LHS Collaboratory with Peter Margolis, MD March 19, 2019 Additional Q&A

1. Can you share your strategies for engaging patients? How do they find out about the data sets in order to contribute?

We have published several articles about patient engagement and co-production that provide more description

- Co-production of healthcare service https://qualitysafety.bmj.com/content/25/7/509
- Engagement, peer production, and the learning healthcare system https://www.ncbi.nlm.nih.gov/pubmed/24446048
- 2. What are the funding mechanisms for these networks?

Networks are funded from a mix of sources including participation fees, support from state payors like Medicaid, and grants to support innovation and research.

3. How are you adapting to the constantly shifting regulatory landscape related to data?

A good description of the infrastructure and approach to building networks can be found in this article.

Britto MT, Fuller SC, Kaplan HC, et al Using a network organisational architecture to support the development of Learning Healthcare Systems *BMJ Qual Saf* 2018;**27**:937-946. https://qualitysafety.bmj.com/content/27/11/937.info

4. How are the contributions to the network from the community validated and/or moderated?

Governance is a central issue for networks based on contribution and generosity. This is known as non-market production or peer production. There is extensive work that has been done on this topic with the most notable being the work of Elinor Ostrom and her Nobel Prize on "Governing the Commons." For a useful introduction to this concept, consider watching Yochai Benkler's TED talk or reading Jeremy Heiman's "New Power" https://hbr.org/2014/12/understanding-new-power