

REGISTRY OF PATIENT REGISTRIES (ROPR) WEB FORUM GOVERNING BOARD CHARTER

Purpose

The Registry of Patient Registries (RoPR) Web Forum Governing Board (“Governing Board”) will advise and provide recommendations to the Agency for Healthcare Research and Quality (“AHRQ”) to help plan, develop, implement, and refine a web-based collaborative registries forum. The Governing Board will not serve in an official decision-making capacity, but its recommendations and advice will be taken into consideration by AHRQ and RoPR project staff (L&M Policy Research, AcademyHealth, and Quintiles Outcome).

RoPR

In 2009, AHRQ launched the Registry of Patient Registries (RoPR), a web-based repository of information about patient registries that is integrated with ClinicalTrials.gov. The goals of the RoPR are to promote collaboration, reduce redundancy, and improve transparency in registry-based research. The five objectives for the system, identified in consultation with stakeholders, are:

- Δ To provide a **searchable central listing** of patient registries in the U.S. to enable interested parties to identify registries in a particular area (to promote collaboration, reduce redundancy, and improve transparency);
- Δ To encourage and facilitate the use of **common data elements** and definitions in similar conditions (to improve opportunities for sharing, comparing, and linkage) through the listing and searching of such elements;
- Δ To provide a central repository of **searchable summary results** (including results for registries that have not published their findings in peer-reviewed literature);
- Δ To offer researchers a **search tool** to locate existing data (from either ongoing studies or closed studies) to request for use in new studies (secondary analyses, linkage studies);
- Δ To serve as a **recruitment tool** for researchers and patients interested in participating in patientregistries.¹

To continue to fulfill the goals of the RoPR, AHRQ funded a second year, which began in 2014. The four major objectives include:

- Δ Maintaining and promoting the RoPR system;
- Δ Implementing and refining the Outcomes Measures Framework;
- Δ Updating the Registry Handbook; and
 - The Registry Handbook includes information on the creation and operation of registries, as well as technical, legal, and analytical considerations for combining registry data with other data sources

¹ Gliklich RE, Levy D, Karl J, et al. Registry of Patient Registries (RoPR): Project Overview. Agency for Healthcare Research and Quality. Effective Health Care Program Research Report No. 40. May 2012. See http://www.effectivehealthcare.ahrq.gov/ehc/products/311/1114/DEcIDE40_Registry-of-patient-registries_FinalReport_20120531.pdf. Accessed February 18, 2015.

- Developing a web-based collaborative registries forum.

RoPR Web Forum

The objective of the RoPR Web Forum is to facilitate discussion of relevant issues related to registry design and use of registry data among individuals or groups that are currently involved with registries, as well as those interested in creating or using registries. The web forum will:

- Enable networking among interested parties;
- Identify potential areas for collaboration or sharing of resources;
- Assist participants in implementing their registry-related work more efficiently;
- Provide a single, organized location for information sharing and broader discussions on how registries can improve patient care and outcomes; and
- Establish an online Community of Practice (CoP).²

The designated individual from AHRQ tasked with overseeing the Governing Board activities is Elise Berliner, Ph.D., Director, Technology Assessment Program, Center for Outcomes and Evidence at AHRQ. Dr. Berliner will be supported by designated project staff, [removed during peer review period] who will oversee day-to-day activities of the Governing Board.

Role and Scope of Work

The primary role of the Governing Board is to provide guidance to AHRQ and project staff on the necessary functions and operational guidelines required for the web forum. Additional responsibilities include:

- Establishing a Charter (this document) that describes the purpose and scope of the web forum and guides the board's activities;
- Outlining key operational and functional aspects of the web forum. This includes assisting with the development of operational policies and procedures (e.g., compliance with federal regulations, site privacy policy, terms and conditions of use);
- Assessing and recommending a suitable off-the-shelf technology platform;
- Assisting in the promotion of the web forum and identifying resources (e.g., publications, presentations, discussion topics) for inclusion on the web forum;
- Establishing metrics for usability and performance of the web forum; and
- Assisting in the refinement of the web forum over the course of the project. The

Governing Board will be active for the full project period (April 2014-April 2019).

Composition

Membership and engagement in the Governing Board will allow for meaningful interactions amongst individuals with different strengths, backgrounds, and areas of expertise. The

² A "Community of Practice" is defined as a group of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis. Wenger, et al. *Cultivating Communities of Practice*. Harvard Business School Press, 2002.

Governing Board will consist of 12 to 18 members representing a diverse set of perspectives, including:

- Clinician organizations
- Health insurance plans
- Life-sciences industry
- Patients/Consumers
- Policymakers
- Registry developers
- Researchers
- Web-user experience experts
- Related federal agencies (FDA, CMS, etc.)

AHRQ and project staff will identify and select potential members to help establish the web forum. Selection will be based on experience, background, ability to contribute to the scope of work described in this Charter, and a prospective member's commitment to help lead, promote, and encourage use of the forum by individuals in their professional or community networks.

A chairperson (and a co-chairperson, if desired) will be selected by AHRQ to facilitate the Governing Board's activities.

Members of the Governing Board are encouraged to serve for the duration of the current project period (2014-2019). Any member may resign at any time by giving written notice to the chairperson and project staff. Vacancies and additions to the Governing Board will be filled at the discretion of AHRQ.

Meetings

The Governing Board will convene at least twice a year by webinar, with additional communication occurring through email or other means of document sharing. All meetings will have an agenda, which will be made available at least 3 business days prior to the meeting.

A majority of the members of the Governing Board shall constitute a quorum, and a roll call shall be taken at the beginning of each meeting. In accordance with the Governing Board's advisory role, all votes and recommendations are non-binding.

Compensation

Members who are not full-time Federal employees are eligible for honoraria as part of their participation in the Governing Board. All payments will be made to individual panel members and not to employers, organizations, or third parties. Individuals serving on the Governing Board may decline honoraria at their discretion.

Conflict of Interest

The Governing Board, with support from project staff, shall establish a conflict of interest policy (a "Conflict of Interest Policy") that is applicable to all members. Each individual Governing Board member shall disclose all conflicts of interest on an annual basis. In order to assure broad

participation in the Governing Board, the Conflict of Interest Policy shall not prevent employees or representatives of organizations that have direct interests in registry related matters from participating in the Governing Board. Conflict of Interest disclosures will be reviewed by project staff on an annual basis. Any and all issues regarding individual conflicts will be documented and provided to AHRQ staff for resolution.

Annual Review

The Governing Board shall review at least annually the adequacy of this Charter and recommend any proposed changes to AHRQ or its designee.

Termination Date

This Charter will remain in effect until April 15, 2019. It is subject to review, reauthorization, amendment, or termination by AHRQ or its designee.

CONTACT INFORMATION**Elise Berliner, Ph.D.**

Agency for Healthcare Research and Quality
Center for Evidence and Practice Improvement

History:

*Approved by the RoPR Web Forum Governing Board on **Month, Date Year.***

REFERENCES

1. Gliklich RE, Levy D, Karl J, et al. Registry of Patient Registries (RoPR): Project Overview. Agency for Healthcare Research and Quality. Effective Health Care Program Research Report No. 40. May 2012.
http://www.effectivehealthcare.ahrq.gov/ehc/products/311/1114/DEcIDE40_Registry-of-patient-registries_FinalReport_20120531.pdf. Accessed February 18, 2015.
2. A “Community of Practice” is defined as a group of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis. Wenger, et al. Cultivating Communities of Practice. Harvard Business School Press, 2002.