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A process for academic societies to develop scientific statements and white papers: experience of the Pediatric Cardiac Intensive Care Society*

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Abstract

There are substantial knowledge gaps, practice variation, and paucity of controlled trials owing to the relatively small number of patients with critical heart disease. The Pediatric Cardiac Intensive Care Society has recognised this knowledge gap as an area needing a more comprehensive and evidence-based approach to the management of the critically ill child with heart disease. To address this, the Pediatric Cardiac Intensive Care Society created a scientific statements and white papers committee. Scientific statements and white papers will present the current state-of-the-art in areas where controversy exists, providing clinicians with guidance in diagnostic and therapeutic strategies, particularly where evidence-based data are lacking. This paper provides a template for other societies and organisations faced with the task of developing scientific statements and white papers. We describe the methods used to perform a systematic literature search and evidence rating that will be used by all scientific statements and white papers emerging from the Pediatric Cardiac Intensive Care Society. The Pediatric Cardiac Intensive Care Society aims to revolutionise the care of children with heart disease by shifting our efforts from individual institution-based practices to national standardised protocols and to lay the ground work for multicentre high-impact research directions.

During the past two decades outstanding accomplishments have occurred in paediatric cardiac critical care. The success of initial palliative and corrective procedures for complex CHD has increased, leading to a steady decrease in patient mortality rate. These achievements are directly attributable to a focussed and multi-disciplinary approach to management, as well as the daring dedication of patients and families. Nonetheless, there are substantial knowledge gaps, practice variation, and paucity of controlled trials owing to the relatively small patient populations. The Pediatric Cardiac Intensive Care Society has recognised this knowledge gap as an area needing a more comprehensive and evidence-based approach to the management of the critically ill child with heart disease.

To address this, Pediatric Cardiac Intensive Care Society developed a new committee structure that focusses on six key areas of our subspecialty: research, education and training, quality, meeting and programme development, international outreach, and connections within the community. This paper focusses on the scientific statement and white papers sub-committee, which was formed under the research committee to identify high priority areas within our subspecialty where controversy exists. Scientific statements and white papers will present the current state-of-the-art in multiple high priority areas, providing clinicians with guidance in diagnostic and therapeutic strategies, especially where evidence-based data are lacking. By recognising and highlighting critical gaps in knowledge, scientific statements and white papers will also serve to identify areas needing future research direction. The scientific statements and white papers committee aims to find a sound balance between scientific accuracy and clinical needs and to improve the care of children with heart disease by shifting our efforts from individual institution-based practices to national standardised protocols. This paper provides a template for other societies and organisations faced with the task of developing scientific statements and white papers.

Committee organisation

The Pediatric Cardiac Intensive Care Society is a professional international forum aimed at strengthening the bonds between clinicians taking care of critically ill infants and children with heart disease by promoting high quality and safe care, education, and scholarship. The

Pediatric Cardiac Intensive Care Society members came together in 2015 to identify opportunities for potential progress in the field of paediatric cardiovascular intensive care and thereby established among others, the research committee. The aims of the Pediatric Cardiac Intensive Care Society research committee are to disseminate new knowledge related to the field, stimulate multicentre research, and develop guidelines where evidence is lacking. The research committee includes three co-chairs and 12 members that have been selected from the Pediatric Cardiac Intensive Care Society membership as well as external liaisons from other organisations whenever needed. Bi-monthly meetings are organised by chairs with *ad hoc* meetings as determined by the committee co-chairs. The research committee oversees the following research sub-committees – science innovation, scientific review, and scientific statements/white papers. A total of 16 international members form the scientific statements and white papers sub-committee. Each member was chosen by the research committee chairs on the basis of their expertise and reputation in the field of clinical research. All sub-committee members meet on a monthly basis by means of conference calls and also meet face-to-face at the annual Pediatric Cardiac Intensive Care Society scientific meeting. All members support their travel and expenses to the annual Pediatric Cardiac Intensive Care Society meeting. Input from members determined the high priority areas to focus future scientific statements and white papers. Members discuss outlines of topics, determine writing assignments, and establish evidence review processes. Figure 1 shows an overview of the Pediatric Cardiac Intensive Care Society scientific statements and white paper writing process adapted from the American Heart Association/American College of Cardiology guidelines.[1]

Priority areas identified by the scientific statements and white papers group

The scientific statements and white papers sub-committee experts agreed on the following topics/priority areas to focus on our initial efforts:

1. *Bleeding and thrombosis during extracorporeal life support and ventricular assist device.* In these papers we will discuss recent data, optimising anticoagulation monitoring, age or diagnosis-related effects on monitoring, outcomes and follow-up needs, as well as comparing extracorporeal membrane oxygenation and ventricular assist device anticoagulation results and complications highlighting differences in short-term versus long-term anticoagulation.
2. *Extracorporeal life support.* This paper will review the literature, identify when to use extracorporeal life support, what mode whether extracorporeal membrane oxygenation or ventricular assist device, patient population, logistics, economics, discuss geographic constraints since some places only have access to certain devices, when to consider changing modes and why, decision tree for transplant, and withdrawal and outcomes.
3. *Follow-up of cardiac recipients from extracorporeal life support.* This paper will review the literature, suggest follow-up with specific tests and intervals described, and how to obtain funding for follow-up.
4. *Ethical challenges in cardiovascular intensive care units.* We will discuss issues related to withholding/withdrawal of life-support in *cardiovascular intensive care units* and when and how to determine futility. New ethical challenges, given the availability of ventricular assist devices in children, are also arising. End-of-life practices across diverse cultural settings also require ethical discussion. Setting up/improving palliative care programmes for children dying in *cardiovascular intensive care units* are also important topics.
5. *Acute decompensated heart failure in children.* This paper will discuss epidemiology and presentation, critical care management, and who benefits from mechanical circulatory support.
6. *Early mobilisation and rehabilitation for cardiovascular intensive care unit patients.* This paper will review the current literature, describe the process based on age and diagnosis, and make recommendations for improvement.

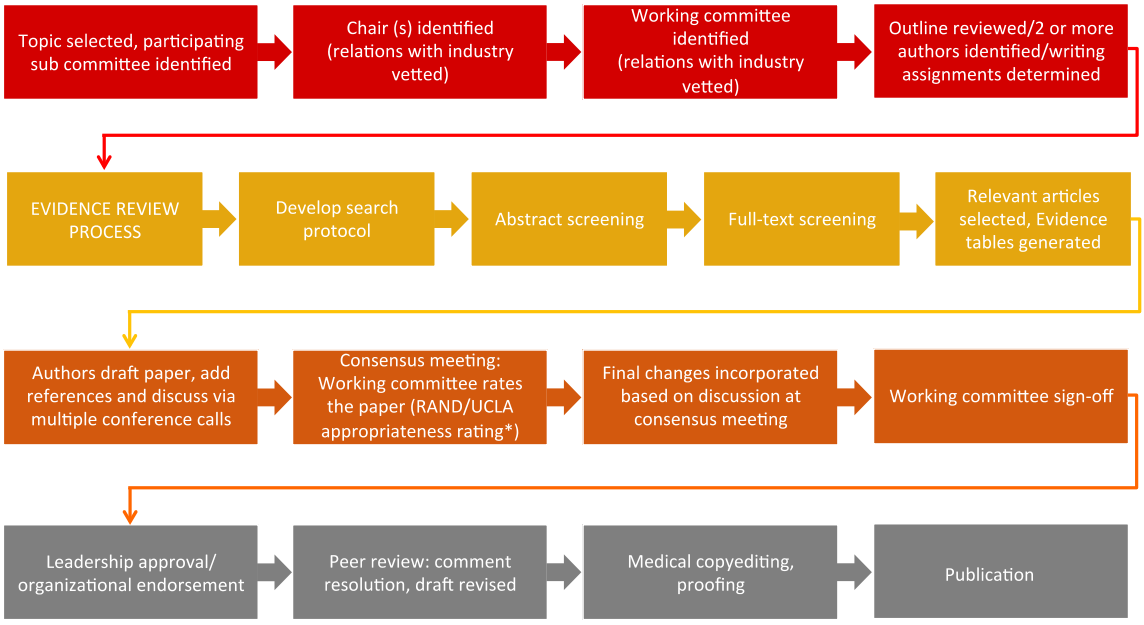

Figure 1. Overview of the white paper writing process.* RAND/UCLA appropriateness rating method is used to achieve consensus where there is limited data and low level of evidence. Project timeline from topic selection to submission for peer review – one year.

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7. *Ancillary monitoring of tissue oxygenation to prevent adverse events.* This paper will compare devices and review the literature, discuss economics, and make recommendations for current and future use.
8. *Single-ventricle patients.* Options and advice from providing comfort care to full repair.
9. *Pros and cons of cardiology-based cardiovascular intensive care units* versus those integrated with general paediatric intensive care units/neonatal intensive care units.
10. *Is regionalisation of paediatric heart surgery feasible and pros and cons?*

Literature search

A literature search process was developed with the goal of making the methodology transparent and reproducible similar to that used by the Pediatric Acute Lung Injury Consensus Group and American Heart Association/American College of Cardiology scientific statements.[1,2] Three databases were interrogated in collaboration with a librarian including PubMed, EMBASE, and SCOPUS. We defined the question, patient population, timeline, inclusion and exclusion criteria as Mesh terms, keywords, and phrases before the systematic review. These detailed searches will be published in the data supplement of each paper. Abstracts generated by these searches will be screened by two members of the sub-committee. If there is a conflict, a third reviewer from the group will be used to resolve the abstracts in question. Selected abstracts will undergo a full text review by two new reviewers with a third reviewer available to resolve any articles where there is conflict regarding their inclusion. The quality of the studies will be assessed by careful screening of the methods and results.

Rating system

Much of the current practice of cardiac intensive care is based on limited data with low level of available evidence, as well as a high variability in clinical practice. We sought to combine the best available scientific evidence with the collective judgment of experts to yield a statement regarding the appropriateness of a recommendation. We used the American Heart Association and the American College of Cardiology Guideline Recommendation Classification System, updated in 2015 to compare the strength and quality of recommendations and evidence between studies.[3] In the American Heart Association/American College of Cardiology guidelines, this includes the range in the Class of Recommendation from I to III, and the range of the Level of Evidence from A to C. Randomised and non-randomised studies are further classified into level of evidence B. Areas with lower-quality evidence are further classified into those where the data are limited, and the level of evidence being C-LD, or because the recommendation is based on clinical evidence or consensus of expert opinion where the level of evidence is C-EO. During a consensus meeting, all experts without disclosed conflict of interest rate the recommendation or the level of evidence. This will maintain objectivity and homogeneity. All experts will use the same system and have an equal vote. This minimises leader effect and gives the opportunity for the minority to give their opinion and increases exchanges.

Work performed

The timeline for the creation of the committees and the process for writing Pediatric Cardiac Intensive Care Society scientific statements and white paper is shown in Figure 2. Three white papers are currently in progress.

Conclusions

The production of white papers and scientific statements will represent a tremendous opportunity for the Pediatric Cardiac Intensive Care Society to advance the field of paediatric cardiovascular intensive care. This paper provides a template for other societies and organisations faced with the task of developing scientific statements and white papers. By reviewing the available knowledge and effective treatments around key topics of our

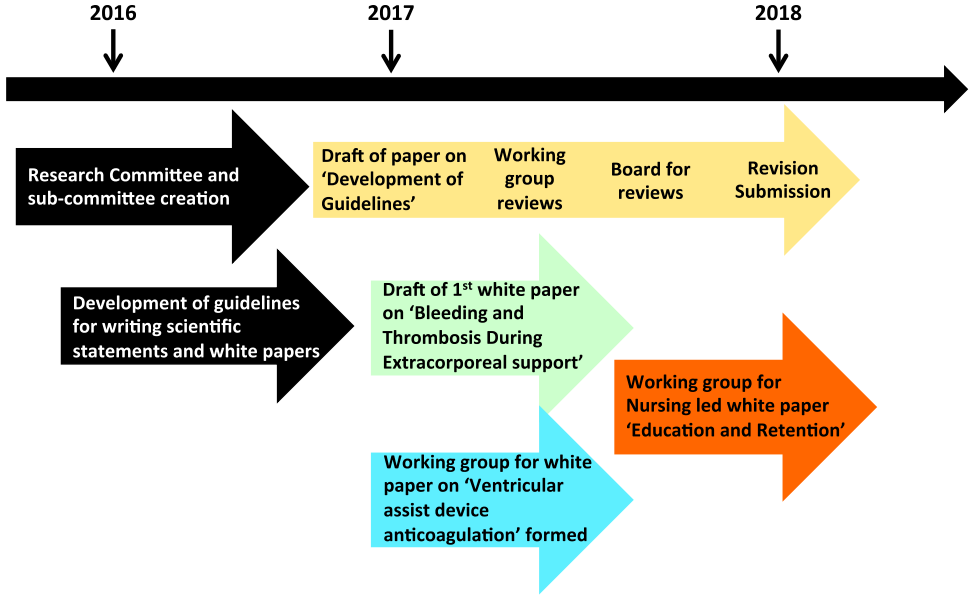

Figure 2. Timeline of the creation of committees and the process for writing scientific statements and white papers. PCICS = Pediatric Cardiovascular Intensive Care Society; VAD = ventricular assist device.

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subspecialty, we will be able to assess the advancements in the care of children with critical heart disease as well as establish a road map for future developments through further investigation. Although some of the conclusions will be inevitably based on limited evidence and extrapolation from adult studies, white papers and scientific statements will guide clinicians through the many areas of uncertainty they have to face in the care of our patients. White papers will present the current state-of-the-art in our understanding and treatment of the high priority areas.

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Conflicts of Interest. None.

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