



# Report: Next Steps to Encourage Registry Adoption of Data Standards

A joint initiative of The Pew Charitable Trusts and PCPI

November 29, 2016



## Today's Speakers

- Stephen L. Davidow, MBA-HCM, CPHQ, APR, Quality Improvement Program Manager, PCPI (host & moderator)
- Anqi Lu, MEPP, Associate, Health Information Technology, The Pew Charitable Trusts
- Kathleen Hewitt, MSN, RN, CPHQ, Associate Vice President, American College of Cardiology
- Anita Walden, Co-Chair HL7 Clinical Interoperability Council, University of Arkansas Medical Sciences
- Seth Blumenthal, MBA, NQRN Program Manager, PCPI



# Agenda

- Introductions
- Problem statement and background
- Recommendations
- Reactions
- Q&A/Discussion



## Problem statement

- Hospitals, health plans and physicians are searching for ways to cut costs and improve patient care.
- One of the best tools available is information contained in clinical registries.
- Registries help clinicians evaluate patient outcomes associated with high-risk procedures such as hip and knee replacement and stent insertions.
- Clinicians use registries to compare their performance to that of their peers
- Registries capture specific, well-defined information.
- Unfortunately, registries lack harmonized standards to guide this process, limiting how effectively they can be used for research or to improve performance.



# Background

- Much of the information recorded in EHR systems used in hospitals and doctors' offices exists as text rather than discrete data and cannot be moved easily into registries
- To transfer the data, staff must translate and re-enter a portion of the patient record manually (a process known as abstraction) to enter it into a registry.
- Even when clinical information is recorded as structured data within an EHR, the specific elements used in the registry could be different.
- Different registries use varying definitions of key clinical concepts making abstraction more difficult because clinical staff must know the specific definition that applies to each registry. Examples include:
  - Heavy bleeding
  - Myocardial infarction



## Coming together

- The Pew Charitable Trusts is an independent, nonprofit research and public policy organization
- PCPI is a national nonprofit organization working to improve patient health outcomes
- NQRN<sup>®</sup>, a PCPI program, is a network of PCPI members interested in clinical registries
- Pew and PCPI agreed to leverage their respective strengths by collaborating on a project to examine challenges and opportunities in adopting data standards in registries
- In June 2016, Pew and PCPI gathered experts from organizations that manage registries (“registry stewards”), federal government officials, standards development groups, and health information technology software vendors for one day to identify the barriers to more widespread use of data standards and to outline ways to encourage their adoption.



# Participating Organizations\*

- Agency for Healthcare Research and Quality
- American Academy of Neurology
- American College of Cardiology
- American College of Gastroenterology
- American College of Surgeons
- American Congress of Obstetricians and Gynecologists
- American Medical Informatics Association
- American Society of Anesthesiology
- American Society of Clinical Oncology
- Centers for Medicaid and Medicare Services
- Cerner
- FIGmd
- Health Level Seven International
- Health Services Platform Consortium
- National Library of Congress
- Office of the National Coordinator for Health Information Technology
- Premier
- Quintiles
- Society of Thoracic Surgeons
- The Joint Commission
- University of Arkansas Medical Services

\*Participation does not mean endorsement or support of the report.



# Recommendations to Encourage Registry Adoption of Data Standards

Anqi Lu

The Pew Charitable Trusts

November 29, 2016





## Next Steps to Encourage Adoption of Data Standards for Clinical Registries

### Overview

As hospitals, health plans, and physicians search for ways to cut costs and improve patient care, one of the best tools at their disposal is information housed in clinical data registries. Researchers can use these data to evaluate patient outcomes associated with high-risk procedures, such as hip and knee replacements and stent insertions. And clinicians can use registries to compare patient outcomes with those of their colleagues. These large databases—which are also used to collect data on drugs and medical devices—rely on the capture of specific, well-defined information. However, registries lack harmonized standards to guide this process, limiting how effectively the data can be used for research or to improve performance. For example:

- Much of the clinical information recorded in electronic health record (EHR) systems used in hospitals and doctors' offices exists as text rather than discrete data and cannot be moved easily into registries. To transfer the information, staff members typically must translate a portion of the patient record—a process known as abstraction—and manually enter the required data into the registry.

<http://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2016/11/next-steps-to-encourage-adoption-of-data-standards-for-clinical-registries>

## Recommendation #1

**Problem:** Registry stewards lack effective coordination.

**Solution:** Registry stewards should develop and implement a roadmap for the path forward.



## Recommendation #2

**Problem:** Existing data standards do not meet the needs of registries.

**Solution:** Registry stewards should engage more with standards development organizations.



## Recommendation #3

**Problem:** It is expensive for registries to develop, use, and steward data standards.

**Solution:** Stakeholders should jointly create and fund a resource center to share knowledge.



## Recommendation #4

**Problem:** Efforts by the federal government to increase interoperability have not focused on registries.

**Solution:** The federal government should incentivize the adoption of data standards.





# Steering Committee Members

- Elise Berliner, Agency for Healthcare Research and Quality
- Arnold Berry, Emory University School of Medicine
- Hans Buitendijk, Cerner
- Kathleen Hewitt, American College of Cardiology
- Amy Sachs, American College of Surgeons
- Anita Walden, University of Arkansas for Medical Sciences
- Wayne Wilbright, Louisiana State University Health Care Services Division
- David Wormuth, The Society of Thoracic Surgeons



## Conclusion

- Registry stewards should continue to work with hospitals and other stakeholders to develop and adopt harmonized data standards that meet their needs.
- The solutions outlined in this document provide a starting point for greater collaboration among registry stewards, standards development organizations, providers, clinicians, payers, and the federal government.
- We look forward to hearing your thoughts and how we can move toward the adoption of common data standards.



# Questions?

Please type your questions and comments  
into the chat window.





Thank you!