Extracorporeal Life Support Organization (ELSO)

Web Based Data Entry Instruction Manual
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Getting Started

In this section you will learn how to log into the system, change your password and set the format you wish to use for the Date/Time fields.

Logging on

From your web browser go to:  www.elso.med.umich.edu/ELSORegistry

Once the log in screen appears enter your user name and password. Note that the password is case sensitive.
Once you have successfully logged on you will be taken to the home page where your most recently submitted patients will appear in the middle of the screen.

**Changing your password**

To change your password click on "My Profile" which is located at the left of the screen. Enter your existing password followed by your new password and the click "Change Password".
Date / Time Format

To set how your date/time fields are displayed click on "My Profile" from the home page and then choose which format you wish to use. The default is “English (United States)”. 
Adding Users

To add additional users click on “Administration” and then “Users” which is located at the left of the screen. If you are an administrator for your center you will be able to add and manage users. To add a new user just enter the Username, First Name, Last Name and e-mail. You will also be able to choose what type of role you wish this user to have. There are three choices: ECLS Center Administrator, ECLS Center Data Manager and ECLS Center Data Entry. The administrator has full rights to the account. The data entry will not be able to access reports or add users. A data manager will be able to generate reports but will not be able to add users.

Clicking on the “Details” link for a user will allow you to edit the information for a user including resetting the password and unlocking the account. An account will be locked if too many attempts are made to login with an incorrect password.
Adding New Patients

From the home page in the “Quick Add” section enter the Unique ID, birth date, admit date, date/time on ECMO, run number, run and support type (pulmonary, cardiac or ECPR). These fields are explained in detail later. Then click on the “Insert” button. Throughout the application if you hold your mouse over a field information is displayed as can be seen in the “Time On” field below.
Patient Data Information

Once you hit “Insert” a new patient is entered and you can now enter patient level data.

Center Identification

Center ID number and Center name

Every center is assigned an ID number from ELSO. When you log into the system your center ID and name are automatically attached to all patients you enter.

Unique ID

Enter the patient's Unique ID number. For those patients with multiple runs, this number will be the same. The Unique ID and Center ID fields identify unique patients within the registry. You will need to be able to identify the patient by this Unique ID. The format that must be used for this field is a ten character identifier that has the following format:

First 3 characters are the Center ID. Next four characters is year they go on ECLS for their first run. Next three characters is the sequence number of that patient for that year within your center.

For example, if your center ID is 8, the year the patient went on for their first run of ECLS is 2011, and they are the third patient to go on ECMO the Unique ID would be: 0082011003.

If you center ID is 167, the year the patient went on ECLS is 2010 and they are the 34'th patient for 2010 the Unique ID would be: 1672010034.
The reason why we encode the Center ID within the Unique ID field and still have it listed as a separate field on the form is to ensure that the form is entered to the correct center. Because the patient name fields have been removed for confidentiality issues, this will act as a check to make sure a centers forms are not mistakenly entered as a different center. If you have questions on this please contact the ELSO Office for clarification.

This is a required field.

Birth Date/Time

Enter the patient's birthday. For neonates, also include the time when the patient was born, for pediatric and adult patients no birth time is necessary. This is a required field.

Gender: (Male, Female)

Select from the drop down list.

Race: (Asian, Black, Hispanic, White, Other)

Select from the drop down list.

The next set of fields are for neonatal patients only.

Birth weight (use kg)

Enter the birth weight in kilograms to the nearest hundredth of a kilogram. Example of a valid weight is 3.78.

Maternal age

Enter the birth mother’s age in years.

Apgar (1 min) and Apgar (5 min)

Enter the 1 and 5 minute Apgar scores. Apgar scores can have a value from 0 through 10.

Gestational age

Enter the gestational age in weeks.

Delivery Vaginal, C-section (emergent), or Elective C-sect

Choose the appropriate delivery type.

Infant Transported? □ (Check if yes)
If the infant was transported check the appropriate box.

**Cardiac arrest at birth?** □ (Check if yes)

If the infant had a cardiac arrest at birth check the appropriate box.

**CDH present?** □ (Check if yes)  If Yes: **Prenatal diagnosis?** □ (Check if yes)

If CDH (Congenital Diaphragmatic Hernia) is present, check the appropriate box. If present and was diagnosed prenatally, check that box as well.

**Side of CDH and CDH Repaired**

If CDH was present select side – Left, Right or Both. For CDH Repaired choose appropriate response – None, Pre-ECLS, On-ECLS or Post-ECLS.
After Patient Data is Entered

Once you hit “Update” you are returned to a screen that shows the patient data and any runs for this patient. From here you can now edit the run information or add a new run. To edit a run hit the “Select” link at the bottom of the screen. To add a new run fill in the information on the right side of the screen in the “Add Run” section.

Run Information

Once you hit “Select” you will see the following. You can change the Run Number by hitting the “Change” link or edit/view the run data by clicking the “Run Details” button.

Run No

Enter the run number for this patient. Normally this will be ‘1’. For those patients who have multiple runs, specify what run is being entered. This is a required field.
After you hit run details you will be able to quickly view/edit your run data. Note that a patient's data will be locked after 90 days of entering the data. You will need to contact the ELSO office if you wish to edit patients entered prior to this.

**Diagnoses**

For the diagnoses fields, enter any valid ICD-9 code or start typing in the diagnoses and the system will display suggestions. The first diagnoses you enter will be listed as the primary diagnoses but this can be changed by clicking on the "Primary Diagnoses" check box after the diagnoses has been added.
Procedures

The procedure fields are for valid CPT codes and also require a date. The date field is used to determine if the procedure was pre-ECLS, on-ECLS or post-ECLS.

Click the arrow button to get to the Organism section.

Infectious Organisms

If an infection was present, enter the organism type, organism name, culture site and the date/time. List as many organisms as needed.
Pre-ECLS Course

Date / Time admitted
Enter the date and time patient was admitted to the center.

Date / Time Intubated
Enter the date and time mechanical ventilation was started.

Current weight (kg)
Enter the patients current weight in kilograms. For neonates, this should be to the nearest hundredth of a kilogram. Examples of a valid weight are 23.5 and 4.67.

Patient Transported:  
Check this box if patient was transported.

Pre-ECLS cardiac arrest:  
Check this box if prior to ECLS the patient had a cardiac arrest. Cardiac arrest is defined as any event(s) that require the use of cardiopulmonary resuscitation (CPR) with the administration of external cardiac massage.

Bridge to transplant:  
If the patient is waiting for transplant check this box.

Pre-ECLS support
Select all Pre-ECLS support that was used. Drop down list has valid entries.
Pre-ECLS Assessment

Pre-ECLS blood gases

**Date/Time:**

Enter the date and time the worst blood gases were drawn in the last 6 hours prior to ECLS.

**pH, PaCO2 (mmHg), PaO2 (mmHg), HCO3 and SaO2(%)**

Enter the worst blood gas values in the last 6 hours prior to ECLS.

Pre-ECLS ventilator settings

**Date/Time:**

Enter the date and time of the worst pre-ECLS ventilator settings in the last 6 hours prior to ECLS.

**Rate/Hz, FiO2(%), PIP/Ampl (mmHg), PEEP (mmHg), MAP**

Enter the worst ventilator settings in the last 6 hours prior to ECLS.

**Hand bagging:**  ☐ (check if yes)

Check if hand bagging was used.

**Vent type:**  ☐ Conventional  ☐ HFO  ☐ Other HFV

Check the appropriate vent type.
Pre-ECLS hemodynamics:

Date/Time: ______

Enter the date and time of the worst pre-ECLS hemodynamics in the last 6 hours prior to ECLS.

BP: - Systolic, Diastolic and Mean; SvO2, PCWP, PAP - Systolic, Diastolic and Mean; CI

Enter the worst pre-ECLS hemodynamics in the last 6 hours prior to ECLS.
**Date/Time on and off ECLS**

Enter the date and time patient was put on and taken off ECLS. This is a required field.

**Reason for support:**  
☐ Pulmonary  
☐ Cardiac  
☐ ECPR

Check one appropriate box for patient category. ECPR denotes Extracorporeal CardioPulmonary Resuscitation, in which ECLS was used as part of the initial resuscitation from cardiac arrest. Patients who are hemodynamically unstable and placed on ECLS emergently without a cardiac arrest are NOT considered ECPR. If you select Cardiac or ECPR, be sure to fill out the additional addendum as well. This is a required field.

**ECLS Mode**

Enter the ECLS mode.
## Cannulations

<table>
<thead>
<tr>
<th>Site</th>
<th>Percutaneous</th>
<th>Manufacturer</th>
<th>Size (Fr)</th>
<th>Length (cm)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Enter the site (RCCA, LCCA, RIJV, RIJVC, LIJV, RFA, LFA, RFV, LFV, RA, LA, PA, Aorta, or Other); if percutaneous, check the box; enter the manufacturer which will contain valid sizes (Fr) and lengths (cm).

## Equipment used:

**Membrane lung, Heat exchanger, Pump and Hemofilter**

Enter the name of the membrane lung, heat exchanger, pump and hemofilter used.

**Pump flow:** Units: □ ml/kg/min □ ml/min □ L/min (Check one)

4<sup>th</sup> hour flow: _________ 24<sup>th</sup> hour: _________

Select the pump flow units and enter the 4<sup>th</sup> and 24<sup>th</sup> hour pump flow.
Enter the best values at 24 on ECLS for the blood gasses, vent setting and hemodynamics.
ECLS Complications

Include all the appropriate complications the patient experienced during the current ECLS run.

A mechanical complication is defined as requiring a change of equipment or an intervention. If equipment is changed due to length of run only, then this is not a complication.

Hemorrhagic complications denotes a transfusion or other intervention.

Pulmonary and Cardiopulmonary complications denotes an intervention was required.

Renal complication definitions

Patients with renal failure will be distinguished by selecting the creatinine 1.5-3.0 and/or Creatinine > 3.0 complications.

Hemodialysis – intermittent hemodialysis (several hours a day) in patients with renal failure.

Hemofiltration – use of continuous ultrafiltration via a hemofilter in the ECLS circuit with or without replacement fluid. Used for fluid or cytokine removal. The SCUF complication has been removed and was combined with hemofiltration.

CAVHD – use of continuous hemofiltration in the ECLS circuit with a dialysis solution concurrent in the system. Wherever the hemofilter is placed in the circuit is considered CAVHD (even if the ECLS circuit is venovenous).
Outcome

Reason for discontinuing ECLS:

If the patient came off ECLS following recovery of organ function, select "Recovery".

If the patient died on ECLS or ECLS was withdrawn, select the one most important reason: Parental or family request, hemorrhage, diagnosis incompatible with life, or irreversible organ failure. If irreversible organ failure, select all that apply from CNS, pulmonary, cardiac, liver, infection and other.

Cannula site repair: None  Carotid artery  Jugular vein  Both  Other

Select the appropriate cannula site repair.

Date / time of final extubation

Enter the date and time of final extubation.

Discharged alive (from ECLS center)

If the patient was discharged home alive from the ECLS center or transferred to another hospital or facility check this box.

Date / time of discharge / transfer

Enter the date and time patient was discharged or transferred.
Discharge location:

Select the appropriate discharge location.

Date / time of death

Enter the date and time patient died. If death, code primary cause of death and contributing causes under Diagnosis and Procedures.

Completed by: and Date completed

Enter your name (the name of the person filling out the form) and date form was filled out.
Cardiac Addendum

If the support type is cardiac after you select a run you will be able to add, edit or delete a cardiac addendum.

Cardiac Diagnosis: Enter the appropriate codes from the ELSO list (1000 series). These are NOT ICD-9 codes. This is a new hierarchical format of diagnosis to ease in data analysis. Use only the 4 digit codes from the right column. You may enter as many codes as are appropriate. The order is not important. All codes used should end in 1-9, but not zero.

Indication for Support: Check the appropriate box to describe why ECMO was required. You may check more than one if appropriate, for example a child with type III TAPVR may not be able to be weaned from CPB because of severe pulmonary hypertension.
**Functional Evaluation, Pathology and Bypass:** In this section, check all the appropriate studies used to obtain the diagnosis that you just coded above. Fill in the Ejection Fraction and/or Shortening Fraction obtained, and the date of the study. If there are multiple studies, pick a representative study that best defined the anatomy or function. Enter the total cardiopulmonary bypass time, the total cross-clamp time, and the circulatory arrest time, if used.

**Cardiac Procedures:** Fill in the codes for the surgical procedures performed, from the ELSO list (2000 series). These are NOT CPT codes. Like the ELSO diagnosis codes, this is hierarchical. Use only codes from the far right column. As before, all codes used should end in 1-9. Each procedure will also requires an associated date.
**Post-op Evaluation:** This section is designed to gather information from patients who did not have successful complete repair for whatever reason.

Residual Shunt(s): Check if there is documented post-op residual shunts that were attempted to be closed with the surgery. This does not mean intended shunts like BT shunts or single ventricle palliations, but rather leaking VSD patches or missed second VSD’s. Describe the direction, size and how the shunt was discovered and diagnosed.

Fill in information on any post-op valve dysfunction documented after a repair, whether found by cath or echo or both (they may disagree on the amount of leak for example).

Abbreviations: AI=Aortic Insufficiency, MR=Mitral Regurgitation, TR=Tricuspid Regurgitation, PI=Pulmonary Insufficiency, and CAVR=Common Atrioventricular Valve Regurgitation.

Finally, check the site of any residual obstruction after a procedure, whether not completely corrected or created by the procedure, and list the estimated gradient at the obstruction as identified by echo and/or cath.

Abbreviations: AS=Aortic Stenosis, MS=Mitral Stenosis, PS=Pulmonary Stenosis, MPA=Main Pulmonary Artery, LPA= Left Pulmonary Artery, RPA=Right Pulmonary Artery, PPS=Peripheral Pulmonic Stenosis, and TS=Tricuspid Stenosis.

**Additional Outcome Information:** Check all boxes that apply.
ECPR Addendum

If the support type is ECPR after you select a run you will be able to add, edit or delete an ECPR addendum.

**ECPR System**: Enter Dry Roller Pump, Pre-Primed Roller Pump, Dry Centrifugal Pump, Pre-Primed Centrifugal Pump or Other.

**Arrest Location**: Enter OR, PICU, NICU, ER, Patient Floor, Hospital Transplant, EMT Transport, Outside Hospital or Other.

**Witnessed Arrest**: Check this box if the arrest was witnessed.

**Patient Required Cardioversion or Defibrillation**: Check this box if the patient required cardioversion or defibrillation.

**Cannulation Location**: Enter OR, ICU, ER, Cath Lab or Other.

**Code Start and Stop Date/Times**: Enter the start and stop date/time of code(s).
Return of spontaneous circulation prior to ECMO: Check if there was a return of spontaneous circulation prior to ECMO. If Yes, then enter the time in minutes to return of spontaneous circulation.

BP and Ph during resuscitation: Enter best and worst values where specified.

Prime: Enter PRBC, PRBC with additives, Whole Blood, Saline/Lacted Ringers, Plasmalyte or Normosol.

HCT prior to ECLS: Enter HCT prior to ECLS along with date/time reported.

1’st HCT on ECLS: Enter first HCT on ECLS.

1’st temp after ECLS: Enter first temperature in Celsius after ECLS initiated.

Intentionally Cooled: Enter Head in ice, Heat Exchanger, Other, Not Cooled.

Hours at various temperatures: Enter the amount of time, in hours, that the patient was at specified temperatures.

Highest temperature in 1’st 72 hours: Enter the highest recorded temperature in 1’st 72 hours.

Heparin Bolus: Enter heparin bolus using U/Kg.

Resuscitation Medications: Enter drug codes for any resuscitation medications used.