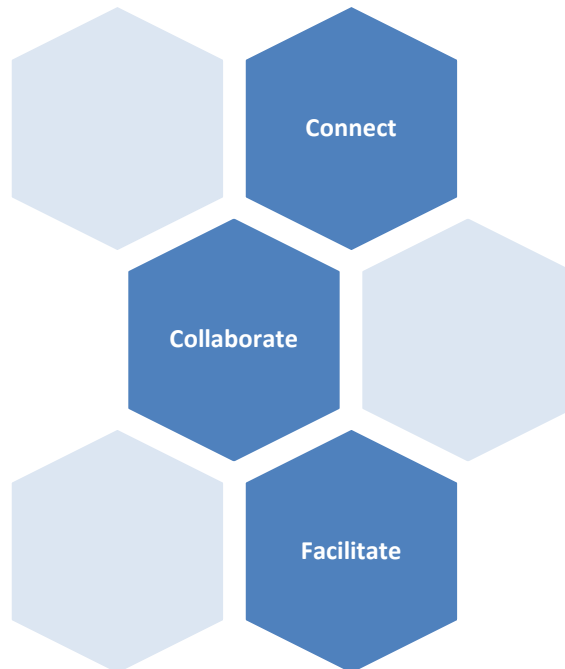


NQRN[®]

National Quality Registry Network

Strategic Plan

2015 – 2017



Credits and Acknowledgements

NQRN 2015 – 2017 Strategic Plan

April 2015



Prepared by the American Medical Association on behalf of the NQRN®

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NQRN Mission

The National Quality Registry Network (NQRN[®]) program aims to promote the increased use and utility of clinical registries to support health care reform and improve patient health outcomes.

Introduction

Clinical data registries record information about the health status of patients and the health care they receive over varying periods of time, and often focus on patients who share a common reason for needing health care. This information can be used to inform patients and their health care professionals as they decide the best course of treatment, and to improve care for patients in the future.

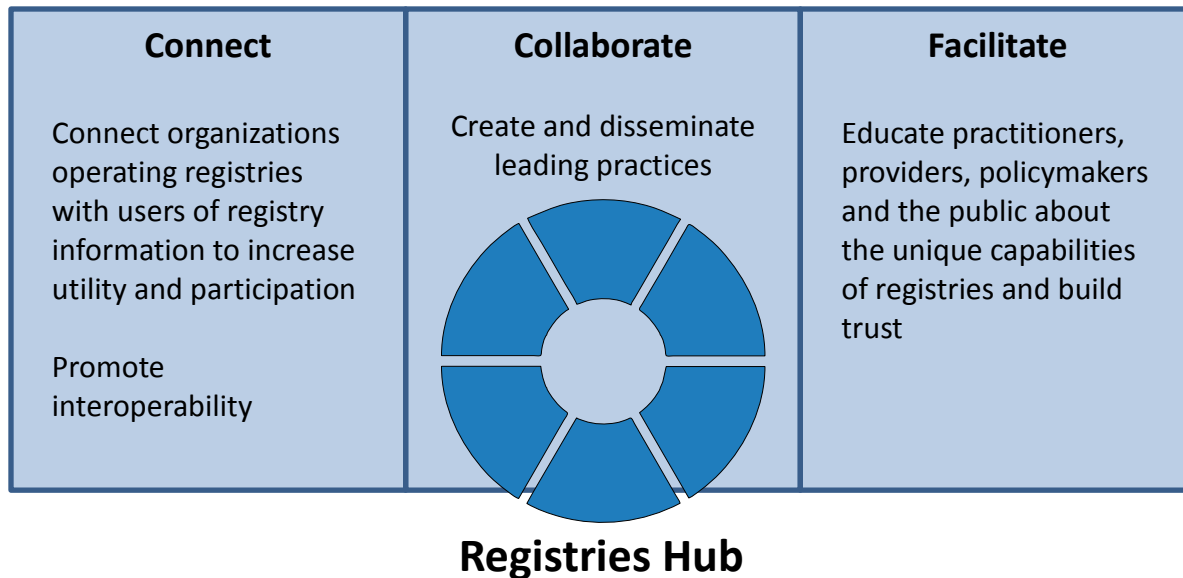
The NQRN is a voluntary network of organizations operating registries and others interested in increasing the usefulness of clinical registries. The NQRN envisions a national health information system created by integrating information from registries with other data sources.

The value proposition of registries

The United States has several hundred national clinical registries across many medical conditions and procedures, with many more around the world. With the expanded use of registries to support value-based purchasing, the need for a national organization to lead and coordinate registry development in the U.S. has increased.

To further understand registries in the US, in 2012 the NQRN conducted an online survey of a subset of AMA-convened Physician Consortium for Performance Improvement[®] (PCPI[®]) members including specialty societies, state medical associations, medical boards and health care provider organizations. The survey results indicated that the most prominent uses of registries are to evaluate variation in care, conduct comparative effectiveness research, identify treatments and procedures that lead to the best outcomes, and aid in developing performance measures and benchmark performance.

Clinical registries play a unique role in our health care information infrastructure as powerful tools for outcomes measurement. They are designed by clinical experts and contain real-world population data that are clinically relevant, structured, precisely-specified, understandable and acceptable to healthcare providers and others. For research, registry data may offer an advantage over traditional randomized clinical trials as rigid study population inclusion and exclusion criteria in the latter may limit the generalizability of their results. Additionally, registry data are collected using standardized electronic methods and include multiple data quality audits to ensure accuracy.



The need for a National Quality Registry Network

The NQRN provides a learning and action forum to exchange leading practices and solve problems to advance registries toward greater capabilities. It seeks to build trust among physicians, other health care professionals, patients and consumers about submitting information to registries and using registries to improve health and health care. By bringing all stakeholders to the table and working toward common needs, the NQRN accelerates the learning curve to advance the registry enterprise.

The NQRN supports multiple stakeholders, including:

Organizations operating or planning registries	Users of information from registries	Organizations providing supporting infrastructure
<ul style="list-style-type: none"> • Physician and health care professional societies • Patient advocacy organizations • Academic research institutions • State governments • Commercial entities • Quality improvement collaboratives 	<ul style="list-style-type: none"> • Hospitals, health systems and clinics • Health plans • Employers • Patients and consumers • Federal and state government 	<ul style="list-style-type: none"> • Registry vendors • Other health IT vendors • Measure & standards developers • Consulting firms

Goals, objectives and priority activities

The NQRN 2015-2017 Strategic Plan describes the NQRN’s strategies to achieve its goals and promote the increased use of information from registries to support health care delivery system reform:

Goal	Objectives
<p>Goal 1: Be a hub for creating and disseminating leading practices to the registry enterprise</p>	<ul style="list-style-type: none"> • Objective A: Provide resources to assist organizations operating, planning or using information from registries • Objective B: Understand how well NQRN is meeting participants’ information needs • Objective C: Provide opportunities for NQRN participants to network, create and share leading practices
<p>Goal 2: Encourage active participation in registries by physicians, health care professionals, hospitals, health systems and patients</p>	<ul style="list-style-type: none"> • Objective A: Engage patients and consumers to partner in defining the registry information of value to them • Objective B: Facilitate communications by providing resources to help promote participation in registries
<p>Goal 3: Support the increased use of registries by health plans, employers, patients, consumers, federal and state government to support health care reform</p>	<ul style="list-style-type: none"> • Objective A: Support quality measurement and public reporting using information from registries • Objective B: Assist organizations operating or planning registries in evaluating registry maturity • Objective C: Share experiences to expand utilization of registry information
<p>Goal 4: Promote a supportive regulatory environment and interoperability while protecting patient privacy</p>	<ul style="list-style-type: none"> • Objective A: Assist registries in supporting multiple uses for their registry while navigating the regulatory environment and building patient trust that registry data will be protected • Objective B: Convene or participate in activities intended to promote interoperability between registries and other health information systems
<p>Goal 5: Engage patients, consumers, policymakers and the public about the unique capabilities of clinical registries</p>	<ul style="list-style-type: none"> • Objective A: Federal government representatives participate in NQRN committees • Objective B: Disseminate information about registries through channels that reach a broad audience • Objective C: Facilitate participation in the CMS Qualified Clinical Data Registry (QCDR) program
<p>Goal 6: Secure external funding to achieve the goals of the NQRN</p>	<ul style="list-style-type: none"> • Objective A: Create a sustainable business plan for the NQRN • Objective B: Seek grant and sponsorship opportunities

Goal 1: Be a hub for creating and disseminating leading practices to the registry enterprise

Over the past several years the NQRN has built a multistakeholder initiative to collaborate and advance the clinical registry enterprise. Through its Leading Practices Webinars program, annual meeting, website and collaboration portal, the NQRN has become a place where organizations involved with registries come together to share ideas, problems and solutions. Over the next three years NQRN aims to leverage its community of experts to provide tools and infrastructure to help registries expand, connect with other health information systems and engage with users.

Tactics

1. Maintain and grow NQRN's collection of registry resources
2. Re-evaluate the registry landscape to identify trends and gaps
3. Survey organizations with quality improvement programs, and examine the use of registry information to drive quality improvement programs
4. Continue the Leading Practices webinar program
5. Provide measure development and public reporting education
6. Maintain the NQRN registry inventory
7. Create a tool to help organizations build a sustainable registry business model
8. Host an annual meeting

Goal 2: Encourage active participation in registries by physicians, health care professionals, hospitals, health systems and patients**Tactics**

1. Identify opportunities to present to external audiences, including organizations representing patients and consumers, that may be interested in operating a registry or using information from registries
2. Evaluate opportunities to reduce the cost of participating in multiple registries
3. Disseminate information about registries on AMA Wire and other communications channels that reach a wide audience

Goal 3: Support the increased use of registries by health plans, employers, patients, consumers, federal and state government to support health care reform

Registry use is expanding and yet tools for objectively and consistently assessing registry capabilities are lacking. Given the increased interest from private and government payers, patients and consumers for easy to understand, trustworthy information about health care, the NQRN wishes to support registries and their users with tools, resources and templates to accomplish these goals in an easier, more consistent way.

Tactics

1. Educate registries on the value of public reporting and overcoming its challenges
2. Create a registry self-assessment tool that provides a reliable and consistent measure of registry capability
3. Seek opportunities to educate payers on the utility of information from registries to support value based payment
4. Investigate registry certification

Goal 4: Promote a supportive regulatory environment and interoperability while protecting patient privacy

As registries are used for an increasing number of purposes, protecting patient privacy remains a high priority. Regulations and guidance are issued from multiple federal and state agencies that at times conflict with each other, or fail to address registries specifically.

Along with helping registries navigate this complexity, there is a need to better connect registries with EHRs and other health information systems. The NQRN will promote the creation of common data standards, and examine registry certification as ways to lower barriers to interoperability.

Tactics

1. Staff the Research and Privacy Task Force; create and disseminate guidance that assists registries in supporting a wide variety of use cases complying with HIPAA and Common Rule requirements.
2. Develop and disseminate common data definitions

Goal 5: Educate patients, consumers, policymakers and the public about the unique capabilities of registries

The NQRN will continue its efforts to communicate the unique capability of registries to the widest possible audience. In addition the NQRN will work to create content to educate policy makers, patients and consumers.

CMS' Qualified Clinical Data Registry (QCDR) program allows registries that pass a qualification process to collect and submit performance measures to CMS to meet the reporting requirements of PQRS and Meaningful Use. QCDRs also provide regular feedback to participants. The NQRN will enable registry participation in the QCDR program with resources, education and other activities to increase participation.

Tactics

1. Continue to involve federal government representatives in NQRN activities
2. Disseminate information about registries to consumer groups and other communications channels to build trust and understanding
3. Create and disseminate informational or educational material on registries aimed at policy makers
4. Provide QCDR education to organizations operating registries that are or plan to become a QCDR

Goal 6: Secure external funding to achieve its goals and ensure long term sustainability

The NQRN has made strides in organizing the registry enterprise. In order to continue to develop this program will need additional human and financial resources.

Tactics

1. Create a sustainable business plan for the NQRN
2. Product development
3. Seek grant opportunities
4. Seek sponsorship opportunities