Stakeholder Engagement Core
Lessons Learned, Update and Plans

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Collaboratory Steering Committee Meeting
February 25, 2014
Presentation Overview

- Review of Stakeholder Engagement Core
- Year 1 Lessons Learned
- Year 2 focus / June 2014 SAG meeting
- Restocking the SAG
- Year 1 and 2 Deliverables
Stakeholder Engagement Core

Statement of Purpose:

The **Stakeholder Engagement (SE) Core** provides the forum within which a wide range of stakeholders can bring their different perspectives and expertise to the work of overcoming barriers to the transformation to a learning health care system.

Through dialogue with stakeholders we will also clarify why this transformation is important for these organizations, their employees and the patients they serve.

→ Primary focus is to identify strategies to promote long term success of Collaboratory.
Why Engage Stakeholders?

- Wide range of barriers to metamorphosis from health care delivery system to research partner
  - Technical, operational, regulatory, financial, cultural
- Health systems and research community don’t have all necessary expertise, authority, resources, insights
  - Optimal “implementation methods and best practices” may require actions by other agents
- Stakeholder Engagement Core provides forum to engage broader healthcare community
- **Sustainable infrastructure depends on compelling business case for patients, clinicians, health systems**
Organizations Represented on SAG

- National Health Council
- Patient Advocates in Research
- American Liver Foundation
- Informed Medical Decisions Foundation
- Public Responsibility in Medicine & Research
- Patient Centered Outcomes Research Institute
- Office of the National Coordinator for Health Information Technology
- Centers for Medicare & Medicaid Services
- Minnesota Healthcare Programs
- Humana of Ohio
- Evolent Health
- Veterans Health Administration
- HCA America
- Good Samaritan Hospital of Maryland
- Cincinnati Children’s Hospital
- Children’s Hospital of Boston
- National Committee for Quality Assurance
- Engelberg Center for Health Care Reform, Brookings Institution
- Oregon Health & Science University
- Leonard Davis Institute of Health Economics, UPenn
- Boston College Connell School of Nursing
- Medtronic, Inc.
- Pfizer
Year 1 Activity Review

- Stakeholder Advisory Group – 24 members recruited
- Topic Identification with SE workgroup and demo PIs
- SAG Orientation to HCS Collab - Webinar (April 24th)
- SAG In-person Meeting - May 9th, 2013 (Baltimore, MD)
- Meeting Summary White Paper completed - August 2013
Stakeholder Advisory Group

Meeting Summary

Engaging Health Care Systems as Partners in Research:
Moving Toward a Sustainable Partnership

May 9th, 2013
World Trade Center Baltimore
Knowledge and Attitudes about LHS

• There is a lot of public education needed to build greater support for the necessity of more efficient learning
  • Uncertainty and risks in clinical care
  • Risk of overprotection/under-protection with current approach

➢ Many people believe their own clinicians provide good care, but can appreciate that they can only know what is known

➢ Understanding clinical trials and randomization is complicated

➢ Easy to underestimate patient/public fears that research results will be used to limit care
The notion that learning will lead to better patient care is not in itself sufficient justification for major reductions in research oversight or regulation.

- Modified consent: Greater disclosure/explanation may be viable alternative to more extensive standard consent for selected experimental studies
  - Not limited to “fully-loaded” consent vs none
- Acceptance of alternative methods varies based on trust
  - Extent to which the provider/system upholds commitments to patients that “learning” is translated into practice
  - Results not used to restrict patient/clinician treatment options
Year 2 Focus for SE Core / SAG

- Ethical & regulatory issues
  - Support Coord Center Ethics Supplement
- Incentives for patients, clinicians and health systems to partner in LHS
  - Value proposition / business case for each
  - Key to potential for sustainability
The Business Case for Learning

- *Healthcare systems* must perceive that there is a reasonable and sustainable business-case to allocate organizational resources to serve as active partners for Collaboratory researchers and future learning efforts.

- *Clinicians* must perceive sufficient monetary or nonmonetary benefits to justify adding extra responsibilities to their already substantial workloads (and the workloads of their nurses and staff).

- *Patients* must be activated as agents of change – to *insist* on conducting more clinical research quickly and efficiently.
  - Requires understanding the benefits of research and risks of *not* doing research.
  - Requires trust that such research is appropriately regulated, safe, ethical, and beneficial to their own healthcare in addition to society as a whole.
Work Plan – Business Case for LHS

- **White paper** in collaboration with the Health Systems Interactions Core: *Toward a sustainable learning health system: roadmap for building health system, clinician and patient support*

- **In-person SAG meeting** in May/June to allow for in-depth dialogue of the issues discussed in the draft white paper

- **Manuscript** based on background research and meeting

- Work will be coordinated with two PCORI-funded IOM workshops on the value proposition of integrating care and research
  - Targeted to Health System Leaders
Extra Slides
Stakeholder Advisory Group

Patients/Consumers/Patient Advocates

Marc Boutin, JD
Executive VP & Chief Operating Officer
National Health Council

Deborah Collyar
Co-chair, Committee on Advocacy, Research Communications, Ethics & Underserved Populations; Founder, Patient Advocates in Research (PAIR)

Donna Cryer, JD
President & CEO
American Liver Foundation

Pam Wescott, MPP
Director of Patient Perspectives
Informed Medical Decisions Foundation

Regulatory and Ethics Stakeholders

Alex Capron, LLB
Chair, Board of Directors
Public Responsibility in Medicine and Research (PRIM&R)

Susan Kornetsky, MPH
Director of Clinical Research Compliance
Children’s Hospital, Boston

Life Sciences Industry

Alexandra Clyde, MS
Vice President, Health Policy and Payment
Medtronic, Inc.

Eleanor Perfetto, PhD, MS
Professor, Pharmaceutical Health Services Research, University of Maryland (Previous: Senior Director, Reimbursement & Regulatory Affairs, Federal Government Relations, Pfizer)
Stakeholder Advisory Group

**Physician / Researcher**

*LJ Fagnan, MD*
Professor, Family Medicine
Oregon Rural PBRN
Oregon Health & Science University

*Robert Chow, MD, MBA*
Program Director, Internal Medicine Residency Program & Vice-Chair, Medicine Director of General Internal Medicine Good Samaritan Hospital of Maryland

**Private Payers**

*Elizabeth Malko, MD, MEng*
Senior VP Clinical Delivery and Operations, Evolent Health; (Previous: Executive VP and CMO, Fallon Community Health Plan)

*Derek van Amerongen, MD, MS*
Chief Medical Officer Humana of Ohio

**Nursing**

*Tam Nguyen, PhD, MSN, MPH*
Assistant Professor Boston College William F. Connell School of Nursing

**Health IT experts**

*Kelly Cronin*
Healthcare Reform Coordinator Office of the National Coordinator for HIT
Stakeholder Advisory Group

Public Payers

Jeff Schiff, MD, MBA
Medical Director
Minnesota Healthcare Programs

Shari Ling, MD
Deputy Chief Medical Officer
CMS Center for Clinical Standards & Quality

William Shrank, MD, MSHS
SVP, CMO and CSO, Provider Innovation & Analytics, CVS Caremark; (Prev: Director, Rapid Cycle Evaluation Group, CMMI)

PCORI

Rachael Fleurence, PhD
Acting Director, Accelerating PCOR Methods Program, Patient-centered Outcomes Research Institute

Thought leaders in QI, practice incentives & innovative care delivery

Scott Halpern, MD, PhD, MBE
Deputy Director
Center for Health Incentives and Behavioral Economics, Penn Leonard Davis Institute

Mary Barton, MD, MPP
VP for Performance Measurement
National Committee for Quality Assurance

Kavita Patel, MD, MS
Managing Director for Clinical Transformation and Delivery,
Engelberg Center for Health Care Reform, Brookings Institution

Michael Seid, PhD
Director, Health Outcomes and Quality Care Research, Cincinnati Children’s Hospital Medical Center

Rethinking Clinical Trials
SE Workgroup Members

- Sean Tunis
- Ellen Tambor
- Rachael Moloney
- Mark Vander Weg
- Sally Retecki
- Alfred Cheung
- Kathryn James
- Carmit McCullen
- Ed Septimus
- Jerry Jarvik
- Lynn DeBar
- Gregory Simon
- Susan Huang
- David Chambers
- Jerry Suls

NIH Collaboratory
Health Care Systems Research Collaboratory

Rethinking Clinical Trials