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MCH Innovations Database Practice Summary & Implementation Guidance

Health Emergency Ready Oregon (HERO) Kids Registry

The HERO Kids Registry is the first-of-its-kind statewide registry to address emergency medical information gaps.



Location

Oregon



Topic Area

Service
Coordination/Integration



Setting

Clinical, Pre-hospital,
Community, Rural and Urban



Population Focus

Child Health, CYSHCN, Cross-
cutting/Systems Building



NPM

NPM 11: Medical Home



Date Added

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Section 1: Practice Summary

PRACTICE DESCRIPTION

Pediatric health emergencies can happen anywhere and at any time. They may occur at school, daycare, respite care, or while spending time with friends. There are 879,800 children 0 through 18 years old that live in Oregon (Kaiser Family Foundation, 2021). In 2021, 16,247 children in this age group experienced a medical emergency requiring a call to Emergency Medical Services (Oregon Health Authority, 2022). Parents or caregivers may not always be on-scene when 9-1-1 is called, and school staff, daycare providers, and peers may not know critical health information or know how to answer emergency medical providers' questions. In addition, distraught parents or caregivers may not be able to provide the necessary information to emergency medical services (EMS) and emergency department (ED) providers. For example, parents have told us:

“I want to save as much time as possible for his treatment. (I want them to) focus on emergency, instead of sitting with me to get background information.” - Parent A, HERO Kids Listening Session 2020
“I want them to know that he is very afraid of needles and not able to follow directions the way they might like.” - Parent B, HERO Kids Listening Session 2020

Almost half (49%) of surveyed families of Oregon children with developmental disabilities reported that crisis or emergency services were not provided when needed during the past year (National Core Indicators [NCI], 2020). A similar percentage of families (47%) reported that they did not discuss how to handle emergencies (such as a medical emergency or a natural disaster) at their child's last service planning meeting (NCI, 2020). Almost a quarter (23%) of Oregon families of children with intellectual or development disabilities did not feel prepared to handle the needs of their child in an emergency such as a medical emergency or a natural disaster (NCI, 2020).

Pediatric emergencies are very different than those involving adult patients and can be traumatic for both the patient and family, and for EMS and ED providers. In addition, pediatric emergency calls are not as frequent as calls for adults, and the emergency often is more acute (Oregon Health Authority representative, personal email communication, March 31, 2021). During pediatric calls, EMS providers must treat the patient and communicate with their parent or other adult(s) present on-scene (Oregon Health Authority representative, personal email communication, March 31, 2021). The adults on-scene may be calm or they may be emotionally charged, increasing the emergency's complexity. Further, the psychological impacts of caring for children in emergency situations can be significant, and responders may be traumatized by the injury or death of a child (Oregon Health Authority representative, personal email communication, March 31, 2021).

The HERO Kids Registry is the first-of-its-kind statewide registry to address emergency medical information gaps. The goals are to: (a) provide key information to EMS and ED providers in the first few moments of care, ensuring they have necessary information to care for the pediatric patient; and (b) provide families with a reliable statewide system for health emergency preparedness.

Oregon Center for Children and Youth with Special Health Needs' (OCCYSHN) Family Involvement Program (FIP) Manager serves as the Family Representative to the Oregon Emergency Medical Services for Children (EMSC) Advisory Committee. In 2018, the FIP Manager led a collaboration between families of CYSHCN, EMSC, and EMS and ED providers that developed an eight-page toolkit for families, Planning for a Health Emergency. The toolkit was introduced at the August 2019 national EMSC Grantee Meeting and has since been disseminated in English and Spanish to families throughout Oregon. It is available to families at events, online, and from case managers and public health nurses. The toolkit and trainings have raised awareness about emergency preparation among Oregon families.



It was at the same 2019 EMSC Grantee Meeting that the FIP Manager and the EMSC Program Manager learned about the STARS (Special Needs Tracking & Awareness Response System), and generated interest in developing a similar program in Oregon. In late 2019, the FIP Manager, EMSC Program Manager, and the OCCYSHN Program Administrator met to discuss the possibility of an Oregon program, which was quickly named the HERO Kids Registry. What followed was a series of Listening Sessions, Business Plan meetings, and requesting letters of support. HERO Kids builds on the early family emergency planning efforts, and the vision for the Registry is that it will replace the need for most paper-based documents and other patchwork approaches to emergency care.

In 2020, OCCYSHN received a grant from the EMSC Innovation and Improvement Center (EIIC) to participate in a learning collaborative aimed at addressing telehealth capacity and improving access to emergency pediatric services (National Emergency Medical Services for Children Centers Demonstration U01MC37471). As part of that grant, OCCYSHN convened a 15-member advisory team of experts. The team consisted of youth and family members, emergency department personnel, EMS providers, pediatricians, and community representatives who work within pediatric disability or emergency systems. Members of the advisory team expressed interest in continuing to volunteer with HERO Kids development after the June 2021 conclusion of the EIIC learning collaborative.

In late 2020, OCCYSHN began a vendor search for the buildout of the HERO Kids Registry. Early in 2021, a technology vendor was selected, and the team started to identify data elements that became the HERO Kids registration form. Input was solicited from families, youth, and EMS and ED professionals in Oregon and nationally. System architecture and data elements were ready for beta testing in the Summer/Fall 2021. The HERO Kids Registry launched in the Fall 2022.

HERO Kids Registry was modeled after Oregon's Portable Orders for Life-Sustaining Treatment (POLST) Registry. The Oregon POLST Registry (OPR) has operated successfully since 2009 and is well known amongst EMS and ED providers. The OPR infrastructure, EMS/ED access model, and business operations set the foundation for HERO Kids which made it easier to implement the HERO Kids Registry

CORE COMPONENTS & PRACTICE ACTIVITIES

The goals are to: (a) provide key information to EMS and ED providers in the first few moments of care, ensuring they have necessary information to care for the pediatric patient; and (b) provide families with a reliable statewide system for health emergency preparedness.

The core components of this program include:

Education – Introducing the Registry to Oregon's 325 transport and non-transport EMS agencies and approximately 12,000 EMS providers, as well as the ED personnel at Oregon's 62 hospitals. Leveraging the Oregon Family-to-Family Health Information Center (OR F2F HIC) to reach families and young adults, with additional outreach to other stakeholder groups. Training sessions are tracked and categorized.

Registry Platform Build – Development of an interoperable registry that is both scalable and replicable.

Registry Operations – Enrollments and records management of children and young adults into the HERO Kids Registry system.



Core Components & Practice Activities

| Core Component | Activities | Operational Details |
|---------------------|---|--|
| Education | In-person trainings Virtual trainings Conference tables Community outreach events Conference presentations Mailings | Provide educational presentations and materials to families, young adults, EMS and ED providers, and other stakeholders through virtual and in-person sessions, as well as recorded presentations, social media, and press releases. Education materials are available in 8 languages. |
| Registry operations | Enrollment records management Interoperability communication with registrants HERO Kids business office HERO Kids provider hotline | Manage incoming registrations, database, welcome packets and reminder letters, interoperability connections, business office, and EMS/ED provider hotline. |

HEALTH EQUITY

A commitment to health equity is a central tenet that drives OCCYSHN’s work. Children and young adults from marginalized and minoritized communities experience disparate health outcomes due to systemic and structural inequities. Through input from exactly the families and young adults who we anticipated we might serve; the HERO Kids team strove to mitigate some of those disparities. The HERO Kids team worked with family advisors to develop the Registry, with a concerted effort to be as inclusive as possible while still aligning most data points with national standards. For example, the gender fields align with recommendations from Basic Rights Oregon, and the race and language fields align with Oregon’s Race, Ethnicity, Language, and Disability (REALD) data standards. As of this writing, HERO Kids Registry educational materials for families and young adults are available in eight languages and the library of translations will continue to grow based on community need and requests. Culturally-specific trainings have been provided to community-based organizations that serve refugee, Latino/Hispanic, and Asian families.

EVIDENCE OF EFFECTIVENESS

HERO Kids Registry’s evaluation plan includes multiple methods:

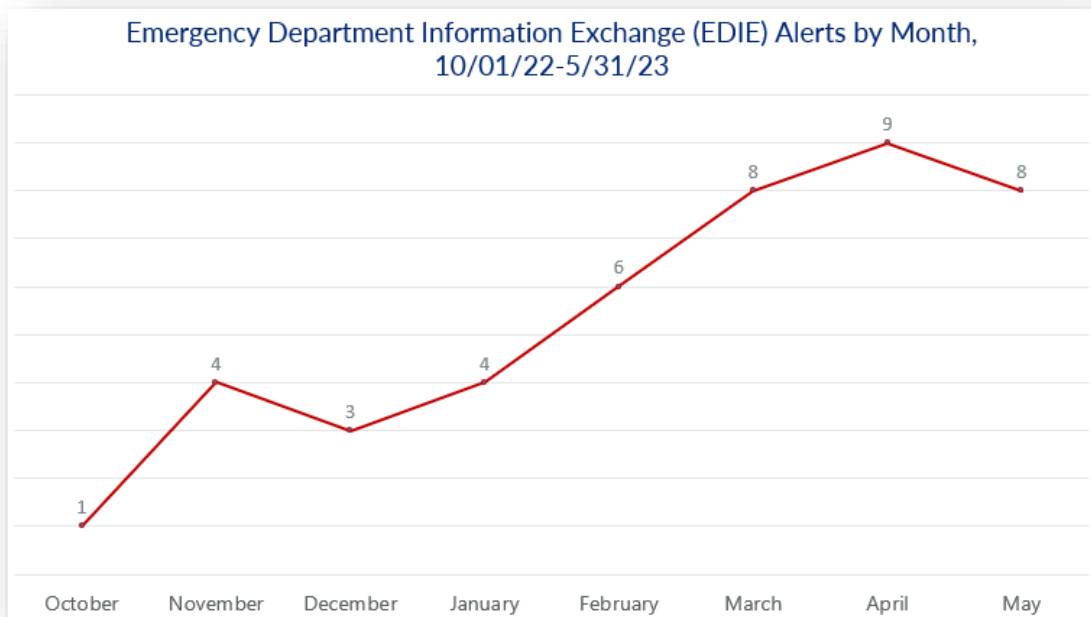
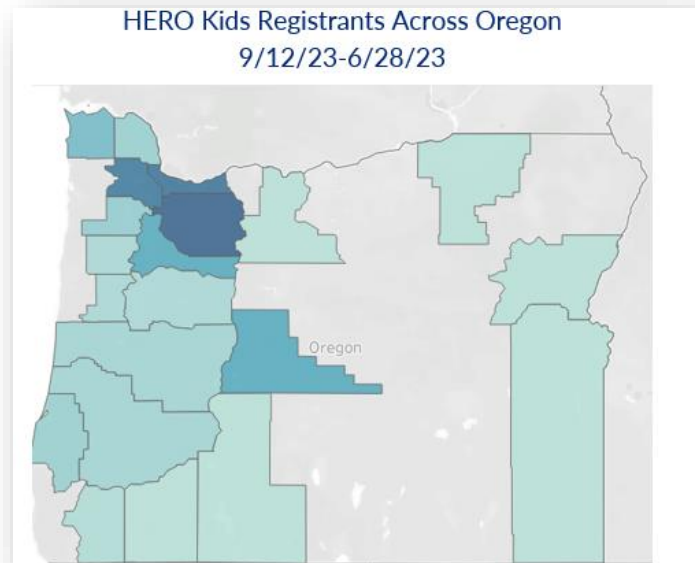
- Quantitative: Monthly and annual data reports are produced showing, but not limited to, registration numbers, Registry usage, and county distribution over time. Data is aggregate and deidentified.
- Post-training assessments: HERO Kids Registry periodically conducts post-training surveys to assess the quality of educational materials.



- Testimonials: HERO Kids Registry will collect and share the experiences of families and young adults who register with HERO Kids and of EMS and ED providers who use HERO Kids information in emergency medical care.

The outcomes currently measured are registration and utilization numbers; specifically, how many children and young adults are registering each month, the county in which they reside, and utilization of the Registry by EMS and ED providers. By measuring registration by county, impacts related to inequities caused by geography (rural vs. urban) can be visualized.

Between, October 2022 and June 2023, the HERO Kids Registry received registrations from 21 of the 36 Oregon counties, which includes coastal, frontier, rural, and urban areas of the state. Since the launch, the Registry has generated 43 Emergency Department Information Exchange (EDIE) notifications, meaning that Emergency Departments received an alert that critical health information was available for the patient in the HERO Kids Registry.



Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

| Practice Collaborators and Partners | | | |
|-------------------------------------|---|--|--|
| Partner/ Collaborator | How are they involved in decision-making throughout practice processes? | How are you partnering with this group? | Does this stakeholder have lived experience/come from a community impacted by the practice? |
| Family and youth representatives | Families and young adults are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, a requirement of the F2F grant is to be staffed by those with lived experience. |
| F2F | F2F plays a key role in HERO Kids Registry operations and leadership. | Serve on HERO Kids Registry leadership team. | Yes, a requirement of the F2F grant is to be staffed by those with lived experience. |
| EMSC | EMSC plays a key role in HERO Kids Registry operations and leadership. | EMSC Program Manager serves on HERO Kids Registry leadership team. The EMSC Advisory Committee provides input at quarterly meetings. | Yes, EMSC serves the emergency medical needs of all Oregon children. |
| EMS and ED Providers | EMS and ED providers are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, EMS and ED providers are the primary utilizers of the program. |



| | | | |
|---|--|--|---|
| Oregon Department of Education | Oregon Department of Education (ODE) staff are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, ODE serves all school aged children in Oregon and oversees all health services provided to CYSHCN. |
| Care Coordinators | Care Coordinators are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, Care Coordinators serve Oregon's medically and behaviorally complex children and young adults. |
| Mental/behavioral health | Mental/behavioral health providers are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, serves Oregon's children and young adults who experience mental or behavioral health conditions. |
| Primary care and specialty care providers | Primary care and specialty care providers are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, serves Oregon's children and young adults. |
| Other Stakeholders | Stakeholders are invited to participate in HERO Kids Registry development, educational materials creation, and ongoing operations. | Listening sessions, workgroups, and advisory committees that meet on an as-needed basis. | Yes, interested in and supportive of the needs of Oregon's children and young adults. |

REPLICATION

This practice has not yet been replicated in any other locations. However, the HERO Kids Registry platform was designed with replication in mind. It can be easily adapted to any state's unique needs. Data fields within the system are primarily based on national EMS information system (NEMSIS) data standards for EMS patient care reporting.



INTERNAL CAPACITY

OCCYSHN is Oregon's Title V Public Health Agency dedicated to CYSHCN. OCCYSHN improves the health, development, and well-being of Oregon's children and youth with special health care needs (CYSHCN). OCCYSHN provides subject matter expertise, data, and provider and family perspective to policymakers and administrators, local public health agencies and other stakeholders. OCCYSHN's work is shaped by the MCHB's Standards for Systems of Care for CYSHCN, the Title V block grant's priorities for CYSHCN, Oregon's health care transformation efforts, and the contract with Oregon Health Authority's Maternal and Child Health Unit. Partnerships with families, community-based providers, Oregon Health & Science University (OHSU) Institute for Development & Disability, and policymakers are foundational to addressing the needs of Oregon CYSHCN and their families. OCCYSHN is located at OHSU and housed within the Institute for Development and Disability.

OCCYSHN has strong partnerships that enable the development of the HERO Kids Registry, including the Oregon Health Authority's Emergency Medical Services for Children (EMSC) program, the Oregon POLST Registry, and Oregon Family-to-Family Health Information Center (ORF2FHIC) for the HERO Kids Registry work. The Oregon EMSC Program works to strengthen EMS systems through education, training, and equipment, in an effort to reduce child and youth mortality and morbidity resulting from severe illness or trauma. The Oregon POLST Registry has been in statewide operations since 2009 and is the sole expert in the development and operation of a registry of this type. Our partnership with ORF2FHIC ensures that the family voice is present through all stages of development and operations.

Key program staff at the HERO Kids Registry include:

- **Tamara Bakewell, MA - Family Involvement Manager, HRSA Emerging Issues Grant**
 - Ms. Bakewell has worked in the field of family support and advocacy since 1990, following the birth of her oldest child who experienced special health needs. As OCCYSHN's Family Involvement Manager, she serves as the Director of the Family-to-Family Health Information Center, and provides technical assistance to Title V related to family experiences and leadership.
- **Rachel Ford, MPH - Oregon EMSC Program Manager**
 - Rachel is the Emergency Medical Services for Children Program Manager for the Oregon Health Authority. Rachel earned her bachelor's degree in Psychology and Business Administration from University of Oregon and her master's degree in Public Health Management and Policy from Portland State University. Rachel has 12 years of public health experience, including tribal public health, hospital system accreditation and compliance, hospital and clinic project management, and state government service.
- **Brittany Tagliaferro Lucas, BS - HERO Kids Registry Program Manager**
 - Brittany is the Program Administrator for the Oregon Center for Children and Youth with Special Health Needs and HERO Kids Registry Project Manager. Brittany has 13 years of experience managing statewide programs and registries. She was a founding member of the Oregon Portable Orders for Life Sustaining Treatment (POLST) Registry and remains active in the POLST community as a consultant to the Oregon POLST Coalition and its education and technology subcommittees.

PRACTICE TIMELINE

The following table offers a recommended timeline for developing the core components of the HERO Kids Registry. Responsible parties include the Oregon Emergency Medical Services for Children (EMSC), Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), Oregon Family-to-Family Health Information Center (ORF2FD), Technology Vendor (TV).



Phase: Planning/Pre-Implementation

| Activity Description | Time Needed | Responsible Party |
|--|-------------------|---------------------------|
| Develop an internal business plan | 4 months | EMSC, OCCYSHN, ORF2FD |
| Conduct listening sessions: Families and youth EMS and emergency department providers Primary care and other stakeholders | 2 months | EMSC, OCCYSHN, ORF2FD |
| Solicit letters of support | 2 months | EMSC, OCCYSHN, ORF2FD |
| Contract and begin platform development and debugging | 12-18 months | EMSC, OCCYSHN, ORF2FD, TV |
| Establish MOU for business office operations and call center | 3-6 months | OCCYSHN |
| Contract and begin EMS App development and debugging (if desired) | 6-12 months | EMSC, OCCYSHN, ORF2FD, TV |
| Contract and begin interoperability development for connections with emergency department information exchange (if desired) | 12-18 months | OCCYSHN, TV |
| Develop educational materials | 6 months; ongoing | EMSC, OCCYSHN, ORF2FD |
| Facilitate educational materials workgroups | 3 months | EMSC, OCCYSHN, ORF2FD |
| Assemble advisory committee | 1 month; ongoing | EMSC, OCCYSHN, ORF2FD |



| | | |
|--|----------|---------|
| Develop and launch public facing educational website | 2 months | OCCYSHN |
|--|----------|---------|

Phase: Implementation

| Activity Description | Time Needed | Responsible Party |
|---|------------------|-----------------------|
| Launch registration site | 1 day | TV |
| Launch EMS and ED access to registry | 1 day | OCCYSHN |
| Marketing: promote on social media | Daily; ongoing | OCCYSHN |
| Marketing: print and local news | As able; ongoing | EMSC; OCCYSHN, ORF2FD |
| Marketing: presentations to families, young adults, EMS, emergency departments, primary care and other stakeholders | Monthly; ongoing | EMSC; OCCYSHN, ORF2FD |

Phase: Sustainability

| Activity Description | Time Needed | Responsible Party |
|----------------------|-------------|-------------------|
| Conduct QA and QI | Ongoing | OCCYSHN |



| | | |
|---|------------------|-----------------------|
| Internal team meetings: collaborate to review key metrics and refine strategies | Monthly; ongoing | EMSC, OCCYSHN, ORF2FD |
| Collaborate with advisory committee to solve any operational issues, review new materials, and provide consultation on ongoing marketing and outreach efforts | Ad hoc; ongoing | EMSC, OCCYSHN, ORF2FD |
| Ongoing marketing to families, young adults, EMS, emergency departments, primary care and other stakeholders | Ongoing | EMSC, OCCYSHN, ORF2FD |

PRACTICE COST

Practice startup costs will vary depending on population size, geography, and implementation options chosen. For more information on this practice startup costs and budgets, please contact Brittany Tagliaferro-Lucas directly at herokids@ohsu.edu.

LESSONS LEARNED

Some of our lessons learned through the implementation of this practice include:

- 1) Build relationships with the F2F and EMSC in your state or U.S. territory, as both operate under HRSA performance measures.
- 2) Include and compensate families and youth with diverse experiences and give them ample time to contribute.
- 3) Include stakeholders early in the process. This allows you to have the necessary expertise, suggestions, and ideas at the outset. This not only saves time but also builds solid partnerships with stakeholders who are invested in the program and able to identify gaps and co-create.
- 4) Children and youth in the foster care system face barriers in registering. This requires strong systems relationships to brainstorm how to overcome barriers. Build in time to understand the needs of the child welfare system and their perspectives on a registry.
- 5) Leverage existing infrastructure. Identify and explore similar programs or registries within your state or U.S. territory. You may be able to leverage work to reduce time and cost.
- 6) Education is ongoing and foundational to successful implementation. Education is not a one and done effort. It is ongoing. HERO Kids continues to modify and refine education materials, to be responsive to stakeholder suggestions and to provide additional translations.



The greatest challenge has been communication and getting the word out to those who need to know about HERO Kids. Oregon is a large, mostly rural state and this creates a challenge when it comes to education. The HERO Kids Registry leadership team has employed multiple strategies to overcome this; including presenting virtually, recorded presentations posted online, and as funding allowed through direct, in-person team outreach. The HERO Kids Registry leadership team has also employed social media strategies to connect with youth and families.

NEXT STEPS

The HERO Kids Registry is operational statewide in Oregon. The Registry will continue to serve children and young adults through age 26. If able to secure permanent funding through legislation, the HERO Kids Registry leadership team has discussed expanding the Registry to all ages, as well as expanding the use of the Registry as a disaster preparedness tool. In addition, the HERO Kids team will be convening a workgroup of families and health care providers to explore development of an electronic Emergency Protocol Letter template.

Future improvements will include updates to the HERO Kids Registry user interface and functionality. Areas for improvement will be identified through feedback from Registry users and advisory committee members.

RESOURCES PROVIDED

- See Program Resources attached on Innovation Hub site for the following:
 - HERO Kids Registration Guide
 - HERO Kids Registry Form Example (completed online)
 - HERO Kids Registry Paper Registration Form

APPENDIX

- See Program Appendix attached on Innovation Hub site for the following:
 - HERO Kids Registry Information for Families and Young Adults
 - HERO Kids Registry Information for EMS
 - HERO Kids Registry Information for Emergency Departments
 - HERO Kids Registry Information for Primary Care and Other Professionals

