

Advancing Consumers' Role in Reporting Electronic Health Data Quality Assessments

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PCORI Disclaimers

- *Research reported in this work was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (ME-1303-5581).*
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Background

- Expansion of data sources
 - Opportunities for CER and PCOR studies
- Potential for poor data quality
- Current data quality (DQ) methods are ad-hoc
- Data quality rarely reported
 - Not in an understandable format to patient advocates and policy-makers
- Public health perspective: Need to utilize health data sets to improve policy effectiveness and health outcomes. Ability to merge health data sets hinges on DQ assessment of those data.

Background (continued)

- PCORI funded grant (awarded Oct 2013)
- Aim 1: Develop, through consensus, an agreed upon standard of terms and definitions for assessing DQ of secondary data
- Aim 1 Activity 3: Convene a group of patient advocates and policy-maker stakeholders to solicit feedback on the concepts and recommendations for DQ assessment and reporting

Objective

- To learn how to involve patient advocates and policymakers in data quality assessment and reporting of secondary health data.

Methods

- Qualitative research methods
 - Discussion guide used broad, open-ended questions to elicit stakeholder's perceptions about and opportunities for data quality assessment and reporting
 - Discussion recorded, transcribed, and analyzed following standard qualitative analytic methods
- July 2014 in Washington, D.C.
- Stakeholders from public policy and professional organizations, federal gov. agencies, patient advocacy groups (N=21)

Main Findings

1. Identified why their stakeholder communities are interested in DQ assessment and reporting (dissemination)
2. Identified role in data cleaning, analysis, and preparation of data for presentation in publication
3. Identified role in DQ assessment
4. Key role in disseminating data quality assessments to improve communication, transparency and trust between their stakeholder community and health care providers and researchers

Main Findings: Finding 1 (The Why)

- Interest in DQ assessment and reporting
 - Patient advocates: Increase engagement with health care
 - Involvement of patients in reviewing the accuracy and completeness of their health information would help them to be “...more engaged and ready to communicate with their doctor and engage in health care decision making as the result of this process.”
 - Policy-makers: Understand impact of policies
 - My organization is focused on DQ assessment “...first of all for health policy very broadly. We’re interested in health care reform... and if you’re going to reform any kind of company or institution you need good data to see whether or not you’re actually accomplishing what you set out to achieve, so I think the issue of data quality [assessment] is fundamental to anything we do in terms of health care reform”

Finding 1: (The Why, continued)

- Professional organization representatives: Provider trust in EHR data
 - “So currently where we are with Meaningful Use is [that] we have a set of measures that are prespecified and providers question them... There is this reluctance that we’ve heard from providers... I think part of it’s driven by a sense of concern that the data that they’re reporting they don’t necessarily trust the data that they have in the report? ... We are trying to... think through how do we overcome that barrier so... providers are actually reporting reliable data that we can then use for benchmarking purposes, telereporting, and ultimately for payment purposes, and all those kinds of things.”

Main Findings: Finding 2 (The How)

- Identified role in data cleaning, analysis, and preparation of data for presentation in publication
 - Advocated a role in advising data collection, data cleaning, analysis, and preparation of data for presentation in publication through stakeholder engagement

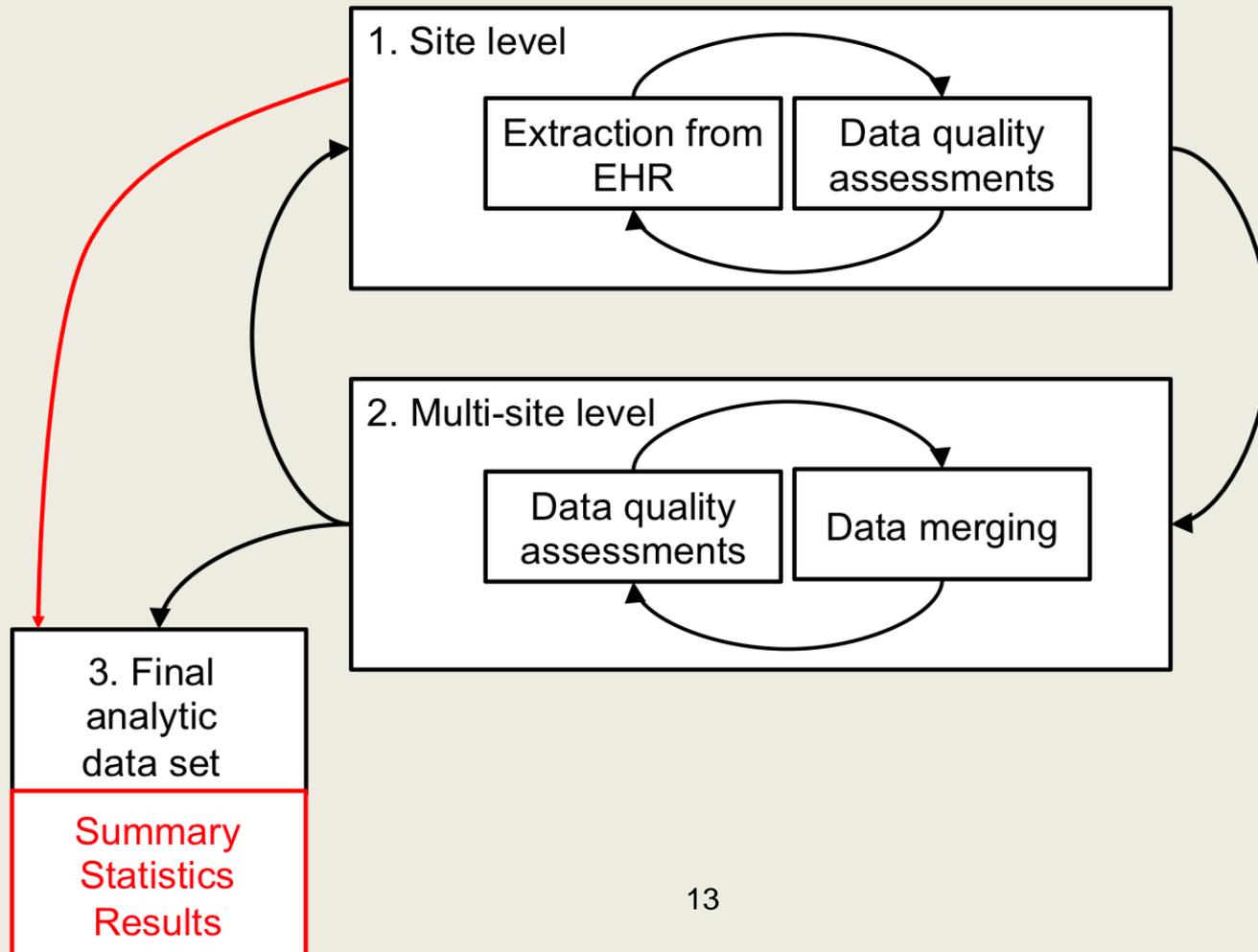
Findings 2 (The How, continued)

- Patient-advocate: Advise entire data life cycle
 - “You bring them [patient/consumers] in at the data collection phase, and you get their input on how to collect the data from different populations, especially underserved populations that might not trust a clinical research system, right, so you bring them in and...that middle area of [data] cleaning, and analysis would really be done by the researchers, and then would be reflected back to the beginning [patient/consumers] group to say ‘This is what we did, and this what we found, and yes our methods are sound; you can trust us’.”

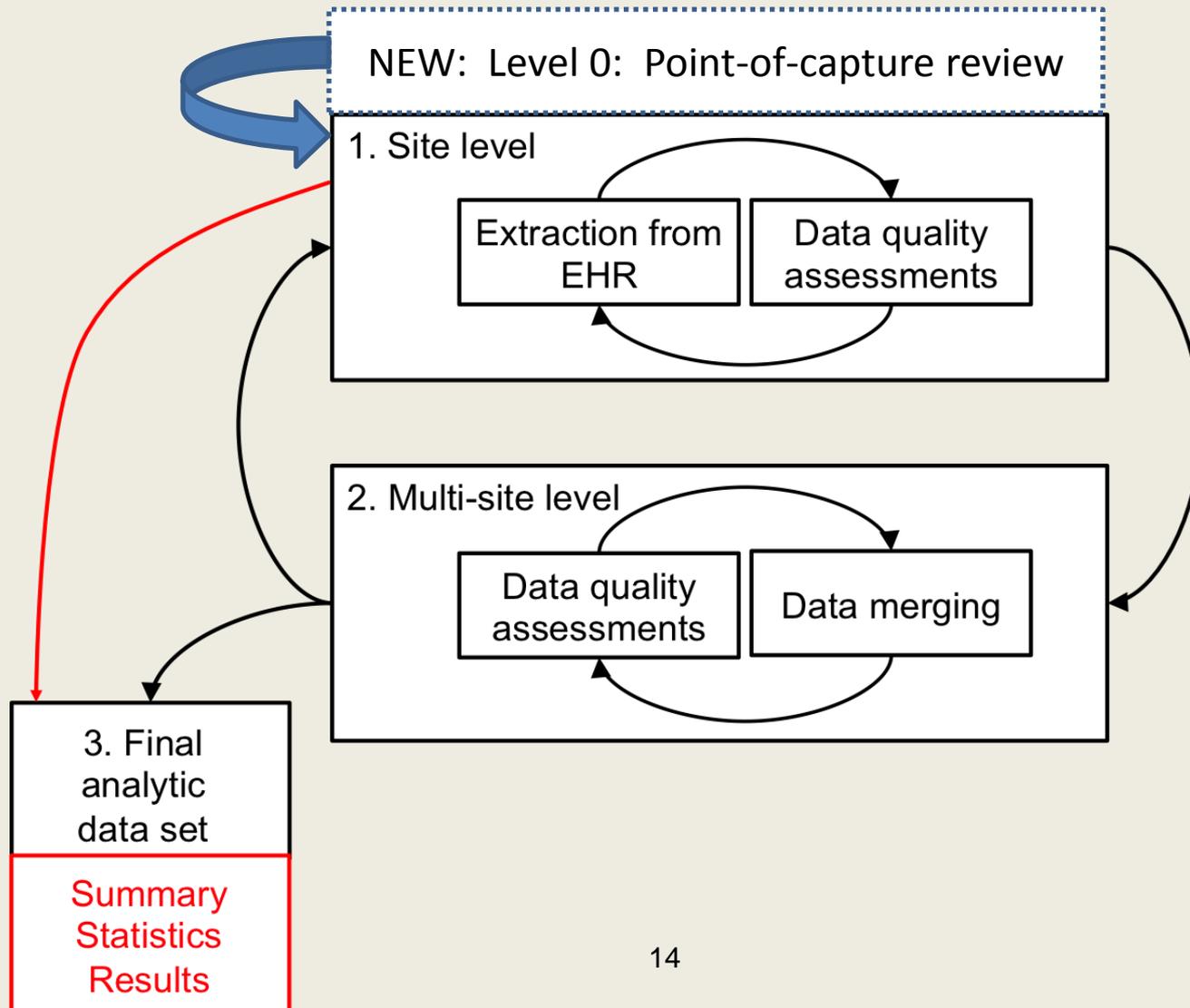
Finding 3 (The How)

- **Expand** role these stakeholders have in DQ assessment

Data & data quality assessment lifecycles – *Original version*



Data & data quality assessment lifecycles – *Revised version*



Main Findings: Finding 4 (The Implications)

- These stakeholders play a key role to:
 - Know and can access communication channels relevant to their stakeholder group
 - Inform dissemination of data quality assessments to improve transparency and trust

Summary

- Interest in engagement with data quality assessment results of secondary data
 - Acknowledgeable technical/expert support may be needed
- Barriers to DQ assessment and reporting exist from lack of access for patients and policy-makers, and provider perception that electronic health data is of poor quality
- Role for these stakeholders to engage in DQ assessment and reporting of secondary data
 - Start at point-of-capture (data collection) and extend through dissemination of data quality assessments
 - Would improve trust in the results and transparency of the research process

Any Questions?

How about you?

- Experiences with stakeholder engagement?
- Experiences with data quality assessment and data quality reporting?

Thank you for your participation and interest in
our work

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