St. Jude Children's Research Hospital

Finding cures. Saving children.

ALSAC •DANNY THOMAS, FOUNDER

St. Jude Global SJCARES

Building your local Registry team

Taking **St. Jude** to the World

The mission of St. Jude Global is to improve the survival rates of children with cancer and other catastrophic diseases worldwide through the sharing of knowledge, technology and organizational skills.

https://www.stjude.org/global/sjcares/registry.html

The **S**t. **J**ude Global Childhood **C**ancer **A**nalytics **R**esource and **E**pidemiological **S**urveillance System (SJ**CARES**) is an Integrated Solution to Support Evidence-Based Pediatric Cancer Care Decision Making in Low- and Middle-Income Countries (LMIC).

Build your local SJCARES Registry team

REGISTRY

Minimum requirements to build your team:

- ✓ Must have 1 MD Monitor
- ✓ Must have 1 Data Entry Specialist
- ✓ Minimum number of members per team is 2
- ✓ The person in charge of monitoring the data (i.e. MD Monitor) must be a different person than the person who enters the data (i.e. Data Entry Specialist)

NOTE: Registry User ID and passwords must never be shared with any other team member. Sharing personal credentials is not allowed.

Registry Site Director

- Representative/leader for the Registry at the local institution
- Key leader who takes responsibilities for project initiatives
- Coordinates project team and keeps up with project progress
- Active roles:
  - Signs Registry Rider Agreements
  - Ensures compliance and updates St. Jude´s Registry team of changes in local team

Helpful tips:

- ✓ The Registry Site Director may or may not serve other functions within the team. For example: a Registry Site Director may also act as an MD monitor, but this is **not** a requirement for the role.
- ✓ There is **only one** Registry Site Director per site.

REGISTRY

REGISTRY SITE DIRECTOR

MD MONITOR

- Responsible for REVIEWING the data entered in the system by the Data Entry Specialist

- This person will ensure data quality by discovering inconsistencies and other anomalies in the data and will improve overall data quality through monitoring

- Credentials:
  - ✓ This person MUST be a physician (i.e. Pediatric Oncologist, Pediatrician or other certified physician)
  - ✓ Highly experienced cancer registrars

Helpful tips:

- ✓ MD monitor may or may not be the Registry Site Director. This is not a requirement for this role.
- ✓ This person has **limited access to the database**. Access is granted for querying and monitoring the data already entered into the Registry or system.
- ✓ There can be multiple MD monitors per institution.

DATA ENTRY SPECIALIST

- Data Coordinator or Data Manager

- Responsible for all pediatric cancer patient data entry at the site

- Credentials:
  - ✓ This person may have a medical background (MD/RN), but this is NOT a requirement for this role

Helpful tips:

- ✓ The data entry specialist should be able to access information from different locations and enter it in the Registry forms.
- ✓ This person has **full access to the database** to enter and/or modify patient data and address data queries in the system.
- ✓ There can be multiple Data Entry Specialists per institution.

If you have any questions about the
SJ**CARES** Registry, please contact:
registry@stjude.org

https://www.stjude.org/global/sjcares/registry.html

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Global Pediatric
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