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A Pilot Project to Implement Follow-Up Guidelines for Pediatric Post-ECMO Patients

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## Abstract

Extracorporeal membrane oxygenation (ECMO) is a short-term therapy that is used for all ages when conventional therapy has failed and the patient has an imminent risk of death. Although this modality is lifesaving, there are known problems of growth and development that are found within the population of survivors that can accompany its use in pediatrics. This practice improvement project implemented the Extracorporeal Life Support Organization (ELSO) guidelines for pediatric post-ECMO follow-up in a development and rehabilitation clinic. Initial implementation was successful but longer evaluation period is necessary to evaluate the true establishment of these guidelines. Many learning opportunities arose during this implementation process. It was learned that flexibility, individual education, and supportive staff could assist in implementation of a new guideline.

## A Pilot Project to Implement Follow-Up Guidelines for Pediatric Post-ECMO Patients

Extracorporeal membrane oxygenation (ECMO) is a short-term therapy that is used to support the function of the heart and/or lung while the organ heals itself from severe injury and/or illness (Extracorporeal Life Support Organization [ELSO], 2016). ECMO is used when conventional therapy has failed and the patient has an imminent risk of death; treatment with ECMO can last days to months (Annich, Lynch, MacLaren, Wilson & Bartlett, 2012; Thiagarjan & Barrett, 2011).

Since the first successful neonatal/pediatric ECMO treatment in 1975, over 36,000 pediatric and neonatal ECMO patients have survived to discharge from the hospital (ELSO, 2017). Unfortunately, there are very few follow-up clinics or providers in the United States that are knowledgeable about the special needs associated with these pediatric patients. Long-term follow-up that screens for ECMO specific problems in growth and development is the best way to recognize problems early and treat accordingly.

In 2014, Ijsselstijn and van Heijst published a review of current data on the medical and neurodevelopmental outcomes associated with a history of neonatal ECMO. Major physical problems identified included decreased exercise capacity, lung function, sensorineural hearing loss, chronic kidney disease, and decreased gross motor function (Fligor, Neault, Mullen, Feldman & Jones, 2005; Ijsselstijn & van Heijst, 2014). The authors also identified complications that can make school problematic. Post-ECMO children were shown to develop behavioral problems such as attention deficit disorder and have difficulties with concentration, memory, and working speed (Hunter, Zwischenberger, & Bhatia, 1992; Ijsselstijn & van Heijst, 2014). Several studies document developmental problems in post-ECMO children with recommendations for post-ECMO follow-up programs (Chandler et al., 2015; Guerra et al, 2014;

Madderom et al., 2016; van der Cammen-van Zijp et al., 2014). Unfortunately, there are still very few ECMO specific follow-up programs for pediatric or neonatal patients.

The purpose of this paper is report on the process of implementing the guidelines published by ELSO for pediatric ECMO follow-up in a development and rehabilitation clinic. These guidelines recommend screening tests, defined by patient age, to screen post-ECMO pediatric patients for known developmental problems (ELSO, 1997). This practice improvement project focused on the process of implementation of these guidelines in a pediatric rehabilitation and development clinic in Portland, Oregon. Implementation evaluation included the number of post ECMO pediatric patients referred to the clinic as well as a post implementation survey sent to the clinic staff. This paper will discuss implementation planning, the process barriers faced in implementation of these guidelines, share our problem solving strategies, and report on the success of the implementation.

### **Implementation Plan**

The planning and implementation of these guidelines occurred from May 2016 until March 2017. Meetings were held with stakeholders from the ECMO team and the Pediatric Rehabilitation and Development Clinic of a Portland area children's hospital with agreements to implement the ELSO guidelines for pediatric post-ECMO follow-up. Experts from the two teams developed the implementation plan in partnership: the ECMO team provided the background knowledge about the modality as well as the original guidelines for follow-up, and the Pediatric Rehabilitation and Development Clinic provided the updated testing schedule. The project received Institutional Review Board (IRB) approval from both University of Portland and the Portland area hospital and an informational sheet with the guideline roadmap was supplied to the

providers and staff. A manual of guidelines with easily readable testing timing and requirements was given to providers and schedulers to provide ease of use.

The clinical practice guideline implementation model guided the overarching implementation of the ELSO guidelines (White, 2012a). This model was developed by the Registered Nurses Association of Ontario and can be used to develop a systematic, planned approach to implementation (White, 2012a). The model recommends a systematic approach to identify a well-developed clinical practice guideline, identify and engage appropriate stakeholders, assess the readiness of the environment in which the guideline will be implemented, utilize evidence based strategies for implementation, plan evaluations of the implementation, and consider implications to the resources of the environment that carries out the guidelines (White, 2012a).

### **The guideline roadmap**

The guideline roadmap followed the requirements of the ELSO follow-up guidelines (ELSO, 1997). Prior to discharge from the hospital, an eligible patient would be referred to the “ECMO follow-up clinic”. Schedulers in the clinic would receive the initial referral and schedule first visit according to the age at which they present. Visits continue to occur at stated age intervals and the type of screening tests conducted per updated guideline. All screening tests would be at the discretion of the provider per standard of care. The ELSO guidelines only provide a type of screening test and timeline. Treatment plan for problems discovered by individual clinicians would follow standard of practice and is outside the scope of these guidelines. The ages and visits are as follows:

- 6 month and 12 month visit will be followed by a Rehabilitation specialist (MD) and an audiologist

- 18 months visit will be followed by an audiologist
- 24 month, 30 month, 3 year, and 4 year visit will be followed by a Pediatric Developmental specialist (MD) and an audiologist
- Year 5 will be followed by a Pediatric Neuropsychologist and an audiologist.

### **Process Barriers**

Implementation of the ELSO guidelines at a pediatric rehabilitation and development clinic was met with many process barriers. These process barriers varied from outdated test recommendations, problems with initial referrals, and a large number of stakeholders in different areas of expertise. Each process barrier was addressed with input from key stakeholders as the problems arose.

### **Outdated guidelines**

One of the first problems faced with the implementation of the ELSO guidelines were that the guidelines were last updated in 1997. The project director contacted ELSO for updated guidelines and, although ELSO had initiated a taskforce to update the guidelines, it was unknown when the updated guidelines would be available. Using the existing guidelines, the provider stakeholders in the Pediatric Rehabilitation and Development Clinic were queried and testing schedules and tests were updated per current standard of care of each specialty. Utilizing the providers in the clinic not only assured up to date testing and timing but it also promoted buy-in from the providers involved.

### **Many stakeholders**

This project included many people who had significant involvement in the care of the ECMO patient, both inpatient and outpatient. Leadership from both the ECMO team and the Pediatric Rehabilitation and Development Clinic agreed and committed their departments to this

project and signed a memorandum of understanding. The stakeholders who had direct patient care were identified, contacted and were involved in this project as their specialty area was needed. These stakeholders and their contributions to this project are explored below.

**Pediatric Rehabilitation and Development Clinic providers.** The clinic contains a multidisciplinary group of practitioners such as occupational therapist, physical therapist, speech therapist, audiology, rehabilitation/physiatry, neuropsychology, & pediatric development specialists. The clinic staff and providers were offered education on ECMO for the outpatient provider as well as the need for implementation of post-ECMO guidelines. Input was elicited from the individual disciplines, individual meetings were held to clarify tests and testing schedules, and an open dialogue was established to explore the impact of these guidelines on their practice. These meetings established that these guidelines were for screening purposes only; all deficits identified would be treated at the discretion of the provider.

**Schedulers.** The schedulers are the fulcrums of a successful implementation plan. The schedulers of the Pediatric Rehabilitation and Development Clinic needed to schedule the patients at accurate intervals to maintain timing of tests needed for screening per the ELSO guidelines. The importance of the schedulers dictated a separate meeting to establish the needs of the schedulers. A physical schedule was an important need identified and, to address this need, a physical binder/manual was created and given to clinic providers & schedulers. Two schedulers were placed in charge of scheduling all post-ECMO patients. Separate meetings were held with each scheduler to establish need, promote understanding of the guideline schedule, and to assure buy-in from these two schedulers.

### **Identification of Post-ECMO Patient by Clinic**



Identification of the post-ECMO child and his or her reason for referral to the clinic was important to streamline the children into the follow-up clinic. As the clinic and associated hospital used an electronic health record (EHR), the patient would be identified through their EHR as a referral to the “ECMO Follow-up Clinic”. Referrals may be made to the Pediatric Rehabilitation and Development Clinic from either an inpatient provider or an outpatient provider. To make this process more efficient, an order set within the EHR is currently in development.

Since this project aimed to capture all post-ECMO patients within the specified age range, the ECMO team of the sent out letters to the families and primary care providers of previous Pediatric patients who were eligible for screening by the post-ECMO follow-up guidelines. These letters, separate from this project, invited the families to have a discussion with and obtain a referral to the post-ECMO follow-up clinic from their primary care provider.

## **Results**

### **Patient Referrals**

There were 10 patients identified as post-ECMO, who lived in a reasonable distance (within 2 hours drive from the facility), and were within the specified age range at the start of the project. Two referrals were received by the post-ECMO follow-up clinic by the end of data collection. These referrals to the clinic were delayed due to insurance approval. As of the writing of this paper five referrals have been placed to the post-ECMO follow-up clinic.

### **Outcome Data**

An online survey was sent out to the clinic providers and staff using the online tool, SurveyMonkey. Due to the ease of use, an online survey was requested by the clinic. The survey

was seven questions long, two questions were demographic and one question was for comments or concerns. Of the 70 surveys sent, two were completed. The results are as follows:

<p>What do you like most about the post-ECMO follow-up guidelines?</p>	<ul style="list-style-type: none"> <li>• They are clearly defined</li> <li>• Clear and concise in regards to timing and responsibilities</li> </ul>
<p>What do you like least about the post-ECMO follow-up guidelines?</p>	<ul style="list-style-type: none"> <li>• Nothing</li> <li>• N/A</li> </ul>
<p>Overall, are you satisfied with the IMPLEMENTATION of the post-ECMO follow-up guidelines, dissatisfied with it, or neither satisfied nor dissatisfied with it?</p>	<ul style="list-style-type: none"> <li>• 1- neither satisfied nor dissatisfied</li> <li>• 1- very satisfied</li> </ul>
<p>What changes would most improve the implementation of the post-ECMO follow-up guidelines?</p>	<ul style="list-style-type: none"> <li>• Appointments being scheduled PRIOR to discharge from the hospital. But, this process was just initiated, so there will be a learning curve</li> </ul>

### **Discussion**

The goal of this project was to implement the ELSO guidelines for follow-up of post-ECMO pediatric patients and that goal was successfully achieved. The team navigated challenges, made decisions, put together a structure, and implemented a process that will help many post-ECMO children achieve their best developmental outcome. Nationally, there are few clinics that identify and screen post-ECMO patients for developmental problems known to be associated with a history of ECMO. These post-ECMO children were given the help to

successfully fight a life-threatening illness, but not given the right support to grow and develop. This project was important due to the rarity of similar programs. It is the hope that this project will help others to implement the ELSO guidelines to benefit this special population.

It is unknown whether these guidelines will lead to improved outcomes since the clinic did not have the opportunity to utilize the testing schedule. Additional investigations should be completed to evaluate for fidelity to the post-ECMO follow up guidelines.

Albeit small in number, the staff evaluation of the implementation process was positive. When queried, the staff of the clinic preferred the online method of completing the survey, unfortunately only two of 70 were completed. Ample time was given to complete the surveys. The online survey was open for one month and emails were sent inviting the staff to fill out the evaluation at the initiation and then at the two week point. The low number of responses can mean many things, including dislike of the program or process, unfamiliarity with online survey, lack of engagement in the implementation process, or lack of interest. A greater number of evaluations could have supplied a better picture of the implementation plan from the clinic point of view. It may be helpful to offer several options for completion of surveys in future endeavors.

This project was large and was complicated by many factors. Working within a large organization afforded expertise in the field, yet yielded a complicated macrosystem. The approval by the management of the different areas did not guarantee staff approval or involvement by the providers. It was found that addressing change by education and with individual providers and staff yielded more buy-in than by management alone. However, even with education and individual meetings, there were several individuals identified as late adopters. These late-adopters were very vocal about their lack of desire to work with this program. Luckily, the clinic was able to find other providers and staff who were willing to participate.

The implementation of a large change/plan required the need to be flexible. When problems arose, it was necessary to troubleshoot the problem and be creative with solutions. With this implementation, identification of the post-ECMO child proved to be the most challenging. The inclusion of a referral to a “post-ECMO follow-up clinic” in the EHR was a direct result of addressing a need as it arose. Adding an order-set to the EHR was complex and approval was needed from parts not initially involved with this project. The referral in the EHR is expected to take some months, thankfully the referral was deemed necessary and the additional work is being completed.

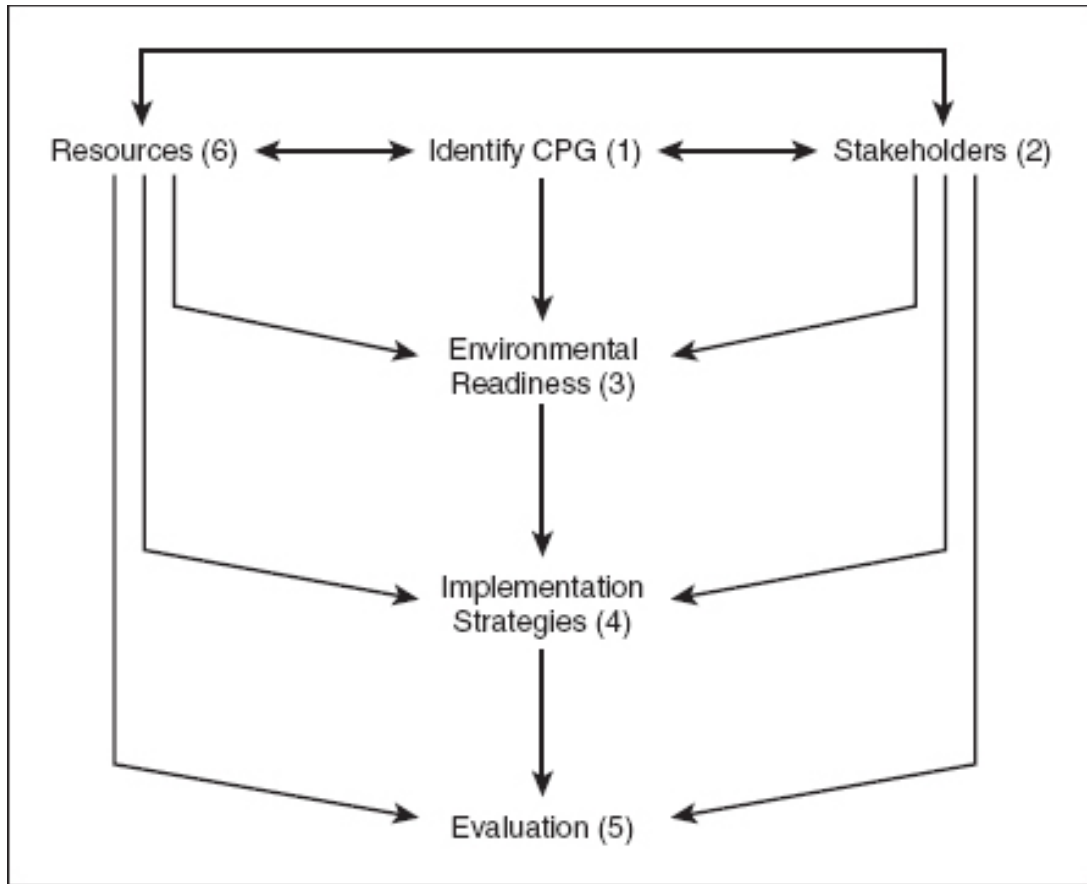
A minor investment in providing long-term follow-up will have lasting repercussions. If the child’s developmental problems are not identified or addressed, the investment in these children by placing them on ECMO is minimized and the child may not receive all the care necessary to become their optimum self. Pediatric ECMO centers owe it to their patients to offer this type of follow-up.

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