



## Health Data: Summary of Common Themes from Stakeholder Interviews

As of 6.1.18

### Background:

- Cambia Grove is a health care innovation hub focused on bridging the gap between entrepreneurs and the traditional health care sectors to drive system-wide transformation
- One of Cambia Grove’s core goals is to break down barriers to innovation in response to the needs of the health care changemaker community
- Health data often presents a barrier to innovation for the community, and was therefore selected as a focus area

### Approach:

- Health data is a complex topic, and challenges and opportunities in this space vary greatly depending on perspective
- To understand the full scope of opportunities, Cambia Grove embarked on a community exploration project, interviewing 74 stakeholders representing 55 unique organizations
- Detailed feedback was distilled down to common themes, specific challenges and community initiatives - - all stakeholder interviews were conducted in confidence to enable candid discussion and open dialogue; feedback has been anonymized and summarized

### Initial Results: Cambia Grove to select projects based on feasibility and impact

ID.	Top Theme Areas	Specific Challenges	Potential Community Initiatives
1.	<b>Clarification &amp; Education</b>	<ul style="list-style-type: none"> <li>▪ There is a need to bridge the gap between data needs and abundant data resources; questions exist around scope and if/how datasets can be leveraged</li> <li>▪ Inconsistencies in data literacy (i.e. data types &amp; differences in data across each of the “5 Points”)</li> </ul>	<ol style="list-style-type: none"> <li>1. Shine a light on existing data resources &amp; tools accessible to changemakers in health care (<b>COMPLETE</b> – Data Resource Directory)</li> <li>2. Develop online “Wiki” resource to describe data types prevalent in health care</li> <li>3. Facilitate a “5-Points” style training to teach basics of health care data</li> </ol>
2.	<b>Collaboration &amp; Coordination</b>	<ul style="list-style-type: none"> <li>▪ Existence of siloed/disparate data sources and warehouses</li> <li>▪ Collaboration and synergy across data collection entities exists, but with limitations</li> <li>▪ Multiple factors contributing to lack of interoperability (e.g. trust, resource requirements, competitive advantage)</li> <li>▪ Need for solutions to 1) span the entire state and 2) cover all populations</li> <li>▪ Integration between/within EHRs is a massive hurdle</li> </ul>	<ol style="list-style-type: none"> <li>4. Provide a convening space to 1) drive alignment across stakeholder groups and 2) select projects to tackle (<b>In Progress</b>)               <ul style="list-style-type: none"> <li>– Include 1) data experts, 2) diverse “5 Points” representation &amp; 3) technology leaders (e.g. Microsoft, Amazon)</li> <li>– Ensure statewide coverage (rural, urban, public, private)</li> <li>– Leverage collaboration to coordinate existing resources and get all stakeholders on same page</li> <li>– Support existing national efforts to make EHRs interoperable (CareEquality, 21<sup>st</sup> Century Cures, CARIN etc.)</li> </ul> </li> </ol>



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3.	<b>Inclusion of Diverse Datasets</b>	<ul style="list-style-type: none"> <li>▪ Behavioral health data is not easily incorporated with medical data</li> <li>▪ Broader linkages are needed between traditional health care data and social determinants of health</li> </ul>	<ol style="list-style-type: none"> <li>5. Ensure solutions address behavioral/social data and can distill down to disparities</li> <li>6. Translate learnings from DSHS for use with commercial populations</li> <li>7. Drive towards inclusion of diverse measures in performance monitoring (see project #10)</li> </ol>
4.	<b>Enhanced Use of Existing Data Resources</b>	<ul style="list-style-type: none"> <li>▪ Opportunity for individual data collection entities to broaden horizons and expand scope</li> </ul>	<ol style="list-style-type: none"> <li>8. Leverage community to identify synergies and expansion opportunities between existing data resources</li> </ol>
5.	<b>Meaningful Application</b>	<ul style="list-style-type: none"> <li>▪ Lack of alignment on why the data is truly needed – what will we use it for?</li> <li>▪ Limitations in ability to apply massive amounts of available data in a universally meaningful, actionable way</li> <li>▪ Multiple disparate methodologies across individual payers, provider organizations, etc. (e.g. attribution, quality, etc.)</li> <li>▪ Heavily relied-upon algorithms might not truly be human-centered</li> </ul>	<ol style="list-style-type: none"> <li>9. Apply data sets to tangible/high-priority use cases (<b>In Progress</b>)</li> <li>10. Leverage community to align upon common set of measures, algorithms, methodologies               <ul style="list-style-type: none"> <li>– Consider inclusion of diverse data-sets</li> <li>– Ensure diversity of approaches to accommodate differences in circumstance (e.g. rural health)</li> </ul> </li> <li>11. Drive towards government-mandated gold standards</li> </ol>
6.	<b>Health Data Laboratories &amp; Portals</b>	<ul style="list-style-type: none"> <li>▪ Robust/easily accessible databases are limited, from the perspective of being able to conduct meaningful analyses, quantify opportunity, conduct demonstrations, etc.</li> <li>▪ Barriers exist for entrepreneurs to obtain data for testing, demonstration or business use</li> <li>▪ People have great ideas, but no way to show them</li> </ul>	<ol style="list-style-type: none"> <li>12. Create “data lake” with real, de-identified data               <ul style="list-style-type: none"> <li>– Provide data infrastructure to enable stakeholders to develop hypotheses and answer critical questions</li> <li>– Start with a specific use case (e.g. cancer/HICOR)</li> </ul> </li> <li>13. Develop dummy databases for entrepreneur access; divide by data type (e.g. claims, clinical, outcomes, SDH) for innovators to easily plug in to &amp; use</li> <li>14. Develop a public utility to make all data available to those who need it; must be able to follow the patient</li> </ol>



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7.	<b>Patient Identification &amp; Tracking</b>	<ul style="list-style-type: none"><li>▪ Lack of unified patient identifier</li><li>▪ Inability to obtain real-time information around patient location, utilization, etc.</li></ul>	<ol style="list-style-type: none"><li>15. Drive efforts to initiate alignment on a master patient identifier</li><li>16. Develop tool to track patient utilization and report back to care management entities</li></ol>
8.	<b>Pathway to Data Access</b>	<ul style="list-style-type: none"><li>▪ Change-makers could benefit from access to existing data sources, but either 1) cannot afford access or 2) have a difficult time navigating associated processes</li><li>▪ Patients do not have easy access to their own information</li><li>▪ Without clear incentives, data-sharing is difficult to drive/enforce</li></ul>	<ol style="list-style-type: none"><li>17. Create streamlined pathways to existing data resources (e.g. purchasing subscriptions, securing discounts, etc.)<ul style="list-style-type: none"><li>– Local health data resources</li><li>– National general data warehouses (e.g. IDC, Gartner, etc.)</li></ul></li><li>18. Tap into existing pathways - - identify organizations interested in sharing subsidized data licenses</li><li>19. Identify potential financial incentives to drive data providers to share information (e.g. providers, data warehouses, even patients [via crowd-sourcing])</li></ol>

*Please submit questions and comments to:*

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