Extracorporeal Life Support Organization (ELSO) Guidelines for Follow-up After Neonatal and Pediatric Extracorporeal Membrane Oxygenation

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Abstract: Neonates and children who have survived critical illness severe enough to require extracorporeal membrane oxygenation (ECMO) are at risk for neurologic insults, neurodevelopmental delays, worsening of underlying medical conditions, and development of new medical comorbidities. Structured neurodevelopmental follow-up is recommended for early identification and prompt interventions of any neurodevelopmental delays. Even children who initially survive this critical illness without new medical or neurologic deficits remain at risk of developing new morbidities/delays at least through adolescence, highlighting the importance of structured follow-up by personnel knowledgeable in the sequelae of critical illness and ECMO. Structured follow-up should be multifaceted, beginning predischarge and continuing as a coordinated effort after discharge through adolescence. Predischarge efforts should consist of medical and neurologic evaluations, family education, and co-ordination of long-term ECMO care. After discharge, programs should recommend a compilation of pediatric care, disease-specific care for underlying or acquired conditions, structured ECMO/neurodevelopmental care including school performance, parental education, and support. Institutionally, regionally, and internationally available resources will impact the design of individual center's follow-up program. Additionally, neurodevelopmental testing will need to be culturally and lingually appropriate for centers' populations. Thus, ECMO centers should adapt follow-up program to their specific populations and resources with the predischarge and postdischarge components described here.

Key Words: extracorporeal life support, brain injury, neurodevelopment, neurodisability, long-term outcomes

I. Introduction

Survivors of critical illness in childhood have significant medical, developmental, social, emotional, and physical needs,[1,2] and children supported on extracorporeal membrane oxygenation (ECMO) often represent the sickest and the most vulnerable of these patients. The latest ELSO Registry international summary data reports survival rates between 42% and 73% following neonatal and pediatric ECMO; thus there is a growing population of ECMO survivors as the utilization of ECMO increases worldwide.[3] However, the long-term medical and neurodevelopmental outcomes remain of concern, particularly in certain diagnostic groups such as congenital diaphragmatic hernia (CDH)[4–6] and critical congenital heart disease.[7–11] If these concerns are not appropriately identified and managed, then they may evolve over time into significant long-term neuropsychologic sequelae with wide-ranging implications for the health, education, and integration of these children into society.[4,12–14] A brief description of the neurodevelopmental and medical outcomes is outlined below. While there are studies reporting on the Health-related Quality of Life (HR-QoL) of ECMO survivors,[9,12,13] this is a distinct outcome and is part of the core outcome set for pediatric critical care.[15] However, multiple factors such as the choice of measures, respondent and timing of evaluation as well as concepts like response shift have to be taken into account when measuring HR-QoL and interpreting findings. Health-related Quality of Life, while clearly important, should therefore be considered separately from neurodevelopmental outcomes and is beyond the scope of the current guidelines. **Figure 1** illustrates the

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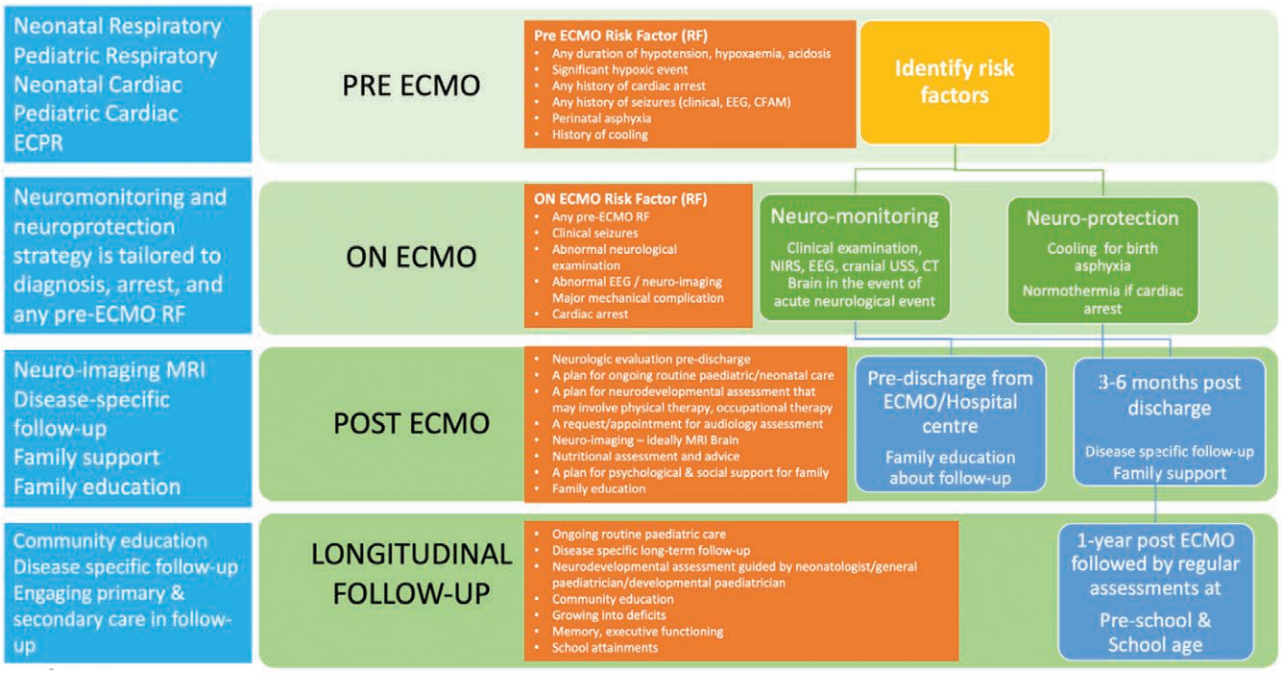

Figure 1. Flowchart for long-term follow-up of ECMO survivors. The above is a reference guide for best practice on current available experience. Neuromonitoring, neuroprotection[16,17] and neurodevelopmental follow-up—all are key components to ensure optimum neurologic outcomes for ECMO survivors. See Table 1 for domains that should be covered in follow-up of ECMO survivors. We recommend that the first assessment be done soon within the first 3–6 months after hospital discharge. Please see Table 2 for the age-specific recommendations for further follow-up which should be sequential with longitudinal follow-up until adolescence. There will be local variations within different countries which will influence the pathway and should be considered by individual ECMO center. CFAM, cerebral function analysis monitor; CT, computed tomography; ECMO, extracorporeal membrane oxygenation; EEG, electroencephalogram; MRI, magnetic resonance imaging; RF, risk factor; USS, ultrasound scan.

spectrum of neurologic monitoring and follow-up recommendations during and after ECMO.

A. Outcomes After Neonatal ECMO

Most of the data on long-term outcomes after neonatal ECMO has become available from a nationwide prospective follow-up program in The Netherlands.[4,18–21] This longitudinal program offered to all survivors of neonatal or pediatric ECMO has provided data on medical and neurodevelopmental outcomes that have informed subsequent interventional studies and neuropsychologic research. A recent overview of the long-term outcomes of neonates treated with ECMO for respiratory failure has been described in Chapter 17 of the *ELSO Red Book*, Edition 5, 2017.[22] The severity of critical illness and the underlying disease which resulted in cardiorespiratory failure and the need for ECMO are the primary determinants of adverse long-term outcomes. An update on the current knowledge obtained during objective and standardized assessments after neonatal ECMO is provided here and the potential risk factors for impaired outcome following neonatal ECMO are outlined in **Table 1**.

Neurodevelopmental outcomes. It has become increasingly evident that approximately 25% of neonatal ECMO survivors will have neuropsychologic deficits that may have potential impact on academic performance in later life.[37,40–43] Serial longitudinal measurements of cognition at 2, 5, and 8 years in 178 neonatal ECMO survivors from the national Dutch cohort have shown that intelligence is stable over time. However, those who later went on to need special educational support were identified to have had lower IQ scores at 2 years of age, and had performed poorly on selective attention tasks at 8 years of age.[37] Thus, the longitudinal data indicate that the measurement of IQ alone at preschool age is insufficient to predict academic performance at school age, and that neuropsychologic assessments are necessary to identify more complex problems. Furthermore, recent studies confirm that children who have survived critical illness in the neonatal period have sustained attention deficits, verbal problems, and visuospatial memory deficits that correlate with reduced hippocampal volumes and impaired global white matter microstructure.[38,44] This may explain the high proportion of ECMO survivors (up to 40%) that need educational support at school.[4,14]

Medical outcomes. The data on the long-term medical outcomes of neonatal ECMO survivors is limited. Published data are primarily available from the UK Collaborative Randomised Trial of Neonatal ECMO[45–49] and The Netherlands multidisciplinary longitudinal follow-up program.[4,19,24,50,51] Physical growth is typically normal, except when considering lung function. Longitudinal measurements indicate that there is mild airflow obstruction, which is stable through adolescence; however, this may be more impaired in certain disease-specific conditions such as CDH.[51] Exercise endurance may range from normal to decreased. Longitudinal assessments of children in the Dutch follow-up program have shown that the percentage of ECMO survivors with reduced exercise tolerance increased from 7% at 5 years to 35% at 12 years.[26] Neonatal ECMO survivors with acute kidney injury have increased risk for signs of chronic kidney disease by 8 years of age, evidenced by proteinuria or hypertension.[52] Hearing loss is frequent. Early ECMO survivor data have reported that

Table 1. Potential Determinants of Impaired Outcome Following Neonatal ECMO

Outcome Parameter	Risk Factor for Poor Outcome
Lung function/airflow obstruction	Diagnosis of RDS,[23] diagnosis of CDH,[24] prolonged duration ECMO,[23,25] chronic lung disease[25]
Exercise capacity	No significant determinants reported[26]
Physical growth	Diagnosis of CDH[27,28]
Sensorineural hearing loss	Diagnosis of CDH,[29] prolonged duration ventilation,*[30,31] prolonged duration ECMO,[29] sepsis/bacterial meningitis,*[30–32] administration of aminoglycosides,[29] severe birth asphyxia,*[31,32] intracranial abnormalities,*[32] clinical seizures before ECMO[33]
Motor function development	Chronic lung disease,[34] intracranial abnormalities,[34] feelings of social competence,[35] sports participation,[35] diagnosis of CDH,[34] duration of hospitalization[36]
Intelligence	Low maternal education level,[37] diagnosis of CDH,[37] duration of hospitalization[36]
Neuropsychologic outcome	Highest mean airway pressure before ECMO,[18] structural brain abnormalities,[38,39] maximum vaso-inotropic score,[40] chromosomal abnormality,[10] acute neurologic event on ECMO,[41] time to lactate clearance[10]
Behavior	Need for extra help at school[18]

*Not specific for ECMO-treatment but for neonatal intensive care treatment.

CDH, congenital diaphragmatic hernia; ECMO, extracorporeal membrane oxygenation; RDS, respiratory distress syndrome.

Adapted from *Semin Perinatol* 38: 114–121, 2014.[4]

the incidence of sensorineural hearing loss ranged from 3% to 25%,[29,53] and that it could even manifest as late as 9–13 years of age, despite having previously tested as normal.[33] However, more recent literature indicate that the incidence of hearing loss is lower than that reported in earlier studies. Nevertheless, the ease and low cost of audiology evaluation favors its utilization, particularly considering the significant impact of hearing loss on speech development.[54] Although most ECMO survivors grow and develop normally, many have significant medical risks or burdens that increase as they get older. Careful monitoring may allow early intervention for these varied outcomes across functional domains.

B. Outcomes After Pediatric ECMO

As indicated in Chapter 25 of the *ELSO Red Book*, Edition 5 (pp. 299–300), the long-term pulmonary, cognitive, or neurodevelopmental outcome data are lacking in children supported on ECMO for acute respiratory failure at an older age beyond the neonatal period.[22] With increasing cumulative experience with pediatric respiratory ECMO, increasingly more complex children with significant comorbid conditions are being supported.[55] Jen and Shew[56] reported that in a cohort of 88 non-neonatal ECMO survivors, 56 (63%) were followed up to a median interval of 3.7 years: of these survivors, up to 62% (excluding those with congenital heart disease) had readmissions (34% for respiratory reasons), and 16% had neurologically debilitating conditions such as epilepsy (7%) and developmental delay (9%). The heterogeneity of the population may explain in part the limited reported data in this group of patients.

C. Outcomes After Cardiac ECMO

A recent overview of long-term outcomes in ECMO-treated children with cardiovascular disease has been described in Chapter 35 of the *ELSO Red Book*, Edition 5, 2017.[57] Given that central nervous system complications on ECMO are reported with the use of extracorporeal-cardiopulmonary resuscitation (ECPR), venoarterial support, severe metabolic acidosis and need for inotropes, use of ventricular assist devices, neurologic complications are inherently more likely in children with cardiovascular disease. A significant proportion (20–73%) of children with cardiovascular disease supported on ECMO have long-term neurodevelopmental issues with a high long-term mortality rate.[7,8,11,58,59] The neurodevelopmental problems described in this population vary across different domains including cognitive function, academic achievement, language, visual perception, attention, executive functioning, gross and fine motor function, and psychosocial maladjustment.[60] The extent of these neurodevelopmental deficits is dependent on the underlying cardiac condition, presence of associated genetic syndromes, age at the time of ECMO exposure, indication for ECMO, any associated cardiac arrest, and any neurologic morbidity experienced on ECMO. An awareness and acknowledgement of the neurodevelopmental issues in children with congenital heart disease has led to publication of a scientific statement from the American Heart Association on surveillance, screening and follow-up for children with cardiac disease.[61]

D. Outcomes After ECPR

The children supported on ECPR represent a unique subset of ECMO survivors who may have a higher incidence of neurologic complications on ECMO and subsequently develop significant neurodevelopmental sequelae. An ELSO Registry-based study on ECPR outcomes, which predominantly reflects cardiac patients, reported a high incidence (22%) of acute neurologic complications on ECMO.[62] As a secondary analysis of hypothermia after cardiac arrest, Meert *et al.* reported the 1 year survival, and neurobehavioral outcome using Vineland Adaptive Behavior Scales [VABS], Second Edition) at baseline and at 1 year follow-up in survivors of ECPR for in-hospital arrest. Although comparing baseline VABS score with the 1 year score, they found that one-third (30.5%) had VABS ≥70 points (good neurobehavioral outcome) while it was decreased by ≤15 points in 22.1%. Importantly, many cardiac ECMO outcome studies include a significant proportion of children supported as ECPR and this may impact on the overall neurodevelopmental outcome findings.[7,43,58,63]

II. Recommendations for follow-up for all types of ECMO

Table 2 illustrates the multidisciplinary follow-up needed for these patients.

A. Long-term follow-up should be offered as "standard of care" in a structured and standardized approach, permitting the evaluation of outcome data and effectiveness of interventions as well as facilitating multi-center collaborations.[64,65]

Table 2. Recommendations and Relevance of Long-Term follow-Up After (Neonatal) Extracorporeal Membrane Oxygenation

	Domains of Interest	Assessments and Tests	Action/Intervention
Infancy 0–2 years	Growth	Anthropometric measurements	Referral to dietician
	Kidney function	Hypertension, urinary protein-to-creatinine ratio	Referral to nephrologist (CKD)
	Hearing	Auditory tests	Early referral to audiology
	Neurologic assessment including imaging	MRI brain	Early referral to general pediatrician/neurologist/ ophthalmologist
	Cognitive development	Age-appropriate locally available formal neuropsychologic test*	Early referral to child development center/ neurorehabilitation center
	Motor development	Age-appropriate locally available formal developmental test*	Referral to physical therapist
Preschool age 2–5 years			
	Growth (mainly CDH)	Anthropometric measurements	Referral to dietician
	Kidney function	Hypertension, urinary protein-to-creatinine ratio	Referral to nephrologist (CKD)
	Neurocognitive assessment	Age-appropriate locally available formal neuropsychologic test*	Referral to Child Development Center or Neurorehabilitation Center
	Language development	Age-appropriate locally available formal developmental test*	Hearing assessment and referral to speech-language pathologist
	Motor development	Age-appropriate locally available formal developmental test*	Referral to physical therapist
School age ≥6 years			
	Growth (mainly CDH)	Anthropometric measurements	Referral to dietician
	Kidney function	Hypertension, urinary protein-to-creatinine ratio	Referral to nephrologist (CKD)
	Lung function (mainly CDH)	Spirometry	Evaluate reversibility of airflow obstruction
	Motor development	Age-appropriate locally available	Referral to physical therapist
	Maximal exercise capacity	formal motor function test*	Sports participation and/or exercise training
	Neuropsychologic assessment	Age-appropriate locally available formal neuropsychologic test*	Referral to early school support
	Intelligence (only once in follow-up)	Age-appropriate locally available formal neuropsychologic test*	Referral to cognitive rehabilitation for acquired brain injury
	Memory/attention/concentration/information processing	Age-appropriate locally available formal neuropsychologic test*	Referral to cognitive rehabilitation
	Behavior: Hyperactivity	Age-appropriate locally available	Referral to behavioral therapist/
	Somatic problems	formal neuropsychologic test*	psychologist
Adolescence >12 years			
	Growth (mainly CDH)	Anthropometric measurements	Referral to dietician
	Kidney function	Hypertension, urinary protein-to-creatinine ratio	Referral to nephrologist (CKD)
	Maximal exercise capacity	Age-appropriate locally available formal test*	Sports participation/exercise training
	Neuropsychologic assessment	Age-appropriate locally available formal neuropsychologic test*	Referral to school support
	Memory/attention/concentration/information processing	Age-appropriate locally available formal neuropsychologic test*	Referral to cognitive rehabilitation
	Behavior: hyperactivity/depressed feelings/ social problems/somatic problems	Age-appropriate locally available formal neuropsychologic test*	Referral to behavioral therapist/psychologist
			Career support/ choice of profession

*For assessments of neurodevelopment, behavior, lung function and exercise capacity, it is preferable to use culturally appropriate and locally available tests with age-appropriate references. When possible, internationally validated testing is preferred to facilitate interpretation and future collaboration.

CDH, congenital diaphragmatic hernia; CKD, chronic kidney disease.

Adapted from *Semin Perinatol* 38:114–121, 2014.[4]

B. Recommendations for follow-up depend on the primary diagnosis, the nature and extent of the underlying disease, the indication for ECMO, presence of neurologic comorbidity, and other medical co-morbidities.

C. Discharge planning

Before discharge from ECMO center. The process for structured ECMO follow-up begins before the child is discharged from the ECMO center, and in ideal circumstances must be

initiated by the ECMO team. The importance of follow-up must be emphasized not only to physicians but also to the parents, and a plan must be put in place for rehabilitation, recovery, and education of the ECMO survivor and their families. An ideal time to discuss this with the family is *before discharge* from the hospital. Any child who has had any high-risk factors pre-ECMO or any acute neurologic events or adverse events on ECMO is at high risk for later neurodevelopmental issues; and these children must be highlighted predischarge. If neurodevelopmental deficits are identified before discharge, it is presumed that interventions and rehabilitation therapies have been initiated while inpatient and enabled upon discharge.

Preparation for discharge should include:

- Neurologic evaluation predischarge from ECMO center.
- Neuro-imaging—Magnetic resonance imaging (MRI) scan of the brain in those who have had any risk factors for neurologic complications pre-ECMO (*e.g.,* cardiac arrest) including those with any acute neurologic event pre/on/post ECMO (*e.g.,* clinical or electrographic seizure) (see **Figure 1**). We also recommend that the MRI of the brain should also be considered for every neonate before discharge as neurologic events such as seizures are not always clearly evident in this population.[66–68]
- A plan for routine neonatal/pediatric care to establish ongoing care and sign out to a secondary care provider (may vary as per local practices).
- A plan for neurodevelopmental assessment that may involve physical therapy, occupational therapy, and speech and language therapy.
- A request/appointment for audiology assessment/hearing test if not already assessed.
- Nutritional assessment and dietetic plan.
- A plan for psychologic and social support provision for the family.
- Family education.
- Community education.

Neurologic evaluation and imaging. All children following decannulation and prehospital discharge should have a bedside routine neurologic evaluation. Neuroimaging in the form of MRI post-ECMO is recommended and useful for the 1) identification of clinically unrecognized brain injury and 2) for categorizing patients at higher risk of adverse neurologic outcomes who may need closer neurologic follow-up,[44] particularly in children with congenital heart disease.[69–71] In a study of 81 neonates supported on ECMO in the first week of life who underwent routine brain MRI at a median age of 26 days of life, Wien *et al*. showed that 37 (46%) demonstrated imaging evidence of neurologic injury; however, they did not conduct neurodevelopmental tests.[72] Furthermore, in a 2 center study, Bembea *et al*. reported that the presence of new neuroimaging abnormalities—cranial ultrasound scan (USS), computed tomography (CT), and/or MRI brain—during ECMO or within 6 weeks post-ECMO was associated with VABS-II score <85 or death within 12 months after ECMO.[43] Various factors can affect the MRI findings including the age of the child, timing of scan since injury, the type of injury, use of therapeutic cooling, and even the MRI protocols, and sequences used.[72,73] Athough the optimal timing of MRI after decannulation remains unclear, prehospital discharge or post discharge from hospital, the timing of the MRI scans should avoid the period of "pseudonormalization" which can be anywhere from 2 to 14 days after an ischemic insult.[73–75] With advances in MRI imaging, the MRI protocols and sequences need to be standardized to improve the uniformity of data acquisition and to develop generalizability for future studies. There are advantages to MRI scans: high sensitivity and specificity and the lack of radiation exposure; however, logistics of organizing MRI scans is dependent on the individual ECMO center characteristics influenced by ready availability of the scanner, anesthesia cover for the ventilated patient, and the need for transferring children post-decannulation to secondary care providers.

Until the evidence to justify routine mandatory MRI post-ECMO is available, clinicians should have a low threshold in organizing brain MRI in high-risk groups with an episode of cardiac arrest, seizures, carotid cannulation approaches, central cannulation in children supported on ECMO post cardiac surgery, any abnormal neurologic examination or imaging (cranial USS/CT brain) and electroencephalography (EEG) findings. Findings on MR Spectroscopy in the first 2 weeks after birth in babies with neonatal encephalopathy have reported a significant correlation to the 2 year neurodevelopmental outcomes.[76,77] Furthermore, late brain MRI imaging in survivors of neonatal ECMO between 8 and 16 years of age has shown hippocampal volume reduction and memory impairment.[39,44]

Ongoing care and Secondary care provider involvement. Children may get transferred from ECMO centers to local/referring secondary care hospital before being transferred home. A plan for ongoing care after discharge—medical and neurodevelopmental needs—should be established. Communication with the child's pediatrician or neonatologist should be commenced by the discharging physician at the ECMO center before discharge. The transfer of information and transition of care from the ECMO center to the secondary-level hospital is crucial so that routine pediatric care and specific post-ECMO management is continued.

Family education. Educating parents on the importance of follow-up is fundamental to the success of the ECMO follow-up program. The awareness and understanding of underlying primary condition that necessitated ECMO, ECMO-related sequelae and adherence to follow-up recommendations need to be emphasized from the very outset of the discharge process. It is the responsibility of the ECMO center to inform the parents about potential sequelae and that some of the ECMO survivors may have neurodevelopmental difficulties, and that early recognition and intervention is critical to optimizing long-term outcomes. Furthermore, based on current knowledge of long-term outcomes and the understanding that survivors of ECMO may "grow into their deficits," that is, that some deficits may only become apparent as they grow older, the parents should be advised to seek medical attention in case of: unexplained growth failure, reduced exercise tolerance, or neurodevelopmental problems such as clumsiness, failure of academic performance, behavioral problems, impaired attention, concentration difficulties, or memory problems (**Tables 1 and 2**).

Community education. Education of the primary and secondary care provider is essential as professionals in the community may not be familiar with ECMO. Often, they are the first port of call for families, and hence, it is important to provide information on current knowledge on medical and neurodevelopmental follow-up after ECMO. This may be done either

as a separate handout or as part of the discharge summary. In a recent study in the United Kingdom, parents highlighted the need for structured follow-up and support in the community and the importance of education and sharing of information about ECMO with general practitioners/family physicians, community professionals and schools.[78]

D. Structure of Follow-up after discharge

1. **Types of services recommended:**

a. *General pediatric or neonatologist follow-up—All children who have survived significant critical illness with ECMO support* need general pediatric or neonatologist follow-up regardless of whether they have had any complications on ECMO, or whether they have an underlying disease or not, and whether there has been an acute neurologic event on ECMO or not. The follow-up pediatrician, neonatologist or general practitioner should have understanding of what ECMO is, what complications can occur on ECMO, and what neurologic and neuropsychologic problems these children and families may face in the short, medium, and long-term timeframes. Serial regular evaluations by the local pediatrician or neonatologist (with appropriate referrals for neurologic and neurodevelopmental assessments) are recommended for children who have survived ECMO as neurologic comorbidity may not be overt at discharge, and all ECMO survivors should be considered to have *potential* neurologic comorbidity.

b. *Child development center/community developmental pediatrician—Children at high risk for neurologic impairment, or those who have had an acute neurologic event on ECMO, significant hypoxemia, hemodynamic compromise, or cardiac arrest,* should be referred for follow-up by a neurologist and/or a neuro-rehabilitation center, or a community developmental pediatrician service or child development center (nomenclature varies in different countries). Neonates and children who have suffered any neurologic morbidity at any time during the course of the ECMO admission should have had neuroimaging, preferably MRI of the brain (predischarge home) and repeated post-discharge only if deemed necessary by the neurologist with timing as directed by the neurologist. This should be seen as a shared care arrangement between the general pediatrician/neonatologist involved and the child development center pediatrician, if not part of the ECMO center follow-up program.

c. *Disease-specific (underlying or acquired) follow-up:* The underlying disease and functional impairments (*e.g.,* cardiovascular disease or lung function impairment) related to the underlying disease or primary diagnosis will need additional disease-specific follow-up that should be arranged by the child's pediatrician. Children with CDH are at high risk for obstructive lung disease, pulmonary hypertension, may require follow-up from pulmonology, cardiology, general surgery, and nutrition in addition and a detailed follow-up plan is available from the American Academy of Pediatrics and the CDH Euro-Consortium.[79,80]

d. *Pediatric and Cardiac ECMO considerations:* From the current literature, it is unknown whether children who need ECMO at an older age have similar long-term problems as neonatal ECMO survivors. Somatic problems may occur at any age due to on-going brain development and myelinization continuing through adolescence; thus, it can be assumed that pediatric ECMO survivors will also benefit from long-term follow-up and timely interventions. Long-term mortality may be particularly high in this group, and special needs may exist for this population requiring close follow-up.[58,81] If there are chronic comorbidities (for example, sickle cell disease, solid organ transplantation, rheumatological conditions (for example, Wegener's granulomatosis), it may be convenient to integrate the follow-up within the chronic care follow-up.

2. **Timing and Location of follow-up. Please see Table 2**.

The timeframe for follow-up should be guided by the patient's clinical condition, the presence of high-risk factors, and access to specialist services either locally or at the ECMO center. *At minimum*:

a. **The first follow-up** should preferably be within the first 3 months of discharge, either by a local neonatologist/pediatrician having familiarity with ECMO follow-up close to the family's home, or by the ECMO center if there is a dedicated ECMO follow-up program that is geographically easily accessible to the families.

b. **Second follow-up/contact** should preferably be around 6 months after ECMO at the ECMO center.

c. **Third follow-up** should preferably be 1 year after ECMO and include a structured assessment targeted at neurodevelopmental assessment, either by a local neonatologist/pediatrician having familiarity with ECMO follow-up close to the family's home, or by the ECMO center if there is a dedicated ECMO follow-up program that is geographically easily accessible to the families.

d. As neurodevelopment is usually normal within the first years of life, health care providers and parents may consider regular follow-up visits redundant, so each visit must stress the importance of long-term surveillance.

e. **Further follow-up through school age and right up to adolescence** should be individually tailored to the patient's needs taking into account the specific domains of interest as illustrated in **Table 2**.

3. **Neurodevelopmental assessments**

a. **There is marked international variation in the use of instruments to assess neurodevelopmental outcome. Various measures are available and should be chosen based on the norm of the country of origin and primary language of the patient.**

b. It is preferable for centers to choose validated, culturally appropriate tests, with age-appropriate references, at standardized intervals to facilitate interpretation and (future) collaboration. The ECMO center should have familiarity with the test used. See Appendix 1, Supplemental Digital Content 1, http://links.lww.com/ASAIO/A685, for one example in an English speaking, US population.

c. At a minimum, the VABS-3 (third edition) can be performed as a telephone questionnaire in English and

Spanish speaking countries at approximately 12 months after ECMO.[82–85] The VABS-3 is a caregiver report measure of functional skills that examines communication, daily living, socialization, and motor skills; and has been used to assess neurodevelopment in ECMO survivors.[43,86] This semistructured interview has been shown to have a high degree of test–retest reliability in examining the domains of communication, daily living skills, socialization, and motor skills.[83] It can be performed in-person or by telephone by trained staff. Reliable telephone administration requires an investment in training and flexibility of staff.[85,87] It is important to bear in mind that normative data are not available in non-English speaking countries, and locally available adaptive behavior assessment tools may be needed.

In lieu of a formal follow-up program, ECMO personnel could be trained to administer the VABS-3 by telephone to the parents, and results shared with the general pediatrician. The parent-reported measures could screen for concerns that could be followed up by formal neurodevelopmental testing. In the absence of availability of VABS-3, other parent reported measures such as Ages and Stages Questionnaires – third edition (ASQ-3) may be used as a minimum dataset; however, this test is available only up to 6 years of age.

d. As the ECMO survivors get older, deficits in executive functioning and memory become more apparent.[39,40] Centers should consider assessments of neurodevelopment at later (school) ages, with testing targeted for assessment of these functions.
4. Families of children supported on ECMO undergo considerable stress and may experience signs of post-traumatic stress disorder.[88–90] Awareness and education of the community and appropriate consideration of psychologic support to the family is important.

III. Conclusions

Neonates and children, who have survived an extremely critical condition requiring ECMO, need structured neurodevelopmental follow-up. It is well established that these children, even those who do not have comorbidities and appear to have had a favorable outcome, are at risk for developing neurodevelopmental delays and new medical problems. Sequelae of this severe illness may not be immediately evident, but rather gradually develop over many years until even adolescence as the child is expected to progress in health and development.

ECMO programs should include predischarge assessments, family education, and co-ordination of structured and standardized long-term follow-up until adolescence and adulthood. Follow-up programs should focus on routine pediatric care with attention for disease-specific underlying and acquired conditions, structured ECMO/neurodevelopmental care including school performance, and parental education and support. We accept that institutional preferences and the international, national and local resource availability and variations in the configuration of primary, secondary and tertiary healthcare services will ultimately influence the final delivery of follow-up program.

Standardization of follow-up is mandatory to perform multicenter outcome studies. Continued research on neurodevelopmental and medical outcomes is imperative as improvements in ECMO techniques and technologies allow for wider applications of this technology with changes in outcomes. With cumulative experience and more research, there may be a minimum dataset of relevant outcomes including HR-QoL which may need to be integrated in future guidelines.

IV. See Figure 1 and Table 2 for overall follow-up.

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