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MCH Innovations Database Practice Summary & Implementation Guidance

Medical Home Portal

The Medical Home Portal is a web-based resource that supports professionals and families in working together to care and advocate for children and youth with special health care needs by providing reliable, practical, and evidence-based information, and local and national services and resources.



Location



Topic Area



Setting

Online

Care Coordination

Community, Clinical



Population Focus



NPM



Date Added

CYSHCN

NPM 11: Medical Home

April 2023

Contact Information

Medical Home Portal, www.medicalhomeportal.org, info@medicalhomeportal.org

Section 1: Practice Summary

PRACTICE DESCRIPTION

The Medical Home Portal aims to assist families and professionals in working together to better care for children and youth with special health care needs by providing reliable and useful information about their conditions and needed care, services, and resources.

The MHP has been in existence for over 20 years and was developed based on the premise that pediatricians could improve their care of children and with chronic conditions through:

- Better knowledge of local resources for their care
- Practice-based care coordinators to link families and resources, and
- Best practice guidelines for common chronic conditions in children.

Efforts to address these needs started as a resource booklet, but much of the information became outdated soon after publishing. In 2006, a web-based information resource was designed and launched of the first iteration of what was then called the MedHome Portal. In February 2015, the MHP unveiled a completely redesigned site aimed to make its content easier to read and navigate on any device and to make its resources easier to find. In April 2023, the MHP again went through an extensive redesign process to make the site more up-to-date and user friendly.

CORE COMPONENTS & PRACTICE ACTIVITIES

Medical Home Portal content is written for a US-wide audience, with the ability to customize information within content sections and provide a state-specific services directory.

As of September 2022, current offerings of the MHP include:

- 60 clinical diagnosis and management modules addressing the comprehensive primary care of various conditions, many of which are uncommon.
- 44 newborn disorder pages providing guidance on the immediate steps a pediatric clinician should consider after being notified of an abnormal newborn screen for a patient.
- 136 additional clinical care topics and issues, such as common concerns, feeding and nutrition, guidelines and algorithms, and screening and prevention.
- 124 pages to help families care for their child and adolescent with special health care needs
- More than 6,200 links to other reliable websites or downloadable information and 5,500 citations to scientific and medical literature with the evidence behind recommendations or to explore topics in greater depth.
- Services Directories for CYSHCN and their families for National providers and additional directories specific to Nevada, New Mexico, Rhode Island, and Utah.



Core Components & Practice Activities

Core Component	Activities	Operational Details
Content for those who care for children and youth with special health care needs (parents, care givers, the child or youth themselves, primary care clinicians, care coordinators, school nurses, educators, other professional on the care team)	<p>Management of new and updated website content on the following topics and for the following audiences:</p> <ul style="list-style-type: none"> • Diagnoses & Conditions • Newborn Screening • For Professionals • For Families 	<p>Content is original, updated regularly, and written by volunteer physician experts, staff physician authors and editors, authors with expertise in the subject, and parent representatives with lived experience. All content is evaluated for quality, structure, readability, appropriate language level, and conciseness. Clinical content also includes evaluation by a physician editor and input from a peer reviewer. Author(s) and editorial staff endeavor to perform a comprehensive update of content every 2-3 years.</p>
Resource Links	<p>Vetting of and adding external links for quality, usefulness. Regular checking that the URL is valid.</p> <p>Adding internal links that have been found to be valuable, such as checklists, questionnaires, growth charts, and other clinical tools.</p> <p>Adding citations to support the content as evidence-based, and other helpful articles.</p>	<p>The Medical Home Portal has over 6200 resource links. A weekly report is run to identify broken links so these can be fixed, removed, or replaced.</p>
Editorial Board	<p>An Editorial Board is involved in directing the website at a high level with approximately 20 members from different states and professional backgrounds.</p>	<p>Board members commit to a one-year of four to six one-hour board meetings.</p>
State-specific Domains and Services Directories	<p>Organizations partnering with the MHP get a sub-domain for their state's custom content, resource links and local service providers' directory.</p>	<p>States can add custom sections and/or resource links to content pages that only show for their specific domain.</p> <p>Each state is given a unique Medical Home Portal URL (e.g., ut.medicalhomeportal.org)</p> <p>Services Directory categorization options are based on AIRS 211 Taxonomy.</p>



Accounts and Custom Lists	MHP users can make a free account with an email address and a password of their choosing. This enables them to make and save custom lists of service providers and provides the MHP with basic demographics on who is using the Portal. (Registration is not required to use the site.)	Lists can be shared, copied, and modified.
Analytics	MHP uses Google Analytics for reporting and evaluation.	<p>State partners are provided with Quarterly Reports, which include the following:</p> <ul style="list-style-type: none"> • Website analytics for the quarter, with comparisons to previous quarter and previous year for Users, Sessions, and Pageviews. • Descriptions of updated features and major projects • Links to updated and new content
Marketing	<p>MHP provides: Sample presentation slides, flier templates, and swag ideas.</p> <p>Ongoing and regular optimization of the site for Google and other search engines.</p>	

HEALTH EQUITY

Recent data suggests that there are inequities to access in quality health care for first generation and lower income by children and youth with special health care needs (CYSHCN).¹ The Medical Home Portal helps improve health equity among CYSHCN by being available free of charge, online 24/7 via an internet connection and/or mobile phone. The website is mobile responsive and uses Google Translate, providing instant translation on the site into 108 languages.

EVIDENCE OF EFFECTIVENESS

The Medical Home Portal had a total of 531,500 visits in 2022 and growth of users to the site has increase by 61% since 2019. The top 10 Medical Home Portal pages visited in 2022 include:

- [Mental Health Screening for Children & Teens](#)
- [Coding for Developmental & Mental Health Screening](#)
- [Apps to Help Kids and Teens with Anxiety](#)



- [Intellectual Disability & Global Developmental Delay](#)
- [Screening for Eating Disorders](#)
- [Sickle Cell Disease](#)
- [Wheelchairs and Adaptive Strollers](#)
- [Childhood Obesity Screening and Prevention](#)
- [Foster Care of Children with Special Needs](#)
- [POTS](#)

The Medical Home Portal is supported by G4 Google Analytics and captures information daily on website utility. We have created custom reports for each state partner based on their reporting needs and requests. Analytic reports are distributed on a monthly basis and include information about overall user acquisition and demographics, a list of top 10 pages viewed, and information to track outbound links (some states use this measure to see how frequently referral agencies are connected to from the MHP site). Quarterly reports include number of users, pageviews and sessions as well as comparisons (with percent changes) to previous quarter and same reporting period of the previous year. The quarterly reports all include a narrative section, which describes what content and features were updated in the previous quarter.

With assistance from the MHP team, some state partners have designed their own quantitative evaluation plans. Examples of these include surveys posted to the website banner space and direct mailings to user accounts curated through the MHP site.

As mentioned above, our outcome measures are largely qualitative (users, sessions, pageviews, etc.). We show effectiveness of the website through gains in use/viewership over time, testimonials stories gathered and user feedback. The Medical Home Portal is powered by Google Translate and the content can be instantly translated into a wide variety of languages. We also put the website through an accessibility audit on a regular basis to ensure that the content is available to all.

We provide monthly analytics to the states and they in turn track their own trends and findings and those interested should contact our state partners to learn more about their summary of findings. For the website as a whole, we have the following statistics:

- In 2023 we had 537,894 website views, resulting in a more than 9% increase compared to our viewership in 2021.
- The top five countries represented by our viewership include USA (82%), India (2%), UK (2%), China (2%), and Canada (2%).

The top five topic pages visited include:

- Mental Health Screening for Children & Teens
- Tapering Antiepileptic Medication
- Intellectual Disability & Global Developmental Delay
- Coding for Developmental & Mental Health Screening
- Wheelchairs & Adapted Strollers



Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

The Medical Home Portal is a project of the Department of Pediatrics at the University of Utah Health. Since its inception in 2001, funding for the Portal has come from foundations, grants, contracts, and gifts from many organizations, none of which involve any commercial stipulations or expectations. The backbone of the Portal comes from in-kind, collaborative, and moral support from many individuals and organizations. Current key collaborators of the project and their contributions are detailed below.

Practice Collaborators and Partners		
Partner/ Collaborator	How are they involved in decision-making throughout practice processes?	Does this stakeholder have lived experience/come from a community impacted by the practice?
University of Utah Health	The Division of General Pediatrics, Department of Pediatrics, University of Utah Health is the Portal's administrative and academic home. Many of the volunteer physician experts and staff physician authors also come from this agency.	Yes
oxygen XML Editor	Through their Support Life License Donations program, Syncro Soft SRL provides the Medical Home Portal with use of oxygen XML Editor.	No
Utah Family Voices	Content in the For Parents and Families section is authored or reviewed by parents of children or youth with special healthcare needs, primarily our Family Consultants from Utah Family Voices.	Yes



Utah Parent Center	The Utah Parent Center partners with us, assisting in identifying and categorizing valuable services and other resources for children and families.	Yes
Utah Department of Health and Human Services	The Utah Department of Health and Human Services provides funding and collaboration to develop the Utah Medical Home Portal and maintain its directory of local service providers for children and youth with special health care needs and their families.	Yes
Utah 2-1-1	Utah 2-1-1, a program of United Way of Salt Lake, is a key collaborator, sharing their robust database of human services relevant to children and families.	Yes
Nevada Department of Health and Human Services	The Nevada Division of Public and Behavioral Health, Nevada Title V Maternal and Child Health Program provides funding and collaboration to develop the Nevada Medical Home Portal and maintain its directory of local service providers for children and youth with special health care needs and their families.	Yes
Rhode Island Department of Health	The Rhode Island Title V/Maternal and Child Health Program provides funding and collaboration to develop the Rhode Island Medical Home Portal and to maintain its directory of local service providers for children and youth with special health care needs and their families.	Yes
New Mexico Department of Health and University of New Mexico Center for	The Children's Medical Services/Children with Special Needs, New Mexico Department of Health	Yes



Development and Disability	and the University of New Mexico Center for Development and Disability collaborate to provide information about local service providers for children and youth with special health care needs and their families for the New Mexico Medical Home Portal.	
Mountain States Regional Genetics Network	Mountain States Regional Genetics Network (MSRGN) offers collaboration with and promotion of the Portal to enhance its use among MSGRN member states and across the Regional Genetics Networks.	Yes

REPLICATION

Originally developed in and for Utah, the Medical Home Portal was reprogrammed between 2005 and 2008 with support from a National Library of Medicine grant (1 G08 LM007680-01A2) to enable partnering with other states and regions to include their local service provider information. This model has now been replicated several times and our current state partners are Nevada, New Mexico, Rhode Island, and Utah.

Each state partner receives a custom URL domain (e.g., nm.medicalhomeportal.org) with state-specific content and individual usage metrics. The MHP site provide a framework for enhancing coordination of care for CYSHCN by care coordinators in primary care practices, insurance companies, and other settings.

INTERNAL CAPACITY

The Portal team includes University faculty and staff. Current team includes:

- Jennifer Goldman, MD, MRP, FAAP - Associate Professor of Pediatrics / Editor-in-Chief and Medical Director of the Medical Home Portal
- Dale-Marie Herring - Managing Editor
- Athena Parker, MPH, CHES - Services Support Manager
- Michelle Redfield - Administrative Assistant

The Medical Home Portal is a service of the University of Utah and exists for educational purposes only. The Medical Home Portal Development Team does not provide information for or about the medical conditions of individual patients.



PRACTICE TIMELINE

States that partner with the Portal can plan for varied timelines based on their own Internal processes.

Phase: Planning/Pre-Implementation		
Activity Description	Time Needed	Responsible Party
Identifying an internal person to support the state's Service Directory.	1-2 months	State Title V program
Identifying a 2-1-1 taxonomy-based data source (optional) and securing any necessary data-sharing agreements.	3-6 months	State Title V program with the assistance of the MHP team
Completing a sole source agreement, MOU, or other required contracting paperwork with the Medical Home Portal.	6-12 months	State Title V program

Phase: Implementation		
Activity Description	Time Needed	Responsible Party
Activating a state specific URL domain of the Medical Home Portal	2 weeks	Medical Home Portal
Participate In training provided by the Medical Home Portal team to learn the back-end functions of the site.	2 weeks	State Title V program



Building a state-specific Service Directory and/or Importing data from an outside source	1-6 months	State Title V program with the assistance of the MHP team
Customizing the site with any state-specific requests	2-5 days per request	State Title V program with the assistance of the MHP team

Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Developing a marketing and outreach plan.	1-3 months	State Title V program with the assistance of the MHP team
Track analytics for the site	Completed quarterly	Medical Home Portal
Continue to import information into the Service directory at regular Intervals.	Varies from monthly to bi-annual based on state preference.	State Title V program with the assistance of the MHP team

PRACTICE COST

The Medical Home Portal is free for individuals to access. However, organizations can partner with the Portal to customize it for their region and make it even more useful for the families they serve.

Costs associated with partnering include:

- State/region’s organizational costs for personnel to coordinate obtaining the local services data, to maintain its accuracy, to work with Portal staff, and to promote use of the Portal by clinicians, families, and organizations in the state/region
- Costs of acquiring data maintained by 2-1-1 or other organizations (this could involve a nominal, or more substantial, charge for periodically downloading the data, in-kind support to assist in obtaining and maintaining the data, partnering in fund raising, etc.)
- Annual partnership fee
- Direct costs related to Portal’s programming, data management, and user support for Partner’s staff, to be billed by the hour or through a negotiated agreement



LESSONS LEARNED

State's that have had the most successful partnerships with the Medical Home Portal include those that have done the following:

- Identify an Internal person that will lead the project.
- Partner with a 2-1-1 taxonomy based data source- this helps lessen Internal staff resources needed for the on-going maintenance of a Services Directory.
- Form an advisory group that can direct priorities of the state-specific MHP site, including reviewing and approving suggestion for customization.
- Develop a comprehensive plan for marketing and outreach of the site once active.
- Partner with local F2FHICs, care coordination groups, and other agencies focused on the care of children and youth with special healthcare needs.

NEXT STEPS

The Medical Home Portal is free for individuals to access. However, organizations can partner with the Portal to customize it for their region and make it even more useful for the families they serve. Contact us for more information on joining as a partner.

Internally, the Medical Home Portal is looking at ways of improving sustainability through possible commercialization. Historically the internal team has been supported through grant funding and those opportunities are less available. Medical Hom Portal is exploring a licensing agreement with Summit Venture Studios to support this work in the future.

RESOURCES PROVIDED

- <https://www.medicalhomeportal.org/link/9122> - MHP AMCHP 2023 poster
- <https://www.medicalhomeportal.org/about-portal/partnering-with-the-portal>

APPENDIX

- Reem M. Ghandour, Ashley H. Hirai, Mary Kay Kenney; Children and Youth With Special Health Care Needs: A Profile. Pediatrics June 2022; 149 (Supplement 7): e2021056150D. 10.1542/peds.2021-056150D

