NQRN® **National Quality Registry Network**

Clinical Registry Business Case Tool
Last updated: June 2016

Completed by the National Quality Registry Network (NQRN®), a PCPI® program.

Suggested citation:
Clinical Registry Business Case Tool. National Quality Registry Network (NQRN). June, 2016. nqrn.org

Credits and Acknowledgements
Clinical Registry Business Case Tool

We gratefully acknowledge the following authors who provided content to the Clinical Registry Business Case Tool.

Seth Blumenthal, MBA	PCPI®
Caryn Etkin, PhD, MPH	American Joint Replacement Registry
Peter Goldschmidt, MD, DrPH, DMS	World Development Group
Kathleen Hewitt, MSN, RN	American College of Cardiology
John Ovretveit, MD, PhD	Karolinska Institute
Darryl Roberts, PhD, MS, RN	Battelle Memorial Institute

Introduction

The National Quality Registry Network (NQRN®) has created a business case template for entities considering development of a clinical data registry. The template can help clearly identify a new or expanded registry program's purpose, goals and objectives, as well as articulate the potential market opportunity for the registry. The enclosed business case template was developed by the NQRN and pilot-tested by organizations in the process of assessing registry feasibility and development. The template is intended to be completed by an organization's senior management while developing the business case for a new or expanded registry.

After the business case has been successfully made and an organization makes the decision to develop or expand a registry, a *business plan* may be developed. Business plans contain organization-level information that will be used to raise capital for registry development. The business plan may then be distributed externally to those entities that have the ability to financially support the registry. Business planning follows the development and use of the business case, but is outside the scope of this document.

Background

Health reform and value-based payment are driving an increased need for standardized performance information about treatment and patient health outcomes. Clinical registries collect highly structured clinical and other data on patient populations that span institutions, geographic areas and varying periods of time. Because of these characteristics, information from registries provides a more complete picture of care for performance measurement and improvement vs. when data for measurement and improvement are sourced solely from EHRs, which typically capture data for a single provider organization only. Additionally clinical data in EHRs, as compared to the administrative claims data they collect, are often not sufficiently structured nor standardized for easy comparison across organizations. Registries provide their participants with usable data on real world populations in their respective clinical focus areas.

Registries leverage these characteristics to help organizations evaluate their overall performance, conduct research, and monitor trends in patient care. There are many reasons for institutions to participate in clinical registries, including but not limited to:

1. *Obtaining performance improvement results in health systems or practices through improvement projects powered by registry information*
2. *Tracking and monitoring important measures tied to payment, e.g. CMS requirements by participating in Qualified Clinical Data Registries (QCDRs),CMS coverage requirements, and other state and health plan performance monitoring*
3. *Improving patient care and helping to reduce variation by learning how best performers get better results*
4. *Identifying higher and lower risk patients, enabling better prediction of outcomes*
5. *Promoting registry participation and commitment to quality in external communications*
6. *Receiving regular reports of local and/or national statistics, including the ability to benchmark against peers in the registry and national performance rates for quality measures (if offered)*
7. *Staying up to date on legislative and regulatory developments that may impact how care is provided, covered or reimbursed*

8. *Receiving relevant information on evidence-based care techniques, tools, products (if applicable)*
9. *Working with leaders in or involved with the clinical profession(s) represented in the registry scope e.g., stakeholder types represented on registry governing bodies, institutions providing financial support to the registry and other collaborators/partners*
10. *The ability to experience continuous improvement through informing physician decisions at the point of care with patients*
11. *Improving information provided to patients and families, improving transparency leading to increased trust and retention*

Objective and contents of business case document

The primary objective of the business case is to articulate the specific purpose of a proposed registry, the benefits of participation, and how those benefits can be drivers of revenue streams to support the development and ongoing operations of the registry. The included business case template begins with an executive summary that makes the case for the registry in brief, with language targeted at decision makers. In the next section, the template calls for a comprehensive business-oriented overview of the registry, including an articulation of registry goals, market characteristics such as potential types of participants and the benefits of participation for each. The template continues with space for a description of an intended approach to developing the registry. Additional sections provide further detail on the proposed registry's functionality, scope and purpose, supporting market research, funding strategies, organizational requirements and a basic financial analysis. Although detailed financial analysis and project planning are outside the scope of this business case, space for high level program planning can provide a basis for the development of a business plan should the decision be made to develop or expand a registry.

Recommended Expertise

The business case intends to provide useful information for prospective registry administrators, health IT personnel, data reporters, and registry users. It supports many aspects of the development of a registry, including financial and business requirements, clinical support and participant training, legal requirements, technology and logistical requirements, reporting and usability requirements. The primary user of the completed business case will be a registry administrator. The role of the registry administrator in this context includes but is not limited to informing decision-makers and activating the necessary funding streams to support a registry as well as obtaining and deploying staff and outsourced resources necessary to plan, develop, implement, maintain a registry and evaluate program performance over time.

NQRN recommends that the prospective registry administrator be a capable and effective project manager who is a director level employee with access to the financial, technology, and human resources necessary to conduct the registry development processes effectively. The prospective registry administrator should have a significant understanding of informatics and health IT processes, particularly those associated with the many steps of the information systems development life cycle, including ongoing maintenance of technical solutions. Since the intent of a clinical registry is to collect and store health- or healthcare-related data, perform analysis and provide reports with relevant information, the prospective registry administrator should have a clinical background i.e., physician, registered nurse, or pharmacist, or have the equivalent knowledge and experience, including expertise in quality management. A registry administrator can also benefit from access to a statistician or

epidemiologist who can inform and support the development of reliable, valid, and useful data collection and reporting methods consistent with their intended purposes.

Developing a registry requires a high level of expertise in a variety of areas. For some content areas, internal expertise may be available. However, for other areas a registry may have requirements above and beyond internal organization capabilities. Table 1 outlines key experience needs for registry business case development and planning. (1)

Table 1: Registry business case considerations for recommended expertise

Content Area	Considerations for in-house staff	Outsourcing potential
Executive leadership	• Developing registry leadership from existing staff vs. hiring for the role • Hiring an executive may be included in a longer term plan to expand registry offerings or stakeholder value	• Not recommended for executive leadership
Analytics	• Ability to identify stakeholder needs and associated value along with key metrics to be disseminated to stakeholders • For a research-focused registry, writing protocols and other scientific documents i.e., grant applications	• Possible, but it is recommended that subject matter experts work closely as a liaison between board/ committees and the third party vendor
Information technology, data capture & submission	• Development of a registry requires a high level of technical expertise both in relation to primary technology and applicable federal, state & local laws and regulations	• Numerous registry vendors have platforms available • Cost may vary depending on the vendor, the data model complexity and the data analysis/presentation capability utilized • Even with a total outsourcing approach, an internal staff person involved with the technology is still recommended to ensure due diligence of vendor selection and continuous monitoring of vendor performance
Legal	• Expertise is needed in contracting with numerous entities including participating organizations and vendors • Significant effort may be needed for contract negotiations with participants	• Hiring outside counsel may provide expertise specific to registries, but at a cost

Instructions

The enclosed template includes instructions to the author, boilerplate text, and fields. In the template:

- Italicized text enclosed in square brackets (*[text]*) provides instructions to the document author, and/or describes the intent, assumptions and context for a narrative section of the business case. After the template has been filled out these instructions may be removed.

- Italicized text enclosed in angle brackets (*<text>*) indicates a short field that should be replaced with relevant information as the template is filled out.

- Other text and tables are provided as boilerplate examples of wording and formats that may be used or modified as appropriate to a specific project. These are offered only as suggestions to assist in developing project documents, and should be modified as needed.

When using the template, the following steps are recommended:

1. Replace all template fields (e.g., *<Registry Name>*) with content appropriate for your use of the template. These angle brackets appear in both the body of the document and in headers and footers.
2. Modify boilerplate text as appropriate for the specific project
3. Remove instruction text (e.g., *[text]*) after use
4. Add or modify sections to the document as needed, ensuring that the header and body text styles are maintained. Styles used for the Section Headings are "Heading 1", "Heading 2" and "Heading 3", with "Body Text" used for boilerplate text.
5. To update the Table of Contents, right-click on it and select "Update field" and choose the option "Update entire table"
6. Before submission of the first draft of this document, delete this instruction section "Notes to the Author" and all instructions to the author throughout the entire document

A list of helpful resources and references are listed in the document appendices. Please note that both this document and the enclosed template have separate appendices.

PCPI encourages users to review this document and/or evaluate their use of it and the included template. Please send comments, suggested edits or insights from using the document to:
Becky Gilbert, PCPI Administrator: rlgilbert@staff.thepcpi.org or call +1 (847) 686-2298.

<Project Name>

Business Case

Version Number: 1.0
Version Date: *<mm/dd/yyy>*

[Template page]
Version History

[Provide information on how the development and distribution of the business case will be controlled and tracked. Use the table below to provide the version number, the author implementing the version, the date of the version, the name of the person approving the version, the date that particular version was approved, and a brief description of the reason for creating the revised version.]

Version Number	Implemented By	Revision Date	Approved By	Approval Date	Description of Change
1.0	*<Author name>*	*<mm/dd/yy>*	*<name>*	*<mm/dd/yy>*	*<description of change>*

[Template page]

Table of Contents

[Template page]

Executive Summary

[Provide a synopsis of the key points of the business case. Outline for the reader the purpose of the registry, the need or problem it will address, and what benefits the registry will provide to internal and external stakeholders. Explain how the registry development project aligns with the goals and objectives of the organization. Suggest an approach to be used for project development i.e., a phased rollout.

Although this section comes first in the template, it is recommended to write it last, after the content in the other sections has been written.]

[Template page]
Overview

General Information

Business Case Submission Date	*<mm/dd/yyyy>*
Requested By	*<Enter full name>*
Registry Sponsor	*<Enter organizational leader supporting this document>*
Contact Info.	*<Enter email address and phone number of primary contact>*
Registry Name	*<Enter a name for the proposed registry>*
Desired Start Date	*<Enter a desired start date for the registry project>*

The Problem

[Enter an explanation of the problem that the registry will solve and/or the need(s) it will address]

Business Purpose

[Describe the general motivation for solving the problem, irrespective of the fact that a registry may be built to help solve the problem]

Primary and Secondary Markets

[Describe the stakeholders for the proposed registry, and briefly summarize why they may be interested/what it will do for them. These could be, but do not have to be the registry participants or patients, but instead could be the ultimate end users of information from the registry.

The primary market is composed of individuals and organizations whose use of information from the registry will be considered a part of the registry's regular workflow, whereas the secondary market includes users performing all other uses. As an example, the primary market for a registry focusing on a particular clinical area might include clinicians in that specialty, administrators in the organizations in which those clinicians practice, as well as evaluating organizations. In this example, secondary users might be researchers requesting registry data for their studies. The primary and secondary designations are somewhat informal and depend on the described scope and purpose(s) of the registry.]

[Template page]
Goals and Objectives
[Return to Table of Contents](#)

Registry services

[Describe the core and ancillary products or services that the registry will offer, noting which services might be considered part of a base level of registry services vs. optional, add-on services. Additionally, describe here what services will be developed and offered initially vs. in later phases of development.]

Registry population

[List and explain the patient populations and/or aspects of health care delivery that will be in scope for the registry e.g., exposure to a class of procedure, drug or type of medical device.]

Registry purpose and data use

[List and explain what the purpose(s) of the registry is(are), and what the data will be used for. Examples in the table below.]

Registry Purposes	Registry data uses
☐ Quality improvement	☐ Qualified Clinical Data Registry (QCDR)
☐ Benchmarking	☐ Payment
☐ Clinical effectiveness	☐ Certification
☐ Cost effectiveness	☐ Licensure
☐ Safety or harm	☐ Measure development
☐ Device surveillance	☐ Guideline development
☐ Public health surveillance	☐ Clinical decision support development
☐ Research	☐ Education development
☐ Population surveillance	☐ Population management
	☐ Public reporting

[Add additional text in support of the purposes/data uses checked. How will the registry program support these? Which are high priority and part of an expected core, vs. others that could be considered secondary and/or could come in a future phase?]

Evaluating registry program performance

[Add in this space an overview description of how the organization will evaluate its registry in terms of operational success, achievement of the organization's mission, and, possibly, contribution to public health.]

[Template page]
Strengths, Weaknesses, Opportunities, Threats
[Return to Table of Contents](#)

[A SWOT exercise addresses four primary areas: Strengths, Weaknesses, Opportunities and Threats. Each item the SWOT table is either a help or a hindrance to developing the registry. Populate each square in the table with attributes internal or external to the registry. For example, when you evaluate what will be helpful for your registry, consider attributes of your organization that would serve as a strength, and external attributes as opportunities. Conversely, internal attributes that are harmful would be identified as weaknesses, and external attributes would be threats. (2)*]*

	Potentially helpful to the registry	Could be a barrier to the registry
Attributes of the registry itself, or its steward organization	**Strengths**: • <Enter your strengths> • Example: We are experts in our field	**Weaknesses**: • <Enter your weaknesses> • Example: We are a small group with limited resources
External attributes potentially impacting the registry (policy, technology, etc.)	**Opportunities**: • <Enter your opportunities> • Example: Commonly accepted treatments or approaches to procedures are changing but need data for evidence development	**Threats**: • <Enter your threats> • Example: Additional data entry burden on participating clinicians

[Template page]
Market Characteristics
[Return to Table of Contents](#)

Target Market

[Identify specific organizations or types of individuals that may be interested in utilizing the registry. List characteristics of these organization/people and how registry participation might be appealing to them. Estimate the size of the target market, any niches the registry can serve well and how to reach this market.]

Stakeholder	Registry benefit	Primary market potential	Secondary market potential
<Enter info in these rows...>			

Competition

[What competitors exist and how do they currently meet a similar need for the stakeholders the registry would seek to target? Additionally, are there alternatives available for potential registry participants to get the information they need or want? Finally, if for example an individual or organization is now participating in the registry and it is time to renew for the year, are there substitute products, services or offerings that could potentially compete with the registry in terms of participant retention?]

Partner Collaboration Model

[If your organization desires to collaborate or enter into partnerships with other organizations for the registry project, flush out here how partners might contribute, the benefits to those organizations and also factors that might work against establishing these relationships. The focus here is not necessarily on normal vendor outsourcing contacts, but on strategic business relationships.

Although this is separate from normal vendor outsourcing, the need or desire for strategic relationships benefits from consideration of similar factors and tradeoffs. One way to approach the area of potential partnerships is to think about the value the registry will or should offer in the marketplace.

- *Given the needs and desires of both primary and secondary users of information from the registry, can the registry program satisfy those needs on its own?*
- *Will there be a need to create, recreate or significantly change something that already exists elsewhere?*
- *Are there be an expansion in the scope of the registry organization's work with an aim to establish credibility in a new area(s)?*
- *Are there expertise or resources that if available would facilitate meeting these objectives, but that are contained within other organizations?*

If the answer to one or more of these is "yes", a search and exploration process for building partnerships for the registry program is recommended.]

[Template page]

Funding Mechanisms

[In lieu of a detailed financial analysis and pro-forma budget, describe why the target market(s) may be willing to pay to participate in the registry. What are the different ways the registry could be funded?

Common funding methods for registries include:
- *Self-funded e.g., through membership dues*
- *Participation fees, individual or organization-based, for a base registry package plus other fees to access additional optional modules*
- *Federal grants*
- *Other grants (non-federal)*
- *Data analysis/custom reporting fees*
- *Data use fees*

Registry participation can be funded entirely by the organization, for example as a benefit of membership. If annual participation fees are to be charged, they can be on an individual or organization basis. There additionally could be a base participation fee and also additional fees for offerings such as other registry databases, clinical coverage areas or other capabilities above and beyond a base level of service.

Funding considerations, including pricing:
- *Will the same level of service be offered or will there be tiers or a menu of fee-based optional services?*
- *Is there differentiation among potential participants in terms of ability to pay?*
- *Where will initial/startup funds come from vs. ongoing funding to sustain registry operation in future years?*
- *Will registry start-up funds be borrowed? If so then content here should be added around repayment schedules and how those moneys will be generated to retire the debt.]*

[Template page]
Registry Program Development

[In this section, map out at a summary level how the registry will be built, tested and made available for use by participants. Additionally, if a phased approach to registry development will be taken, this section could be expanded to also include a table of phases and what functionality will be offered in each phase.]

[Example table with basic registry development steps]

Phase	Timing
Development	
1. Review other similar registries; solicit comments and input	<Date>
2. Create business plan including organizational structure, leadership and funding model, IT resources, detailed three-year budget and recruitment plan	<…>
3. Determine what work will be done in-house vs. outsourced to vendors	
4. Develop registry data model, including data elements, definitions, and technical specifications	
5. Create a reporting structure and develop metrics for the registry	
6. Run pilot study (if necessary/desired)	
7. Finalize marketing/communication plans	
8. Develop mechanisms for customer support and training functions	
9. Confirm principal registry features i.e., QI, research	
10. Understand federal regulations related to registry implementation i.e., how your registry will operate with respect to federal payment programs	
11. Develop participant and other stakeholder contracts as needed	
12. Submit HIPAA authorization and IRB application(s)	
Implementation	
1. Enroll participants	
2. Execute training and support	
Maintenance	
1. Engage with other stakeholders e.g., researchers, regulators	
2. Begin next registry update	
3. Begin research and publications efforts	
4. Identify gaps in care and explore quality improvement opportunities	

[Template page]
Organizational Requirements

[Describe the organizational structure, including key staff and volunteer roles and responsibilities, committee structure and other resource requirements for launching and sustaining the registry.

At a minimum, the following staff resources are recommended to develop, implement and operate a clinical data registry. The exact structure will be dependent on your organizational model, and how your organization will approach and staff a clinical data registry e.g., full time vs. part time staff, staff dedicated to one or multiple registries.]

Key staff area	Roles and responsibilities	Suggested staff, volunteer or third-party personnel
Administrative assistance	• Committee coordination, and other office support functions	*<Staff>*
Project Management expertise	• Provides project management expertise to ensure projects are properly scoped, resources and planned	*<Staff>*
Clinical and Scientific Expertise	• Provides clinical direction for registry development, develops data elements/definitions, measure development, reporting requirements, and research project oversight, provides ongoing participant training and support	*<Staff>* *<Volunteers>* *<Committees>*
Performance Measurement	• Stays on top of the quality reporting landscape, regulatory and otherwise, as well as updates to measure specifications and data elements • Develops or manages the development of measures for the registry	*<Volunteer, staff or third party>*
Data Analysis	• Analyzes registry data, develops reports for all stakeholders	*<Staff (with volunteer assistance)>*
Executive	• Coordinates staff, facilitates board interactions, provides financial accountability	*<Staff and/or collaboration with volunteer board>*
Government relations (Regulatory, federal and other initiatives)	• Monitors all external influencers including federal government, payers, medical specialties, Joint Commission, etc.	*<Volunteer, staff or third party>*
Human Resources	• Responsible for recruiting, screening, interviewing and placing workers. • Employee relations, payroll and benefits and training	*<Staff or third party>*

Key staff area	Roles and responsibilities	Suggested staff, volunteer or third-party personnel
IT infrastructure	• Provides desktop support, analysis tools, email, website, help desk	*<Staff or third party>*
Marketing	• Promotes registry to key stakeholders • Identification of stakeholder needs and translation to tangible solutions via registry. • Communication with external stakeholders. • Works to retain participants by fostering ongoing relationships	*<Staff>*
Privacy and Security	• Ensures compliance with HIPAA and HITECH to address organizational needs, participant and regulatory requirements	*{Staff or third party>*
Recruitment (hospitals, clinics, practice groups, physicians)	• Provides outreach to entities of interest to enroll those groups in to the registry	*<Staff>*
Registry Technology	• Translates registry needs to registry functionality • Manages vendor and coordination of development activities	*<Staff or third party>*

[Template page]
Financial Analysis

[Build a basic financial analysis in this section. Detail the financial benefits to different types of participants in the registry's target market, the cost, and how you project your participants to achieve return on investment (ROI) for their participation. Next, show how their ROI translates to benefit for the organization, or if the registry will be primarily a cost center, narrate how the benefit to members outweighs the cost e.g., the cost of inaction or of using a method other than a registry to accomplish your goals.

The below sample financial analysis table segments costs categorically as well as by initial and ongoing, and then adds revenue sources for a projection of profit/loss. Revenue sources include base participation fees, as well as fees from additional modules. These could be new services that the registry offers e.g., covering an additional disease/condition area, providing measure reporting to additional payers or reporting to certification/accreditation/licensing organizations. This table should be modified to reflect registry program costs and expected revenue streams. The table does not account for capital costs, if any.]

| Description | Initial Cost | | | Annual and five-year costs | | |
	Unit cost	Quantity	Initial cost	Year 1	Years 2-5	5-yr cost
Data hosting/storage			$ -			$ -
License fees			$ -			$ -
Interface fees			$ -			$ -
TOTAL: Infrastructure	$ -	$ -	$ -	$ -	$ -	$ -
Registry design & implementation			$ -			$ -
Training			$ -			$ -
TOTAL: Implementation	$ -	$ -	$ -	$ -	$ -	$ -
Personnel salaries and benefits			$ -			$ -
Legal			$ -			$ -
Marketing			$ -			$ -
Contractors			$ -			$ -
TOTAL: Professional Support			$ -	$ -	$ -	$ -
TOTAL	$ -	$ -	$ -	$ -	$ -	$ -

Total cost

Five year cost	$ -
Net present value	$ -

Five-year cost, discount rate: X%

	Initial	Year 1	Year 2	Year 3	Year 4	Year 5
Date paid	1/1/YYYY1	7/1/YYYY1	7/1/YYYY2	7/1/YYYY3	7/1/YYYY4	7/1/YYYY5
Amount paid	$ -	$ -	$ -	$ -	$ -	$ -

[Template page]

Projected Revenue

Description	Amount	Quantity		Year 1 revenue	Years 2-5	5-yr revenue
Federal grants				$ -		$ -
Other (non-federal) grants				$ -		$ -
TOTAL: One-time	$ -	$ -		$ -	$ -	$ -
Base participation fees (annual)				$ -		$ -
Additional module #1				$ -		$ -
Additional module #2				$ -		$ -
Data use fees				$ -		$ -
Data analysis/reporting fees				$ -		$ -
TOTAL: Ongoing	$ -	$ -		$ -	$ -	$ -
TOTAL	$ -	$ -		$ -	$ -	$ -

Total revenue Five year revenue | $ - |

Profit/loss TOTAL | $ - | $ - | $ - |

[Template page]
Return on Investment

[Discuss the costs and benefits of pursuing the proposed registry program here. This section could include a quantitative financial "break even" assessment, as well as discussion of the qualitative benefits to members. Articulate how and why the value of the database should be expected to increase over time as more sites join, more diverse patients are served, and longitudinal analyses can be performed.]

Conclusions and Recommendations

[Relate back to the executive summary at the beginning of the template. Give specific recommendations as to what the registry should do, for whom, and the best way forward to make the registry a reality.]

[Template page]
Appendix A: Key Terms
Return to Table of Contents

The following table provides definitions and explanations for terms and acronyms relevant to the content presented within this document.

Term	Definition
<Insert Term>	*<Provide definition of term and acronyms used in this document.>*
Electronic Health Record (EHR)	The EHR is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. (3) EHRs typically capture data on patient encounters within a single health system or practice.
Clinical registry	A clinical registry is "…an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes." (4) Registries capture data across multiple health system organizations or practices.
Qualified Clinical Data Registry (QCDR)	"…A CQDR is a CMS-approved entity that collects medical and/or clinical data for the purpose of patient and disease tracking to foster improvement in the quality of care provided to patients." (5)
Registry business case	A document that captures the reasoning behind initiating or expanding a registry
Registry business plan	A document that describes in detail how, having successfully made the business case for starting or expanding a registry, the organization will get from there to past go-live and into a growth phase.
Registry purpose(s)	Typically a broad reason(s) why the registry exists, related to overall health and health care goals. Purposes can and do change over time.
Registry data uses	Specific uses of registry information aligned with the purpose(s). Successful registries may find that scope of use expands over time.

[Template page]
Appendix B: Business Case Approval

The undersigned acknowledge that they have reviewed the *<Registry Name>* business case and agree with the information presented within this document. Changes to this business case will be coordinated with, and approved by, the undersigned, or their designated representatives.

[List the individuals whose signatures are desired. Examples of such individuals are members of the governing body eg., Board of Directors, Project Manager (if identified), and any appropriate stakeholders. Add additional lines for signature as necessary.]

Signature: _____   Date: _____

Print Name: _____

Title: _____

Role: _____

Signature: _____   Date: _____

Print Name: _____

Title: _____

Role: _____

Signature: _____   Date: _____

Print Name: _____

Title: _____

Role: _____

[This is the last page of the template]

Appendix A: Helpful Resources

NQRN has released a variety of documents and resources for registries, including introductory descriptive materials, communications collateral as well as tools including a registry vendor assessment tool. (6) (1) (7)

The Council of Medical Specialty Societies (CMSS) has published a primer on clinical registries that complements this document in several areas. (8)

Consideration of a business case can be considered in a layered fashion based on two successive questions: 1) is it worthwhile and 2) is it worth doing? Registries for Evaluating Patient Outcomes: A User's Guide: 3rd Edition contains material that may help organizations answer these questions. Table 2 lists recommended chapters. (4)

Table 2: Chapters in the AHRQ registry user's guide

Topic	Recommended chapters
Is a registry worthwhile?	2, 3, 5, 6, and 7
Is a registry practical considering cost, benefit and operational issues?	3, 5, 6, 8, 9, 10, and 11
Do the circumstances fit based on available data sources?	15, 16, 17, and 18
Is there a fit based on targets e.g., purpose, population?	19, 20, 21, 22, and 23

Appendix B: References

1. **American Medical Association.** National Quality Registry Network. *American Medical Association.* [Online] 2014. http://www.ama-assn.org/resources/doc/cqi/x-pub/nqrn-registry-vendor-assessment.pdf.

2. **Wikipedia contributors.** SWOT analysis. *en.wikipedia.org.* [Online] [Cited: May 24, 2016.] https://en.wikipedia.org/w/index.php?title=SWOT_analysis&oldid=720843665.

3. **HIMSS.** Electronic Health Records. *himss.org.* [Online] [Cited: May 31, 2016.] http://www.himss.org/library/ehr/.

4. **Gliklich, R., & Dreyer, N.** *Registries for Evaluating Patient Outcomes: A User's Guide. Third Edition.* Rockville, MD : Agency for Healthcare Research and Quality, 2014.

5. **CMS.** Qualified Clinical Data Registry Reporting. *cms.gov.* [Online] May 27, 2016. [Cited: May 31, 2016.] https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/pqrs/qualified-clinical-data-registry-reporting.html.

6. **American Medical Association.** National Quality Registry Network (NQRN). *American Medical Association.* [Online] nqrn.org.

7. **PCPI.** [Online] thepcpi.org.

8. **CMSS.** *cmss.org.* [Online] January 2016. [Cited: May 31, 2016.] http://cmss.org/wp-content/uploads/2016/02/CMSS_Registry_Primer_1.2.pdf.