Sustainability Considerations for Health Research and Analytic Data Infrastructures

Adam B. Wilcox, PhD1; Gurvaneet Randhawa, MD, MPh2; Peter J. Embi, MD, MS3; Hui Cao, MD, PhD4; Gil Kuperman, MD, PhD5

1Intermountain Healthcare; 2Agency for Healthcare Research and Quality; 3The Ohio State University; 4Astrazeneca Pharmaceuticals; 5NewYork Presbyterian Hospital

Introduction
- Recent large investments in creating data infrastructures to support the important goals of patient-centered outcomes research (PCOR) and comparative effectiveness research (CER), while critical to the creation of the infrastructures, are not expected to sustain them far beyond the initial development.
- To provide the maximum benefit, the infrastructures need to be sustained while they provide value to PCOR and CER researchers.
- We define considerations of the scope of sustaining infrastructures and potential strategies for sustainability, as well as how various stakeholders can participate in maintaining an infrastructure.

Key Considerations for Sustainability

### Assets
- Structural
- Human
- Scientific

Each infrastructure is made up of structural, human and scientific components that must be maintained. Different component types require different strategies for sustainability.

### Expansion
- Different components of an infrastructure have different sustainability requirements, according to the level of expansion needed to keep it functional. Some components have to grow to be useful, while others can just be maintained.

### Complexity
- Some components are more complex than others to sustain. Technical assets are often well-defined, while governance and collaborations require constant navigation to sustain.

### Stakeholders
- The value of a resource is critical to its sustainability, and value is determined by groups outside the resource. Stakeholders provide resources for sustaining, but they also have diverse needs that can complicate or even redirect the functions of a resource.

Lessons Learned

**There are significant ongoing costs to support a research and analytic infrastructure**

- Industry annual maintenance costs are typically 20% of the purchase costs, but data infrastructure maintenance can be higher, about 35-40%.
- Informatics issues alone can be >20%.
- Almost half of ongoing maintenance costs are for analysts to extract data out of the system. Any costs savings efforts should target this functions.
- Governance and maintaining collaborations is also significant.

**Costs can be covered if value can be created**

- While initial investments to create an infrastructure are often hopeful, based on the potential of the idea, ongoing maintenance is dependent on a demonstration of value.
- Ongoing support will have to come from stakeholders receiving value.
- Researchers who use the infrastructure could contribute some maintenance support.
- For-profit companies have been show to be successful in contributing to maintenance.

**Having multiple stakeholders increases the opportunity and complexity of sustaining an infrastructure**

- Single stakeholders are generally unable to solely support an infrastructure, so multiple different stakeholders should be pursued. This allows cost sharing across multiple groups.
- Multiple stakeholders increase the complexity and governance of the infrastructure, which increases maintenance costs.
- Focus should be on areas of shared interest.

**Stakeholders may support an infrastructure to keep flexibility in an emerging area**

- Sometimes the value provided from a data infrastructure is its potential, rather than its direct use.
- If developed resources are seen as strategic in an emerging area, stakeholders may find it more efficient to maintain the resource rather than risk having to rebuild it later, even when it is not providing direct value currently.
- Perceived value of data infrastructures remains high.