



September 26, 2019 Kick-Off Meeting Summary Key Challenges and Opportunities

Data/Data Access

Challenges

- Lack of data standards
- Lack of consistent data
- Missing data
- Ease of access to EHR data

Opportunities

- Learn from others who have developed standards, tools, common data model, etc.
 - Observational Health Data Sciences and Informatics (OHDSI)
 - Patient-Centered Outcomes Research Institute (PCORI)
 - Professional Societies (e.g. American College of Obstetricians and Gynecologists)
- Develop a WIKI; provide a shared commons - - a searchable knowledge base to facilitate information-sharing about data
- Develop a consortium, or, tap into an existing consortium of academic medical centers to focus on data issues
- Use Collaboratory as a convener to bring people together around data issues
- Approach data issues using a framing analogy: e.g. need to work all of the 'Lug Nuts' at the same time – can't just work on one at a time:
 - Data purpose
 - Data standards (collection and displaying)
 - Common models
 - Theory of change

Collaboration

Challenges

- The pace or speed of a project (e.g. slow vs. extremely quick)
- Competing priorities
- Funding:
 - Groups can "melt" while waiting for it
 - Often obtained in silos and not as a shared resource to facilitate collaboration
- Training needs related to organizing and sustaining collaborations
- Leadership priorities – e.g. resources are allocated to a project and then shift over time
- "Problems of interest" change and shift
- Inclusion - there is a danger of leaving people out of the group; must recognize the need to be inclusive, especially of those at greater risk of marginalization
- Trying to sustain a partnership over time

Opportunities

- Develop long-lasting partnerships after establishing collaborative groups
- Recognize good ideas and tie recognition to mission (or financial) goals
- Need experts in social partnerships to help build collaboration
- Reward and incentivize the Learning Community members
- Link the form of collaboration with the type of mission (i.e. is it a membership of peers, if not what kind of leveling is advantageous and how do we attain it?)
- Stress the importance of early teambuilding:
 - Builds trust
 - Increases commitment
 - Coordinates shared mental model of project (what, how, when, who, why)
- Provide clarity of project/team onboarding process and roles for participants and members
- Uncover funding opportunities for Collaborative partnerships

Overcoming Resistance to Change

Challenges

- Learning Health Systems – may require reorganization of the current biomedical research and health care enterprises to succeed
 - People may need to be re-orientated to a different set of core responsibilities
 - New role functions are hard to scope out because of rigid HR structure
- Conflicts of Interest
- Time-lag in collecting data in a Learning Health System
- Encouraging buy-in; enabling the ability of all to see/feel problem

Opportunities

- Create a community of learners
 - Requires adequate infrastructure to be successful
- Use participatory design approach
 - Can point to specific projects that have developed e.g. learning communities
 - Balance current workload capacity
 - Economics – how will someone benefit from the “new ideas” and where will the resources come from to pay for the learner?
- Tap into existing literature – “burning platform”
 - What is the shared problem that we all have?
- Evidence/data can be used to show how/why need for change; take advantage of what’s already known in this space and build on it
- Reward ideas for change
 - The reward should be baked into the culture of change – the change is the reward

Sustainability

Challenges

- Keeping programs going when funding runs out
- Successful LHS examples/programs stop or dwindle
- Shortage of resources (data, people, ideas, money, time, knowledge)

- Misunderstanding (leading to disagreements, silo thinking, hiding, failures, unrealistic expectations or no expectations)
- Email storms
- Pilot projects don't take off (spread). Why? People are left out – then they say “no”
- Lacking money
- Poor infrastructure to support work
- Short term fill gap versus systems thinking
- Organizational instability (rearranging)

Opportunities

- At the outset, create a long-term plan for: Resources (data, people, ideas, money, time, knowledge)
- Enable consensus and empowerment
- Share info, truth telling (PDSA cycle)
- Set proper expectations
- Acknowledge mistakes (you learn so much from mistakes!)
- Educate; role model; train the trainer
- Better spread of pilots (pilots should come after pilots). Through succession of pilots - who is next? What is learned? How do we modify?
- Communicate; talk to users, whoever has questions, people who are impacted by work, etc.
- Understand organization's capacity for stability
- Build infrastructure to withstand organizational instability

Funding

Challenges

- Difficulty in framing the message about what an LHS is; e.g. what would happen without a learning health system for donors?
- Difficulty in being able to show the impact on the individual - how will improving health infrastructure and implementing LHSs impact individual health?
- LHS is applicable to any health system or disease – both a blessing and a curse; individual donors are more likely to want to fund a specific health issue in relation to LHS

Opportunities

- Framing the problem in an identifiable way (postal system is broken in Mexico) may evoke innovative solutions (e.g. courier mail service in Mexico)
- Applying the LHS to a specific health issue makes it relatable to potential donors
- Gather resources, literature, boiler plate descriptions of LHS
- Develop a clear and concise value proposition
- Create profiles of each member initiative that could be presented to funders as a portfolio of options
- Centralize the early discovery/search for opportunities - regular search of grants.gov, relationships with federal funders; send a monthly digest of funding opportunities
- Research what competitor institutions are doing with LHS research
- Pull in selected collaborators