Summary Proposed Action Plans (Friday, 12/9/2016)

Breakout Groups Categories:

Breakout Groups:
- Group #1) DISSEMINATE LHS CULTURE – PROMOTION
- Group #2) ORGANIZATIONAL CULTURE – ORGANIZATIONAL INFRASTRUCTURE & ECOSYSTEM – SCALE
- Group #3) BUILD COMPONENTS
- Group #4) CONSUMER FOCUS
- Groups #5 and #6) P2D & D2K PLUS K2P
- Group #7) FUND LHS – POLICY/GOVERNMENT – SUSTAINABILITY

Summary Notes from Breakout Groups from Day Two (Friday, 12/9/2016):

Group #1) DISSEMINATE LHS CULTURE – PROMOTION (12/9/2016)
* Learning Health Community Purpose – Implementation and Adoption – Create a demand from all stakeholders for the Learning Health System (LHS).

Proposed actions:
1. Identify who will undertake the action/responsibility to create the demand for the LHS by the stakeholders (see purpose above).
2. Need to understand who are the stakeholders. What are their needs and priorities need to support this effort to implement a LHS?
   a. Share and review list of stakeholder groups, make sure it is complete (patients, clinicians, consumer groups, government, pharma, payers, CEOs, BOD).
3. Define value proposition for each stakeholder group – why does this matter for our us or our organization?
   a. Develop stories/narratives - choose 5 stories that could bring to life and show the value of a LHS and how it can be life-changing for patients and their families. These stories already exist, should turn these into short videos to get the message across. Develop these for the various stakeholders (patients, clinicians, industry, etc.) - see ACTION #2. What would a LHS would mean to their group (publicize at professional society meetings). Show what will the future look like.
4. Branding messaging strategy to increase awareness of the existence of a LHS - message the vision in order to increase the excitement and passion to identify additional LHS Endorsers (professional societies, for example).
   a. Encapsulate a story into the newsletter for professional societies, develop core content for presentations, annual meetings, slide decks.
   b. Introduce “something small” soon to demonstrate the value and increase awareness, advertise and make it highly visible.
   c. VA will demonstrate VA IT Marketplace Platform and how to use it.
5. Introduce LHS Awards - provide recognition for early adopters of LHS – pharma, hospital, researchers, for having an impact that “moves the needle”. Can also give awards within specific fields and indications. (Measurement level for adoption, similar to HIMMS certification.)
Group #2) ORGANIZATIONAL CULTURE – ORGANIZATIONAL INFRASTRUCTURE & ECOSYSTEM – SCALE (12/9/2016)

Action steps:

1. Use these models and key characteristics as a roadmap, to create a “kit” or guide for creating, developing and maturing a learning health system at whatever scale
   a. Readiness assessment – what are your assets?
   b. What does each of the stakeholder groups need to do to make it happen?
   c. How will progress be monitored?
   d. Need to identify what this guidebook, roadmap look like – who will do this?

2. Can Billings Clinic be used as a test case for evaluation of readiness to develop a learning health system? Who from LHS would like to help?
   a. Largest health system in Montana
   b. 400 physicians
   c. Tertiary care hospital, network of small critical care hospitals, primary care
   d. Can inform a community of practice and readiness for LHS implementation

3. Based on the experience at Billings Clinic, invite other interested “organizations or communities” at different scales to test model, assessment tool, roadmap, modify.

4. Invite these and other organizations to join a Community of Practice to foster learning and progress.

5. Refer to the following for context:
   a. Identify and describe models that may work in different settings
      i. Disease registries / practice settings
      ii. Integrated healthcare systems
      iii. Specialty care
      iv. Patient-powered models
   b. Identify key characteristics that promote learning health systems at all scales
      i. Data sharing (ultimately)
      ii. Regulatory aspects
   c. Key aspects of collecting data and making it usable (P2D)
      i. Meta-data regarding data collection
      ii. Open-source software
      iii. Structured data whenever possible and appropriate
      iv. Build upon standards that already exist
      v. Data provenance
      vi. Agreement not necessarily on the technical level, more the conceptual level
      vii. Federated and centralized databases that complement each other
   d. Key approaches toward analyzing and interpreting data (D2K)
      i. Understand biases and limitations
      ii. Appropriate study designs
   e. Development of ways to implement knowledge (K2P)
   f. Identify communities of practice
      i. Learning how to learn

Group #3) BUILD COMPONENTS (12/9/2016)
* Three key LHS functions underpin all actions:
  - 1.) Put in place a robust system that improves the health of the population
  - 2.) Conduct research that is integrated into practice
- 3.) Participate in continuous quality improvement

* Proposed framework for driving data sharing:
  - 1.) Develop a common language
  - 2.) Develop motivation for that common language
  - 3.) Share and disseminate successful models

Proposed action plan:
1. Name a core set of standards (content standards, exchange standards, and terminology standards) for purposes of supporting the LHS, and vet them.
2. Survey existing LHS initiatives to find out what is working well (and the specific build components supporting them); identify them by reaching out to LHS Core Values endorsers for input.
3. Establish a maturity model that would support evaluating the level of implementation of a LHS, covering structure, process, and outcomes.
4. Develop a list of build components and develop a common understanding of what they are.
5. Create an assessment tool that could be used by organizations desiring to implement LHS to identify gaps and assess organizational readiness.
6. Create and host a collaborative repository of LHS best practices, using the maturity model.

Group #4) CONSUMER FOCUS (12/9/2016)
* Motto: Learn, connect, share, empower.
* Focus: Focus on language.

Consumer focus proposed action plan:
1. Identify early adopter LHS communities and how they have empowered consumers to transform health through their shared experiences. (1yr) 2017
   a. Create a survey of the LHS community to identify early adopters.
   b. Interview and/or conduct focus groups of early adopters to determine best practices for engaging consumers as partners in learning health.
   c. Create summary of early adopter activities for dissemination (including the LHS Journal, professional organizations, and consumer groups).
2. Create consumer engagement campaign. (1yr) 2018
   a. Review best practices from early LHS adopters.
   b. Develop messaging for consumers.
   c. Conduct focus group review of messaging.
   d. Identify marketing partner.
3. Provide consumers with real-time convenient access to their health data in usable and actionable forms. (2017 – 2019)
   a. Convene diverse consumers to elicit information on how they define usable and actionable information.
   b. Convene technology vendors to review consumer recommendations.
   c. Convene consumers and technology vendors to agree on best practices for development of usable technology solutions that meet consumer information needs.
4. Develop a framework for a consumer-mediated learning health information ecosystem that includes the consumer-owned and controlled health record. (2019)
   a. Review lessons-learned from steps #1 - #3.
b. Draft a framework that includes best practices for consumer engaged LHS implementation.
c. Distribute framework to stakeholders for critical review and adoption.
d. Develop a toolkit that includes an actionable implementation guide and sample content and timelines.
e. Disseminate framework and toolkit to professional organizations and consumer.

Groups #5 and #6) P2D & D2K PLUS K2P (12/9/2016)
Breakout groups #5 and #6 combined action plan:
1. Educate stakeholders on K2P
2. Produce monograph on K2P best practices
   a. Needs to be living document
   b. Wiki-like site on LHC website
3. Resolve the centralized vs. federated database question
   a. Do we need a single large database with >50M patients covering all diseases?
4. Promote consensus on data quality standards
5. Engage professional/patient society partners
   a. Begin with the believers
6. Support development of K2P platforms
   a. Address concern about validity of knowledge; importance of provenance
7. Build “LHS thinking” into education, beginning in high school
   a. Create LHS competency set and LHS workforce
   b. Offer LHS badge for curricula

Group #7) FUND LHS – POLICY/GOVERNMENT – SUSTAINABILITY (12/9/2016)
Envisioned actions:
1. Create an advocacy body for policy change is needed
   a. Enable comparative cost effectiveness research
   b. Clarify the regulations and guidance around explicit consent and approval for learning activities including quality improvement
2. LHS community to admit that business opportunity is limited within the current healthcare or legacy system
   a. Encourage disruptive organizational innovation in healthcare system
   b. Create a new kind of stakeholder
3. Create a method of aggregating all available data (who?)
4. Involve local government in LHS prototype
   a. Regional public health funding
   b. Community networks (local scientists)
   c. CMMI Trials run locally
5. Encourage academics: health economists/business schools
   a. Generate evidence of the low-cost benefit
   b. For example: Harvard Business School and Harvard Medical School