to voice their opinion pertaining to their medical treatment, their opinion shall be considered. The focus of working within this guideline shall include the contributions of the child, the guardian(s), and the family (when applicable). There may be opportunity for the child to request or be appointed legal counsel or an Advocate from the Office of the Child and Youth Advocate (OCYA) office to represent their opinion.
- 3.5 The MRHP shall involve the attending Physician group to develop a reasonable health care treatment consensus that is discussed with the guardian(s), child and family (when applicable).

- a) The MRHP and Physicians within the attending group shall discuss the medical treatment options and develop health care consensus regarding the:
- (i) appropriate treatment options;
 - (ii) risks and benefits of treatment and non-treatment including a discussion of harm to the child (see Section 3.5e below);
 - (iii) a determination of essential medical care; and
 - (iv) any clinical support for the recommended treatment option(s).
- b) Compromise in the medical treatment shall be considered where appropriate (i.e., concurrent alternative medical treatments, partial treatment or 'trials' of therapy).
- c) All involved Physicians shall communicate information and options consistently (decided upon by consensus within the attending Physician group) to the guardian(s), child, family (when applicable) and health care team, to avoid inconsistent medical opinions and options.
- d) Specialist opinions should be sought as appropriate. When multiple Physicians within a specialty are involved in the child's care, a consensus opinion should be obtained within the specialty group.
- e) Medical discussions should include identifying or determining if harm is being done to the child due to lack of agreement about the course of care for the child.
- (i) The legal system and CS will consider the best interests of the child. From a medical perspective, the best interests of a child considers a number of factors including but not limited to:
 - the child's condition and prognosis;
 - the medical treatment that is recommended; and
 - the wishes, values and beliefs of the child as expressed by the child or the guardian(s), and family.
 - (ii) The courts, in general, support parental decision-making unless their decision results in harm to the child including when the decision is determined to not be in the best interests of the child per the *Child, Youth and Family Enhancement Act*. This is different than the subjective perspective of the guardian(s) or family regarding what is best for the child which is influenced by a host of personal factors.

- f) External second opinions should be considered to help determine best practice, any other clinical recommendations and any resulting harm to the child given the clinical scenario. Second opinions can also assess the potential for another site to agree to provision of care that aligns with the values and input of the guardian(s), child and family (when applicable).
- 3.6 The MRHP shall support clear communication to facilitate consensus building with the guardian(s), child and family, as applicable.
- a) All possible attempts shall be made for care to be discussed, agreed upon and delivered through collaboration and communication with the guardian(s), child and family (when applicable), using the principles of family-centred care.
 - b) All discussions and meetings should be documented, including:
 - (i) the recommended treatment and basis for such treatment;
 - (ii) risks and benefits of treatment and non-treatment;
 - (iii) decisions made during the discussions; and
 - (iv) information about the stated values, beliefs and wishes of the guardian(s), child or family (when applicable).
 - c) During transitions of care, diligence should be taken to ensure complete transfer of information.
- 3.7 The MRHP shall consider the following supports to help facilitate optimal communication of medical information and the values, beliefs and wishes of the guardian(s), child and family (when applicable):
- a) language and cultural supports;
 - (i) engage with a translator and multicultural brokers (i.e., Aboriginal liaison) when appropriate.
 - b) a Clinical Ethics consultation;
 - c) a Social Worker; and
 - d) other community and family supports or services that may aid in understanding (e.g., pastoral care, Aboriginal health practitioners, alternative medicine practitioners, Family Physician).
- 3.8 If the conflict is not resolved, the MRHP shall initiate the Joint Advisory Group to assist with prevention and resolution of the conflict through ongoing communication with the health care providers and the guardian(s), child and family (when applicable) to attempt to resolve the conflict.

- a) The group should include at a minimum, medical representatives, Site Administration, Children Services (CS), and Clinical Ethics.
 - b) The purpose of the Joint Advisory Group is to support the *Essential Pediatric Medical Needs Conflict Prevention and Resolution Process* (refer to *Appendix B*) and attempt to find a means of achieving consensus, obtain the agreement of the guardian(s) and/or child (if appropriate), provide essential or recommended medical care, and avoid involving the courts in the conflict.
 - c) The Joint Advisory Group shall meet together to review the case:
 - (i) at regularly set intervals until the case conflict is resolved;
 - (ii) at intervals relevant to ensure timeliness of decision-making;
 - (iii) to ensure the *Essential Pediatric Medical Needs Conflict Prevention and Resolution Process* algorithm is followed and all available options are openly explored;
 - (iv) to ensure appropriate documentation; and
 - (v) to provide supports for the involved parties inclusive of guardian(s), child and family (when applicable).
- 3.9 Site Administration should consult with the AHS Health Law Team and Physicians should consult with the Canadian Medical Protective Association (CMPA).
- 3.10 Proceeding when agreement is not provided for recommended medical care, and resolution is not believed to be achievable:
- a) Once all reasonable attempts to come to consensus have been made without agreement being obtained or other resolution of the matter:
 - (i) the MRHP should consider involving the following supports if they have not previously been engaged: Site Administration, Clinical Ethics, AHS Health Law Team, and the CMPA.
 - (ii) If the above processes and supports are not successful in achieving consent, an AHS member of the Joint Advisory Group shall notify CS. CS should become involved in the case to determine the appropriateness of the case for the CS Mandate.
 - The determination of whether the case meets the CS Mandate by CS shall be communicated clearly and in a formal meeting with the guardian(s) and/or child (if appropriate).

- If the case does not meet CS mandate, CS will communicate this and maintain a collaborative role and continue to work with AHS to explore options to resolve the conflict.
- b) If the above actions and involvement do not result in the resolution of the conflict and agreement for the recommended medical treatment by the guardian(s) and/or child (if appropriate), the Facility Medical Director shall involve Senior Leadership. The Facility Medical Director shall consult with the Chief Medical Officer (CMO) who may require the development of a briefing note. If so, it shall be completed and circulated to all applicable stakeholders.
- c) The briefing note should include a detailed list of all the actions taken to date to resolve the conflict and be sent to the CMO. The CMO may then inform the AHS Executive Leadership Team (ELT) and the attending Physician of their support or any recommended actions to be taken.
- d) In situations of impasse, when the guardian(s), child or family (when applicable) is requesting treatment or interventions considered by the health care team to be harmful, or futile, or not clinically indicated, or not in the child's best interests, and does not agree with the MRHP determination of appropriate treatment options, Section 3.8 of the AHS *Dispute Resolution in Critical Care Settings* Procedure should apply.

4. Timeliness

- 4.1 The processes identified in this guideline shall occur in a timely manner based on the clinical situation.
- 4.2 The *Complex Pediatric Medical Situations Involving CS Process* is available any time and every day (i.e., 24/7) to meet the needs of the child. A joint leadership meeting with AHS and CS may be held within two (2) hours for immediate risk (refer to *Appendix A*).
- 4.3 If there is immediate risk of harm when agreement is not obtained to provide recommended medical care, the rapid mobilization of AHS (Site Administration, Legal Services, Ethics, etc.) as well as CS shall occur.

5. Information Sharing and Collaboration

- 5.1 Refer to AHS Insite for supporting education resources such as: *Children's Services (CS) Internal Processes; Orders and Agreements under the Child Youth and Family Enhancement Act (CYFEA); Legal Status Decision Making Chart; Collaborative Medical Protocol Development Formal Information Sharing; and First Nations in Alberta.*

6. Review Period

- 6.1 For the purposes of improving care and collaboration, this guideline shall be reviewed one (1) year after initial implementation. Subsequent reviews or revisions shall occur every three (3) years.
- 6.2 Each situation shall be debriefed jointly by AHS and CS to ensure critical successes and learnings are captured.

DEFINITIONS

Child means, for the purposes of this guideline, a patient and may refer to infants, children or youth or mature minors.

Family(ies) means one or more individuals identified by the patient as an important support, and who the patient wishes to be included in any encounters with the health care system, including, but not limited to, family members, legal guardians, friends and informal caregivers. This may or may not be legally identified as the patient's legal co-decision maker or an alternate decision-maker.

Guardian means, where applicable:

For a Minor:

- a) A guardian as defined by the *Family Law Act*, a divorced parent with custody of the minor, or a person appointed pursuant to a will, personal directive, court order, agreement or by authorization of legislation (e.g. *Child, Youth and Family Enhancement Act*).

Harm means, for the purpose of this guideline, an outcome for the patient, resulting from the care and/or services provided or lack thereof, that negatively affects the patient's health and/or quality of life.

Health care professional means an individual who is a member of a regulated health discipline, as defined by the *Health Disciplines Act* (Alberta) or the *Health Professions Act* (Alberta), and who practises within scope or role.

Health care provider means any person who provides goods or services to a patient, inclusive of health care professionals, staff, students, volunteers and other persons acting on behalf of or in conjunction with Alberta Health Services.

Health Record means the Alberta Health Services legal record of the patient's diagnostic, treatment and care information.

Informed Consent means the patient's agreement (or alternate decision-maker) to undergo a treatment/procedure after being provided, in a manner the patient can understand, with the relevant information about the nature of the treatment/procedure(s), its benefits, risks and alternatives, and the potential consequences of refusal.

Mature minor means a person aged less than eighteen (18) years, who has been assessed and determined as having the intelligence and maturity to appreciate the nature, risks, benefits, consequences, and alternatives of the proposed treatment/procedure(s), including the ethical, emotional and physical aspects.

Most responsible health practitioner means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s) within the scope of their practice.

REFERENCES

- *Appendix A - Complex Pediatric Medical Situations Involving CS Process*
- *Appendix B - Essential Pediatric Medical Needs Conflict Prevention and Resolution Process*
- *Appendix C - Pediatric Blood/Blood Product Algorithm*
- Alberta Health Services Governance Documents:
 - *Advanced Care Planning and Goals of Care Designations Policy (#HCS-38)*
 - *Advanced Care Planning and Goals of Care Designations Procedure (#HCS-38-01)*
 - *Consent to Treatment/Procedure(s) Minors / Mature Minors Procedure (#PRR-01-03)*
 - *Dispute Prevention and Resolution in Critical Care Settings Policy (#PRR-03)*
 - *Dispute Prevention and Resolution in Critical Care Settings Procedure (#PRR-03-01)*
- Alberta Health Services Resources:
 - *Supporting Resources: Complex and Essential Pediatric Process Guideline*
 - *AHS Family Centered Principles*
 - *Children's Services (CS) Core Principles*
 - *About Children's Services – Child Intervention Internal Processes*
 - *Orders and Agreements under the Child, Youth and Family Enhancement Act*
 - *AHS & CS Collaborative Information Sharing*
 - *Legal Authority Status and Decision Making Chart*
 - *Summary of Alberta Legislation Supporting Collaborative Information Sharing*
 - *Children's Services Consent Process for Health Care and Surgical Care*
 - *Practice Guidance for AHS Social Workers Working with Children's Services*
- Non-Alberta Health Services Documents:
 - *Child, Youth, and Family Enhancement Act (Alberta)*
 - *Children First Act (Alberta)*
 - *Family Law Act (Alberta)*
 - *Freedom of Information and Protection of Privacy Act (Alberta)*
 - *Health Information Act (Alberta)*

VERSION HISTORY

Date	Action Taken
	Optional: Choose an item

APPENDIX A

Complex Pediatric Medical Situations Involving CS Process

AHS and CS require a process to bring together decision makers from both systems when either system is concerned about complicated medical situations and decisions that involve:

- care of the child;
- decisions that appear to be detrimental to the safety of the child; and
- an immediate or urgent need that has to be addressed.

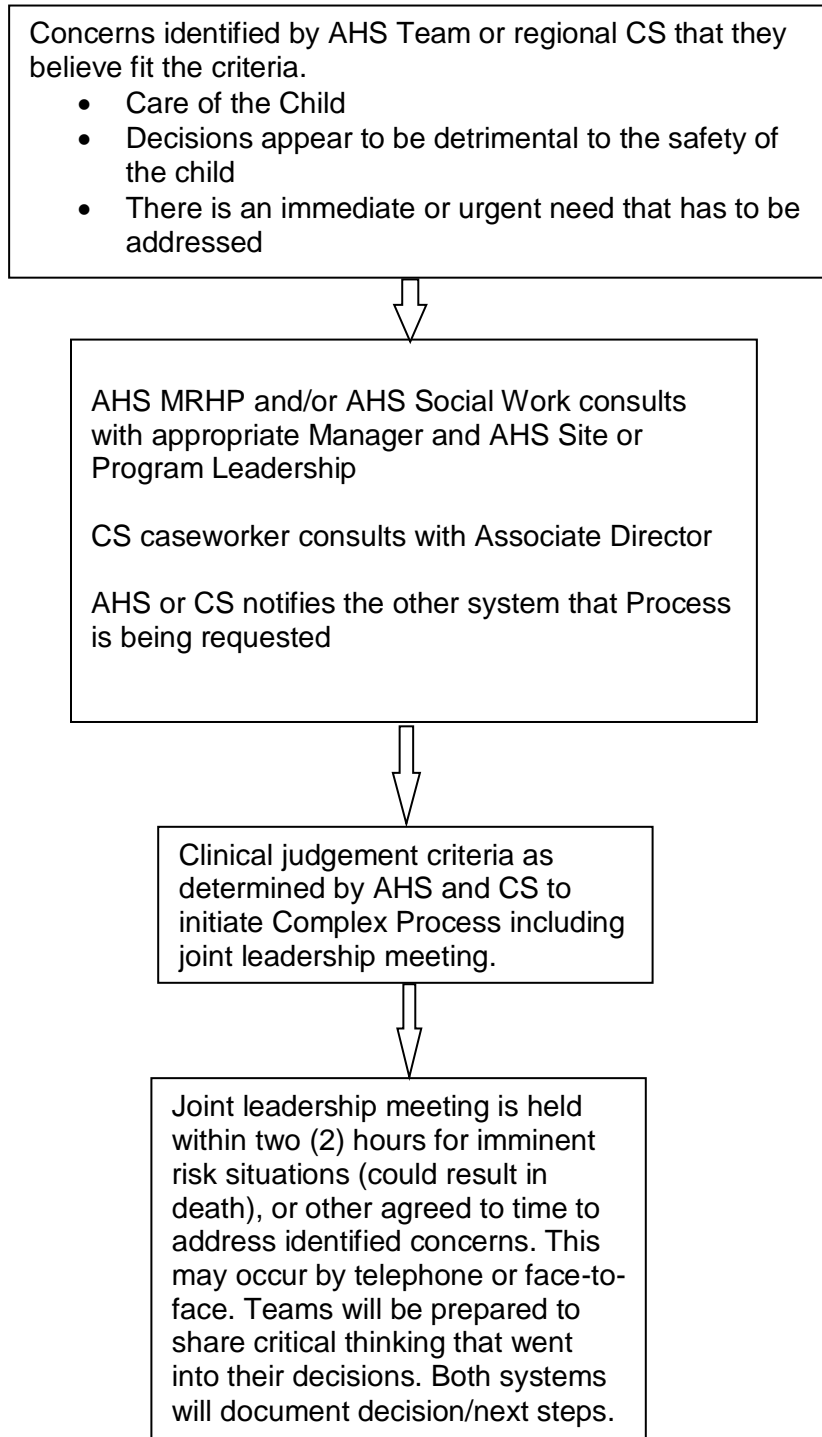
Purpose

This Complex Medical Situations process shall bring decision makers from both systems together to discuss and understand each system's perspective (as appropriate). It is key that each system come to the meeting prepared to look at the situation collaboratively (as appropriate) and to consider all relevant information to make the best decision for the child within each system's mandated services.

Process

- It is expected that AHS or CS involve regional CS in discussions prior to initiating this process.
- This process may be initiated on a 24/7 basis in order to meet the needs of children (and families as appropriate).
- Any new referrals to CS shall be routed through the CS North/South After-hours service, available 24 hours a day (Calgary: 403-297-2995, Edmonton: 780-422-2001).
- If it is an urgent need after regular work hours, the CS After-hours Manager shall become involved.
- CS will have an identified liaison role (Associate Director) to assist in directing AHS teams to the Leadership team involved with any child/family.
- AHS shall have an identified liaison role to assist in directing regional CS (Site or Program lead) to the medical team involved with the child/family. The medical team consists of the Attending Physician and Section Chief or other Department representation as determined by the medical team.
- Direct and ongoing communication of the MRHP with Social Work and AHS Site Administration will be essential collaborations for the AHS team.
- The regional CS and AHS team will extend an invitation to other partners to attend as appropriate based on the case, such as Disability Services (liaison role for Senior Manager Family Support for Children with Disabilities Program).
- Throughout this process, both CS and AHS will recognize each system's expertise and legal decision-making authority.
- When a meeting of CS and AHS has been called, it shall occur within two hours for imminent risk situations, or other agreed to time.
- A Five Step Decision Making Process shall guide the meetings. In summary, the five steps are: (1) Clarify the question(s), (2) Identify the facts, (3) Determine what is important, (4) Identify the options and (5) Make a decision and evaluate.

Summary of Complex Pediatric Medical Situations Involving CS Process



APPENDIX B

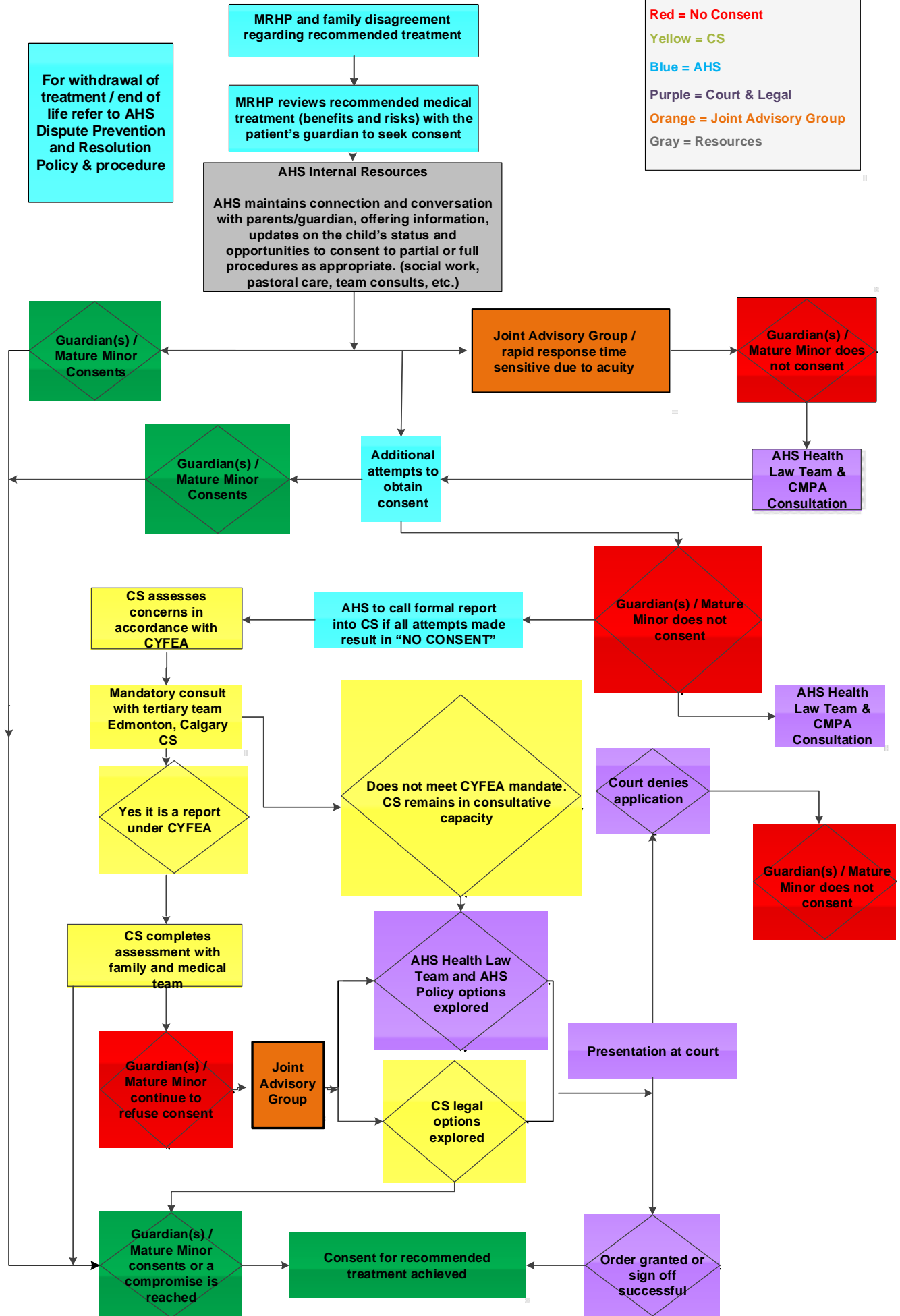
Essential Pediatric Medical Needs Conflict Prevention and Resolution Process

For Blood Products refer to Pediatric Blood/Blood Product Algorithm to be used in conjunction with this process.

Legend

- Green = Consent
- Red = No Consent
- Yellow = CS
- Blue = AHS
- Purple = Court & Legal
- Orange = Joint Advisory Group
- Gray = Resources

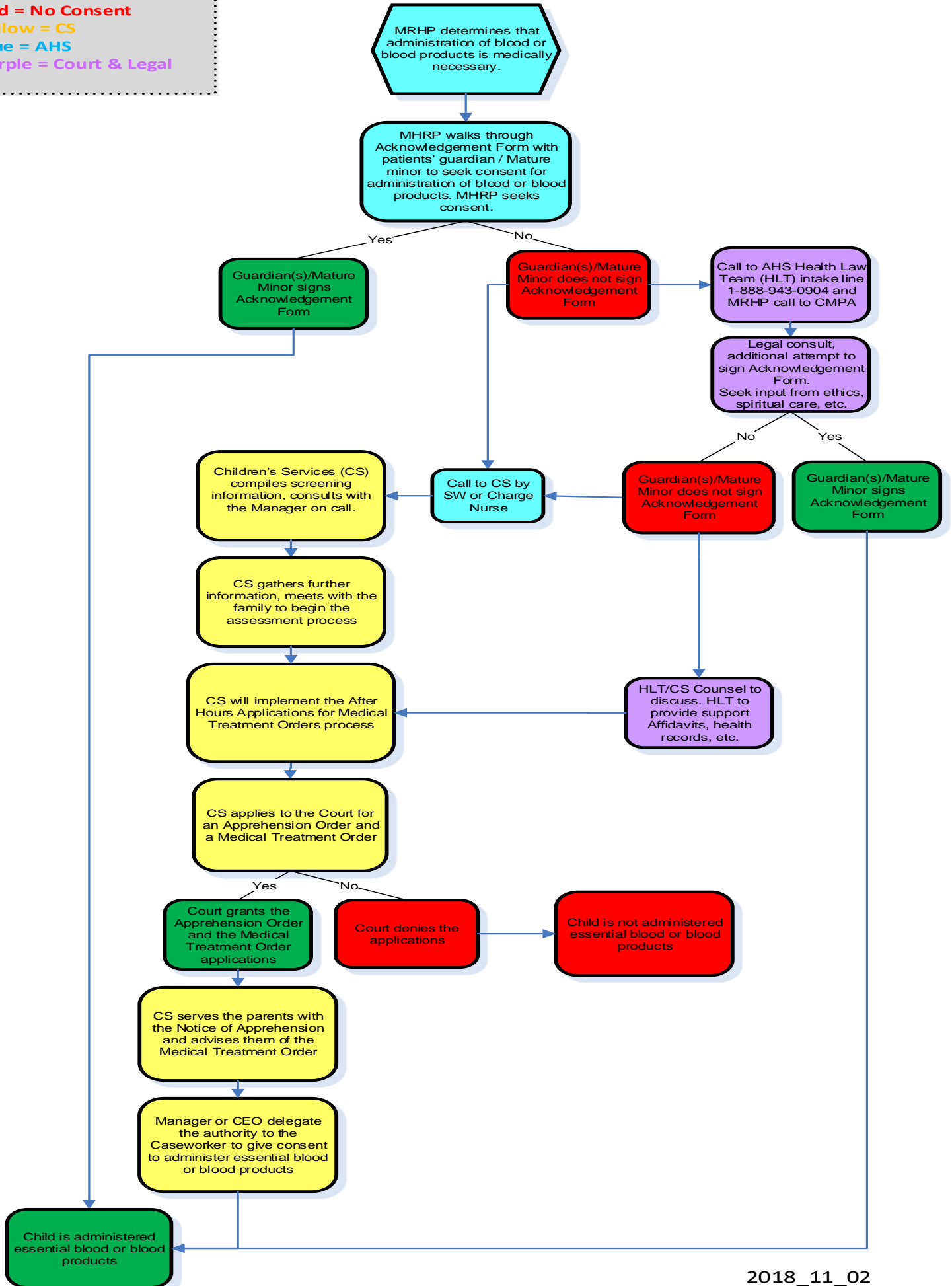
For withdrawal of treatment / end of life refer to AHS Dispute Prevention and Resolution Policy & procedure



APPENDIX C

PEDIATRIC BLOOD/BLOOD PRODUCT ALGORITHM

KEY:
 Green = Consent
 Red = No Consent
 Yellow = CS
 Blue = AHS
 Purple = Court & Legal



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