Leveraging Data and Technology for Healthy, Equitable and Sustainable Communities

Research Findings and Recommendations

Presented to: Kaiser Permanente and the W.K. Kellogg Foundation

By

NETWORK IMPACT

October 12, 2015

Origin and Context

- Increasing numbers of change agents are exploring and applying new tools and technology for data, mapping and analysis that can inform decision-making, build engagement and track impact.
- In this context, Kaiser Permanente (KP), the W.K. Kellogg Foundation (WKKF) and other partners see a timely and strategic opportunity for funders to learn with and from each other in a more deliberate way.
- KP and WKKF engaged Network Impact to conduct research that highlights opportunities for funders and organizations to advance their goals while creating shared value and leveraging current investments in data and technology across organizations.

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Goals of the Project

- Understand the current environment for leveraging data and technology for healthy, equitable, and sustainable communities
  - Identify gaps and opportunities for innovation
  - Surface and frame ideas, areas of alignment or leading opportunities for funders
- Use a listening and ideation process to draw insights from key stakeholders in different sectors

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Methodology

- Document review and desk research (Fall 2014)
- Survey of select organizations (n=25) and funders (n=36) that use or fund technology in their work (Jan 2015)
- Interviews with technology innovators to gather insights on areas of greatest potential and barriers to overcome (Winter-Spring 2015)
- Interviews with platform and tool developers (Spring 2015)
- Interviews with funders, including program as well as IT and other staff who support and use technology (Summer 2015)

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Stakeholder Interviews:

- **Innovators:**
  - **City of Chicago, Dept. of Innovation and Technology**, Raed Mansour, Chicago Department of Public Health Innovation Projects Lead & Tom Schenk, Chief Data Officer
  - **Data.gov**, Rebecca Williams, Senior Engagement Liaison, Open Data expert
  - **DataKind**, Jake Porway, CEO and Erin Akred, Data Scientist
  - **Google Social Impact/Civic Innovation Team**, Anthea Watson Strong, Technologist, Community Organizer
  - **HHS Idea Lab**, Damon Davis, Dir for Health Data
  - **Ideo**, Dave Blakely, Technology Strategy Lead (now independent consultant)
  - **National Institute of Health, Big Data to Knowledge Initiative**, Jennie Larkin, Ph.D., Senior Advisor
  - **Ushahidi**, Nathaniel Manning, COO
  - **Impact Lab/Do Good Data Conference**, Andrew Means, Founder
  - **Context Partners**, Stewart Sarkozy Barkozy, Managing Director
  - **Markets for Good/Gates Foundation**, Victoria Vrana, Senior Program Officer, Charitable Sector Support
  - **Dallant Networks**, Victor d'Allant, CEO; Mark Durham, CTO
  - **Tableau Foundation**, Neal Myrick, Director
  - **US Department of Health and Human Service, ONC, IT Health**, Maya Uppaluru, Policy Analyst for Health Innovation, Division of Science & Innovation
  - **LiquidNet for Good**, Brian Walsh, Head of Corporate Impact
  - **Digital Civil Society Lab, Stanford Center on Philanthropy + Civil Society**, Lucy Bernholz, Co Lead

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Stakeholder Interviews:

- **Platform and Tool Developers**
  - **Community Commons** – Roxanne Fulcher, Executive Dir, IP3 & Chris Fulcher, CARES Co-Director
  - **Esri** – Dr. Este Geraghty, Head of Health and Human services division
  - **PolicyMap** – Maggie McCullough, CEO

- **Philanthropy Support Organizations**
  - **The Foundation Center Knowledge Services** - Renee Westmoreland, Director of Web Services
  - **Grantmakers in Health,** Osula Rushing, *Vice President for Program and Strategy;* Ann McMillan, Program Director

- **Grantee Intermediaries**
  - **Data Across Sectors for Health (DASH)** –Peter Eckhart, , MA, Director, Center for Health and Information Technology; Melissa Moorehead, Sr. Policy Analyst, Innovative Solutions Team
  - **Public Health Institute –** Amy Neuwelt, CDC Public Health Prevention Service Fellow

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Stakeholder Interviews

- **Funders**
  - **Kaiser Permanente**, Michael Johnson, Executive Director, Utility for Care Data Analysis at Kaiser Permanente
  - **Robert Wood Johnson Foundation:** Laura C. Leviton, Senior Adviser for Evaluation; Steve Downs, CTO; Michael Painter, Senior Program Officer, Quality/Equality team, Tina Kauh, Evaluation
  - **Center for Disease Control and Prevention**, Denise Koo, Office of the Director; Brian Lee, Chief Public Health Informatics Officer
  - **The California Endowment**, Lori Nascimento, Program Manager for Learning and Evaluation
  - **Kresge Foundation**, David Fukuzawa, Managing Director, Health program; Bill Moses, Education team lead
  - **Ford Foundation**, David Roth, Chief Technology Officer
  - **Colorado Trust**, Nancy Baughman Csuti, DrPH, Director of Research, Evaluation & Strategic Learning
  - **Dignity Health**, Michael Bilton, Senior Director, Community Health and Benefit; Ji Im, Director Community and Population Health
  - **W.K. Kellogg Foundation**: Ross Comstock; VP, IT; Chantal Foster, Consultant; Lihn Ngyeun, COO; Huilan Krenn, Director of Evaluation
  - **Mozilla Foundation**, Dan Sinker, Director of Knight-Mozilla OpenNews and Erika Owens, Program Manager
  - **California HealthCare Foundation**, Andy Krackov, Associate Director, External Engagement, Free the Data Lead
  - **Gates Foundation** – Ben Pierson, Principal Technology Advisor

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Quotes and examples used throughout have been pulled directly from the survey research and interviews

Confidentiality of participants has been preserved

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Overarching Themes that Emerged from the Research

Three Overarching Themes

1. Invest in a *Data Ecosystem* that Accelerates Social Change Goals

> *"A healthy ecosystem means the social sector has the information they need at the right time, in the right format, using the right tools that are built on standardized flows of information that allow them to be more effective."*

2. Advance Equity and Social Justice

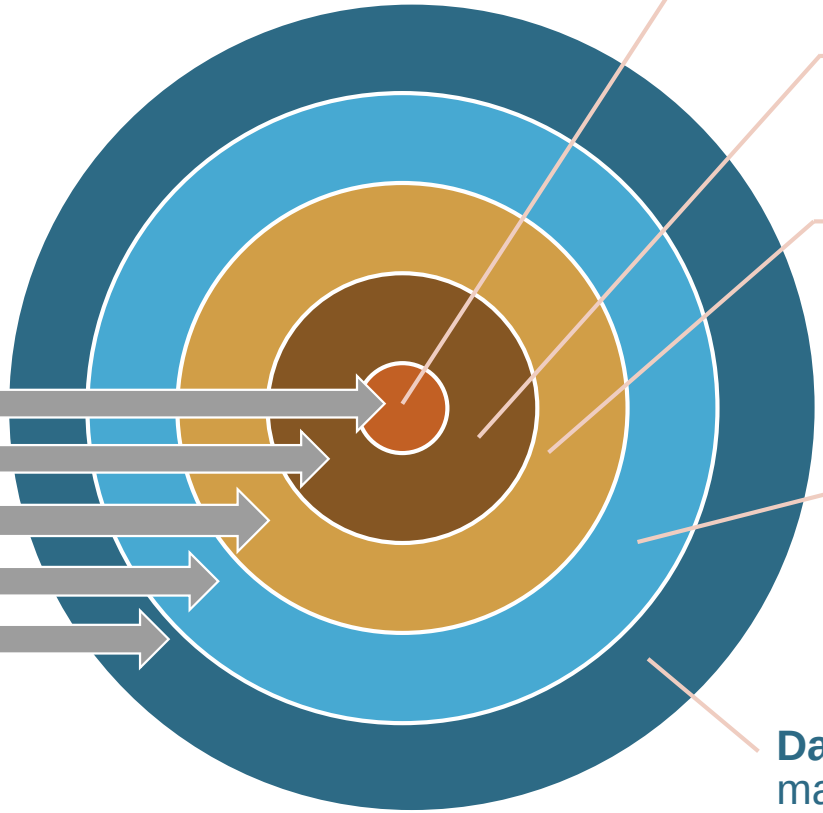
> *"Big data is one of today's key civil rights issues."*

3. Build a Data-Informed Culture

> *"The best situation is one in which everyone to some extent or another sees data as part of their job, because basically anyone who's making decisions in an organization should be making decisions based on evidence."*

1. Invest in a Data Ecosystem That Accelerates Social Change Goals

Elements of Ecosystem



Stakeholders
Individuals
Communities
Government
Funders
NPOs
Companies

Data -- Data collection, access to data

Infrastructure -- Definitions, regulations, unique identifiers, interoperability to ensure sharing, accessibility, security, and privacy.

Knowledge & Collaboration Tools -- Platforms, tools and apps for aggregation, interpretation, analysis, visualization, mapping

Bridges and supports for capacity -- Technical assistance, more highly skilled workforce to use tools & technological bridges that increase use of data

Data-informed culture -- Decision makers, policies, attitudes, behaviors

Graphic created by Network Impact, informed by Markets for Good

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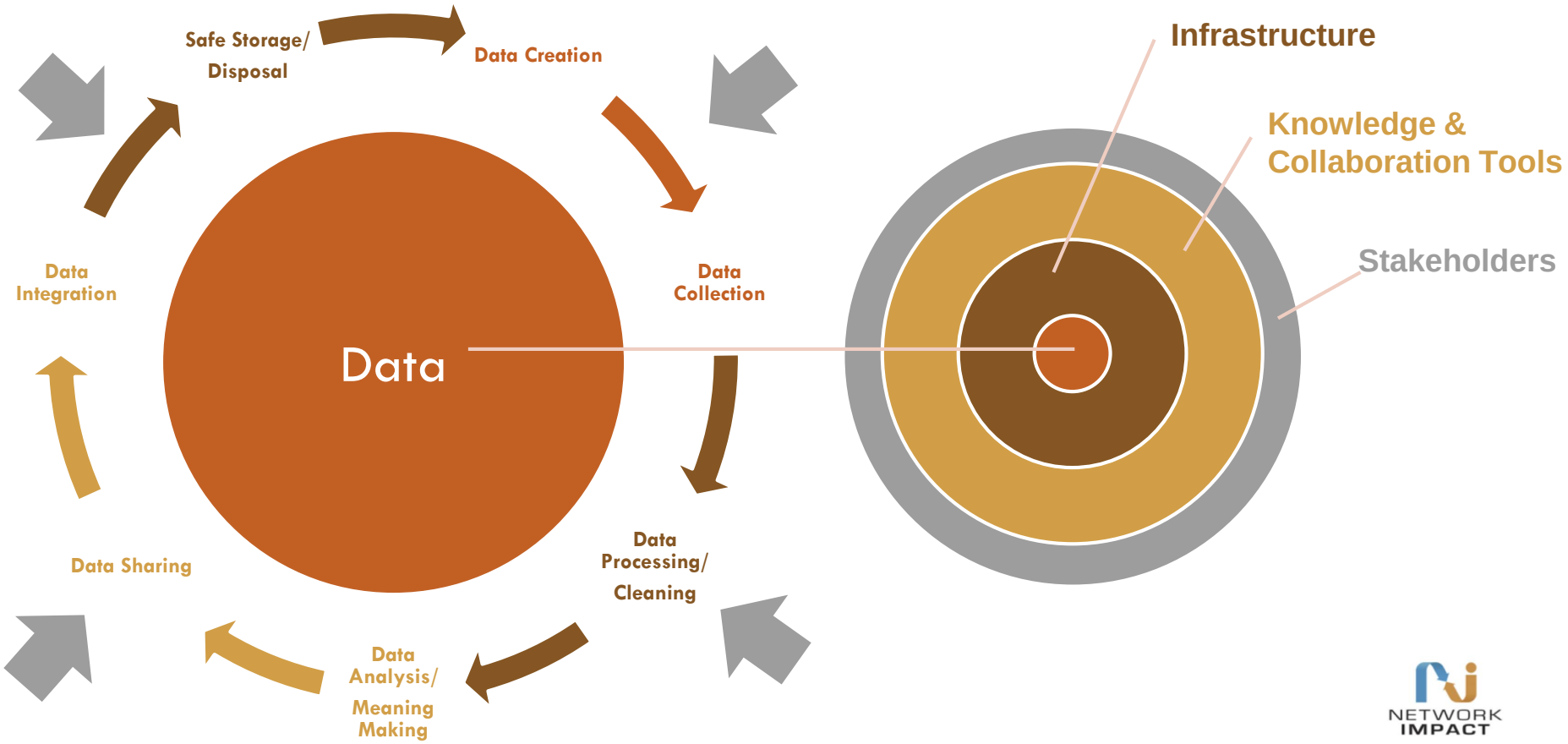
1. Data Ecosystem: Consider Full Data Lifecycle

- Stakeholders interact throughout the data lifecycle as contributors, users and custodians:



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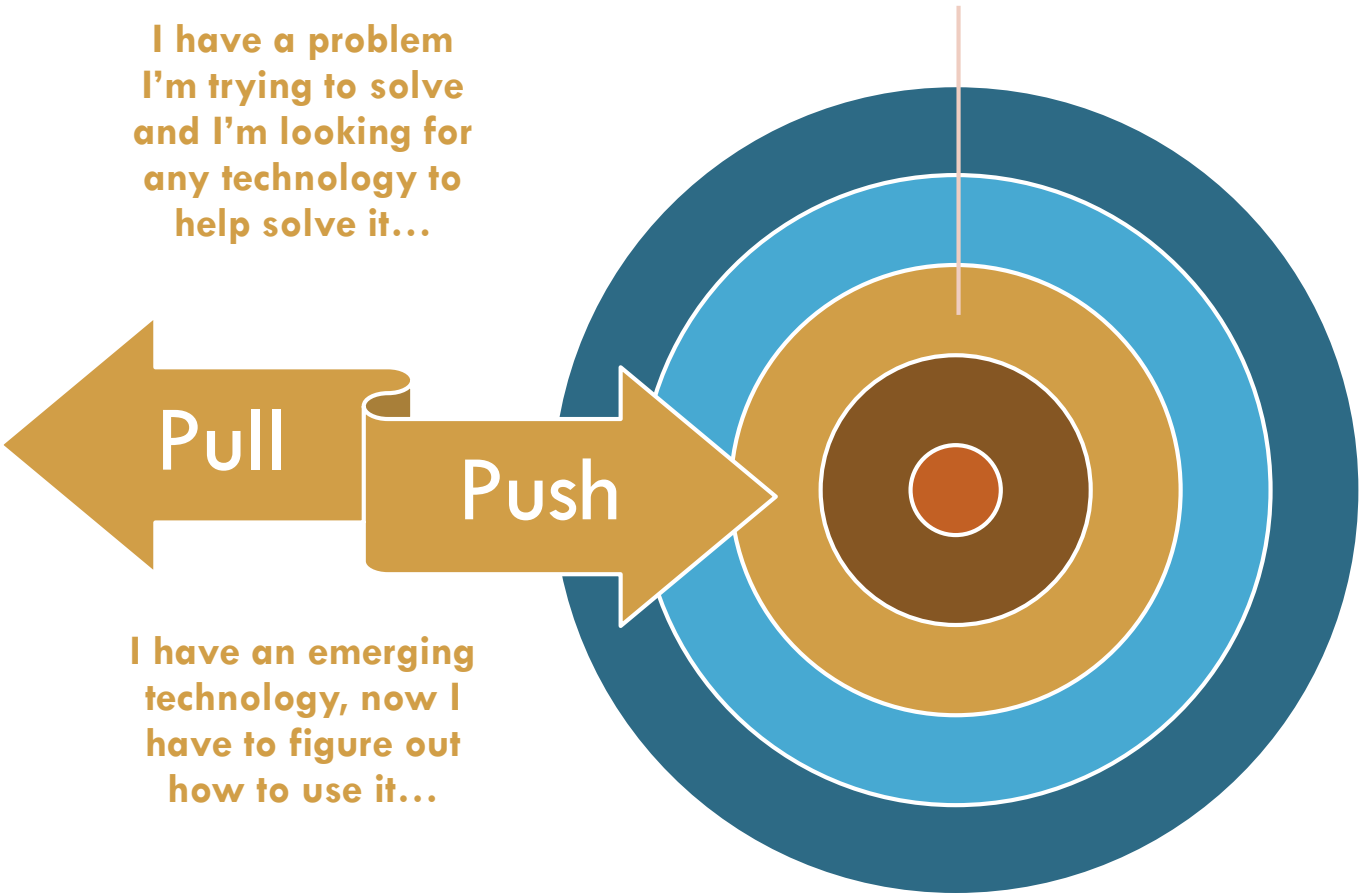
1. Data Ecosystem: Tension between Technology Push & Pull

Creation of knowledge and collaboration tools is driven by technology push and pull

I have a problem I'm trying to solve and I'm looking for any technology to help solve it…



I have an emerging technology, now I have to figure out how to use it…

"I consistently see the best, sustained record of innovation and of fantastic solutions coming out of organizations that create a healthy tension between technology push and pull, and demand that their people keep both tech push and tech pull perspectives in mind simultaneously."

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2. Advance Equity and Social Justice

- Data as tool to reveal disparities and inform action and progress

> *"To the degree that people see the numbers, see the stories behind the numbers, see the actions that they can take behind the numbers -- Ultimately I think we have an opportunity to engage folks on an ongoing basis around, what are you going to do about it?"*

- Data and technology literacy for people, organizations and communities

> *"One of the underpinnings of our philosophy is that communities collaborate and engage in their own solutions and advocate for their own answers. That's predicated on the communities coming together and agreeing – comprehending, understanding, and agreeing on what data defines the problems."*

- Privacy and data sharing policies and roles for all stakeholders

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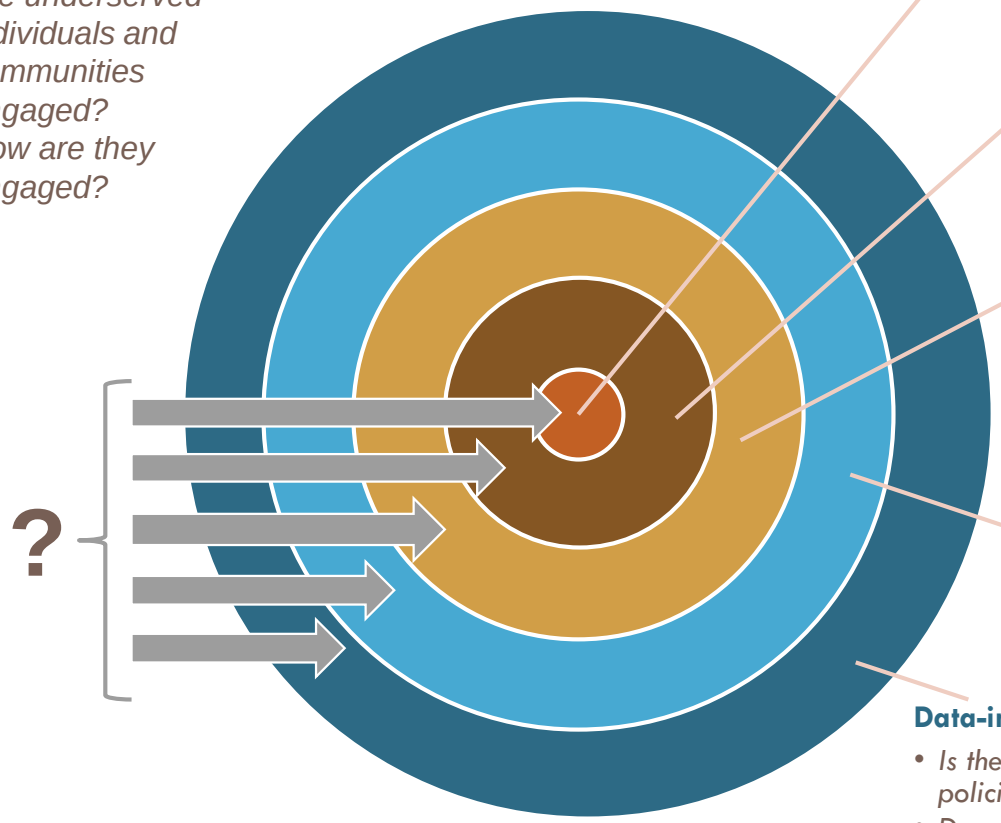
2. Advance Equity and Social Justice

Stakeholders

- *Who are stakeholders?*
- *Are underserved individuals and communities engaged?*
- *How are they engaged?*

Key Questions to Consider



Data

- *Who decides what the relevant data are?*
- *Whose problems are data being collected to help solve?*
- *Who is represented in data?*
- *How is data being collected?*

Infrastructure

- *Who has access to data?*
- *Who is included in decisionmaking about data privacy and ethics?*

Knowledge & Collaboration Tools

- *Who has access to tools?*
- *Do new data-informed tools strengthen the values of equity and justice?*
- *Do tools shed light on inequity and discrimination?*

Bridges and supports for capacity

- *Who is part of the data science workforce?*
- *Do efforts to build capacity engage underserved communities?*

Data-informed culture

- *Is the use of data to address inequity prioritized in policies and by decisionmakers?*
- *Do people and decisionmakers have the information they need to support equity and justice?*

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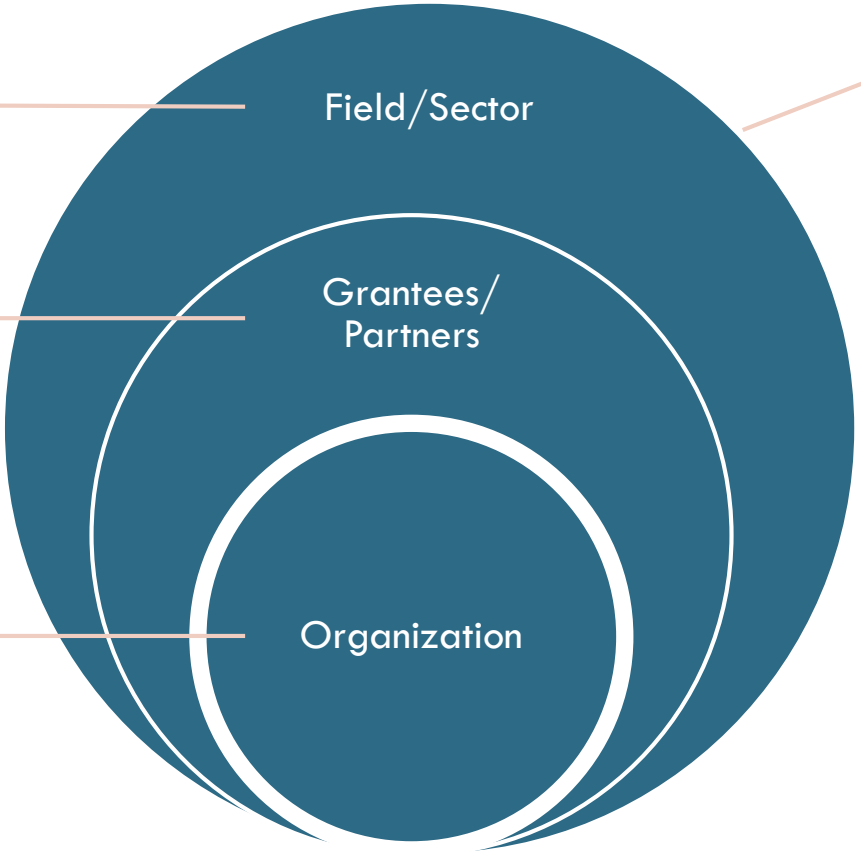
3. Build a Data-Informed Culture

- Organizations should cultivate a data-informed culture by considering what that means ***internally*** for their organization and ***externally*** for their partners and the field.

- Access to a supportive technology and data infrastructure

- Resources to use and leverage data
- Data collection and sharing, data-informed strategy incentivized

- Enterprise-level data integration
- Data-informed strategy
- Learning through feed-back loops



Data-informed culture

- Decision makers, policies, attitudes, behaviors

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Four Critical Investment Priorities
(+ Leadership Opportunity)

A Systems Approach is Vital

- A systems approach is essential to ensure that field-level opportunities for linking and leveraging data and technology are identified and acted upon.

"If you don't have a system by design, you have a system by default. And right now I think we have a system by default. There's a lot of great work being done, but there's a lot of room and opportunity for even greater impact out of the resources that are already in the system. But I think there's room to unlock even more resources if we were able to more effectively demonstrate the impact of all of these efforts."

"There are a lot of great organizations out there that are trying to work on different pieces of this puzzle. But this is about systems. It's about how do we bring together the right people and create the right alignment of incentives and the right opportunities and the right environment for collaboration to happen to allow these systems to emerge."

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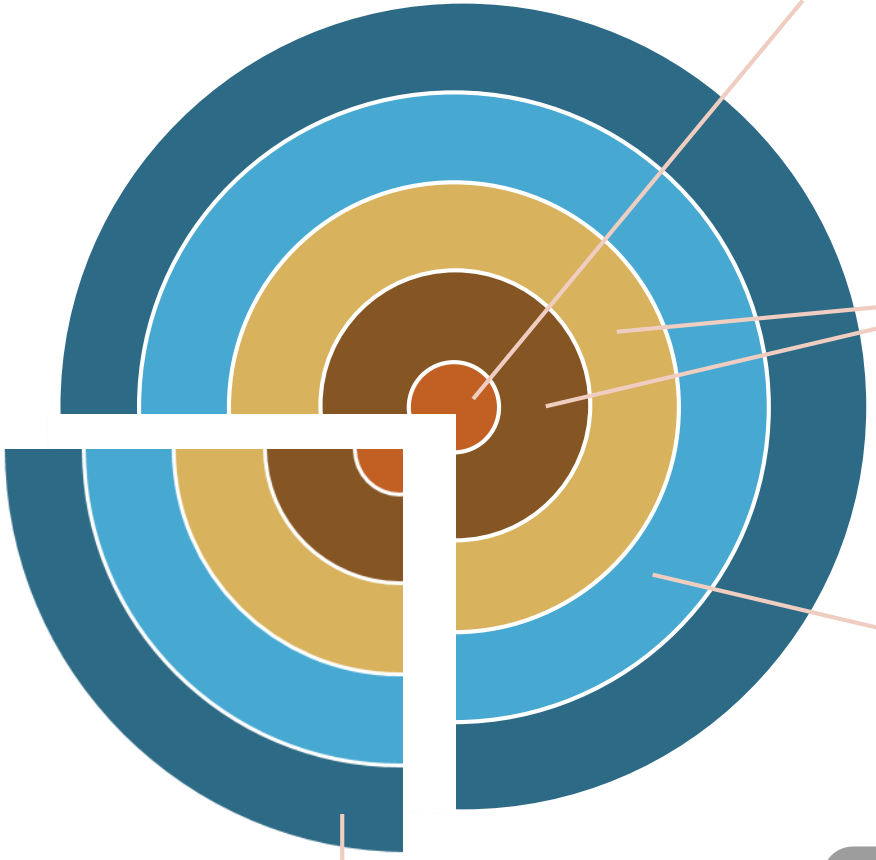
Four Critical Areas for Investment Emerged from the Research



Data Infrastructure

"…there are millions, and millions of people out in the American public. And so, clearly, many of the great ideas are going to be out in the American public, and so our obligation is to make the data available so that people can find interesting, and cool things to do with it."

Technology Infrastructure

"Right now it's very, very hard to share data across organizations…going back to a private sector counter-example, if there was a different Netflix in every city, it's called something different, they never share data, that kind of stuff, they would never be able to predict what movies I like…"

Bridges and Supports for Capacity

"We don't need to buy more tools, but we need to figure out how to use them…"

Research & Discovery

"Get the forward thinking, successful, state or local governments or whoever is doing it right and share what they have done"

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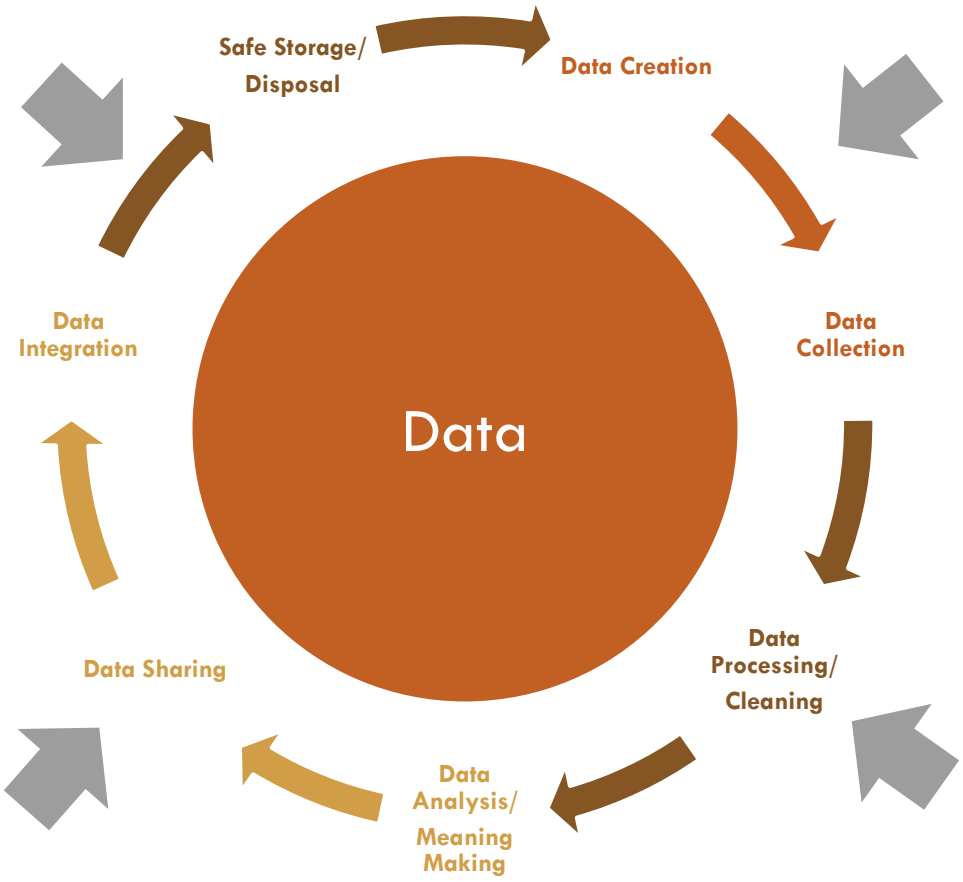
1. Investment Needed in **Data Infrastructure**

Privacy/Anonymization – Address ethical issues related to use of data head-on as part of all decision-making processes, including requiring ethics advisory panels for data projects and fostering of discussion of ethical standards.



Access to Data Ensure that more and different types of end users have access to open, machine readable data so that more apps and resources can be built with/on top of that data.

Data Sharing and Integration Facilitate linking and sharing data across sectors by supporting the standards and interoperability necessary to link data

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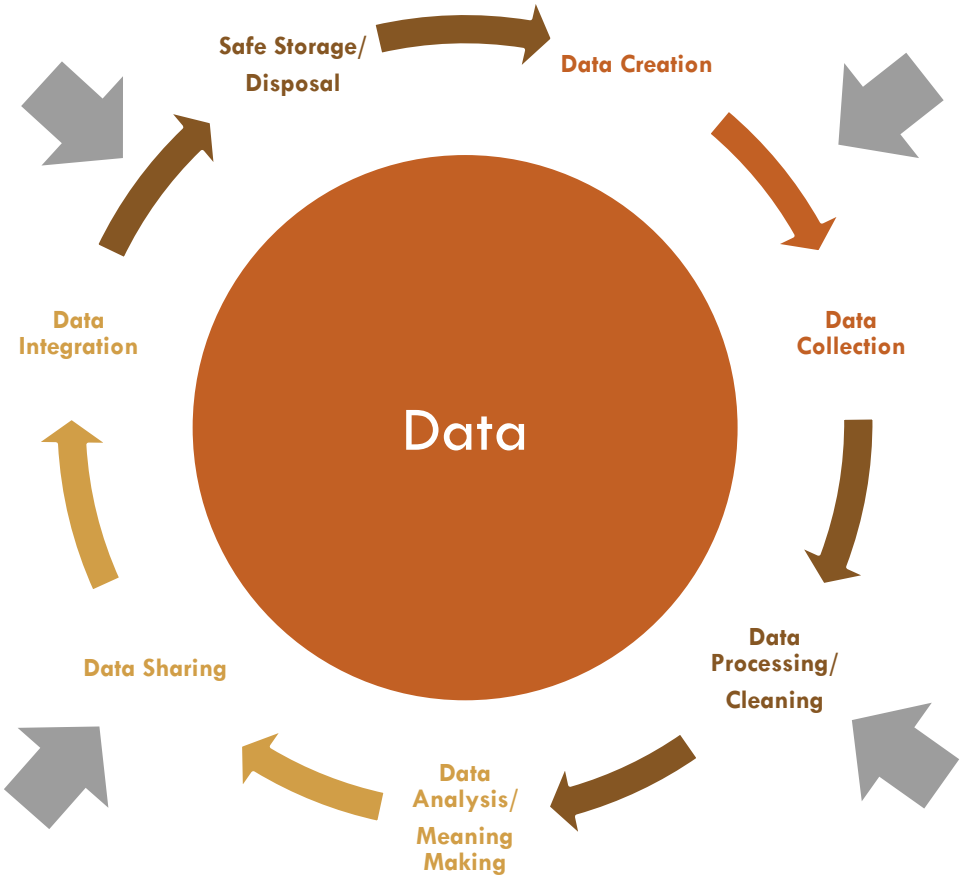
1. Investment Needed in **Data Infrastructure**

Data Sharing and Integration Example

Markets for Good, *an effort funded by the Bill and Melinda Gates Foundation and LiquidNet to improve data collection and standardization about the social sector (grant data, IRS 990 data, investment taxonomies) to help organizations be more effective and fuel investment. The initiative seeks to develop data protocols to address the sector's under-funded, uncoordinated information infrastructure, and develop the core building blocks for information sharing.*



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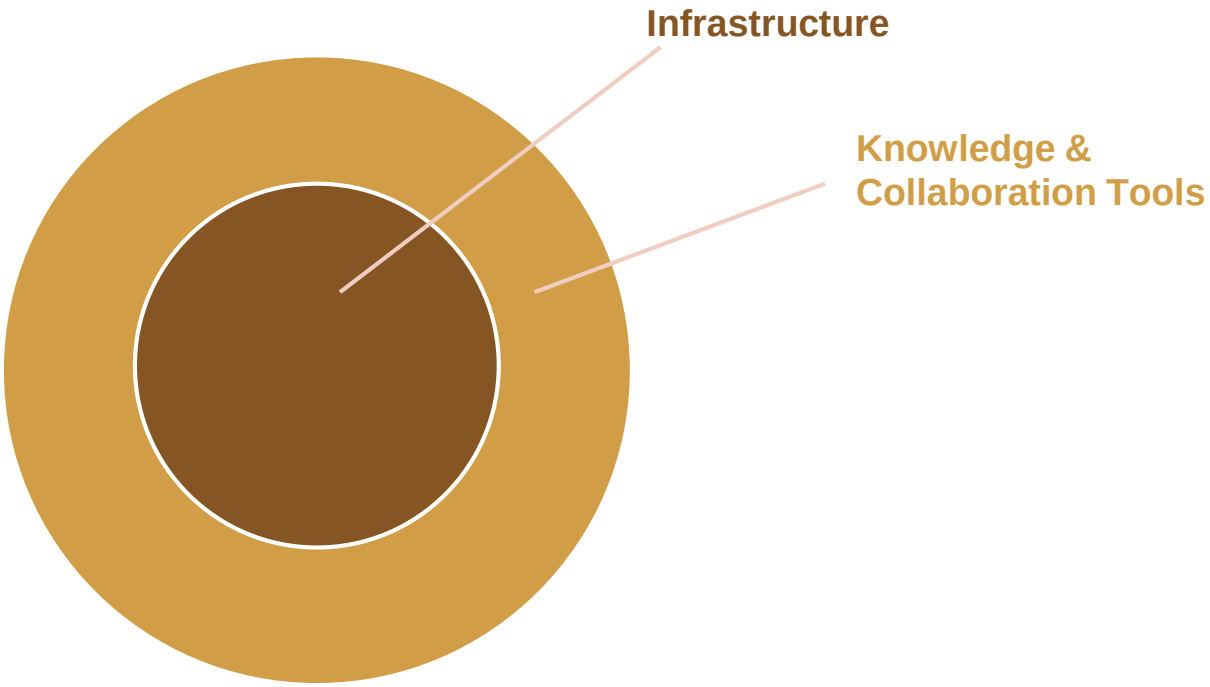
2. Investment Needed in **Tech Infrastructure**

Technology Upgrades and Maintenance: Support organizations and even state and local agencies that have out of date systems that need upgrades to take advantage of new data and analysis opportunities

Data Sharing: Invest in creation/maintenance of data commons or other mechanisms to provide a safe infrastructure for data sharing across organizations and sectors; support open source tools to take data sharing and analysis to scale



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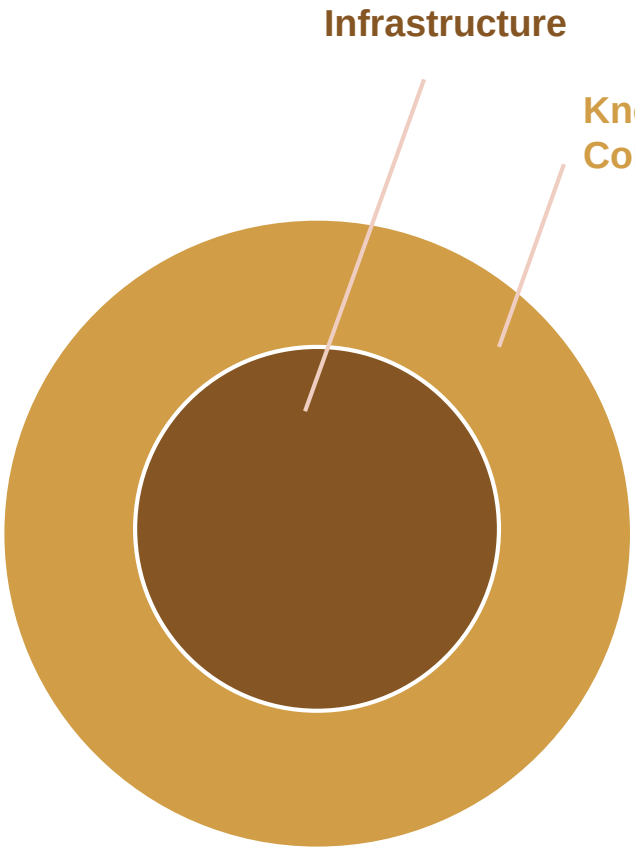
2. Investment Needed in **Tech Infrastructure**



Technology Upgrades and Maintenance Example

As part of ACA implementation, funders in CT and CO funded their state's All-Claims Payer databases as a tool for the states and for consumer advocates; funders in NY funded upgrades of the state's IT systems so that the systems could support integration with new marketplace websites and systems.

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3. Investment Needed in **Capacity Building**

Skills and Knowledge: Create and support training and technical assistance for organizations to build their capacity; fund dedicated staff member time at organizations to use data to ensure adequate organizational capacity for leveraging data & technology

Bridges: Create or support intermediaries that can step into the capacity gap by working with organizations on the problems they are trying to solve

Recruitment: Support in-depth fellowship programs that bring skilled talent into sector; nurture extended network of skilled data & technology staff; create incentives for existing data scientists to work in social sector full-time, create higher educations scholarships or other incentives for data scientists to go into social sector

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3. Investment Needed in **Capacity Building**

Recruitment Example

Knight-Mozilla Fellowships *originally launched to bring change agents into news rooms to help the evolution of newsrooms towards the more open web and embracing of open web technologies. Now in its fourth year, the year-long fellowship has evolved to focus on both bringing new talent in, and, nurturing the existing network of technologists in newsrooms by focusing intentionally on the "connective tissue" in the network.*

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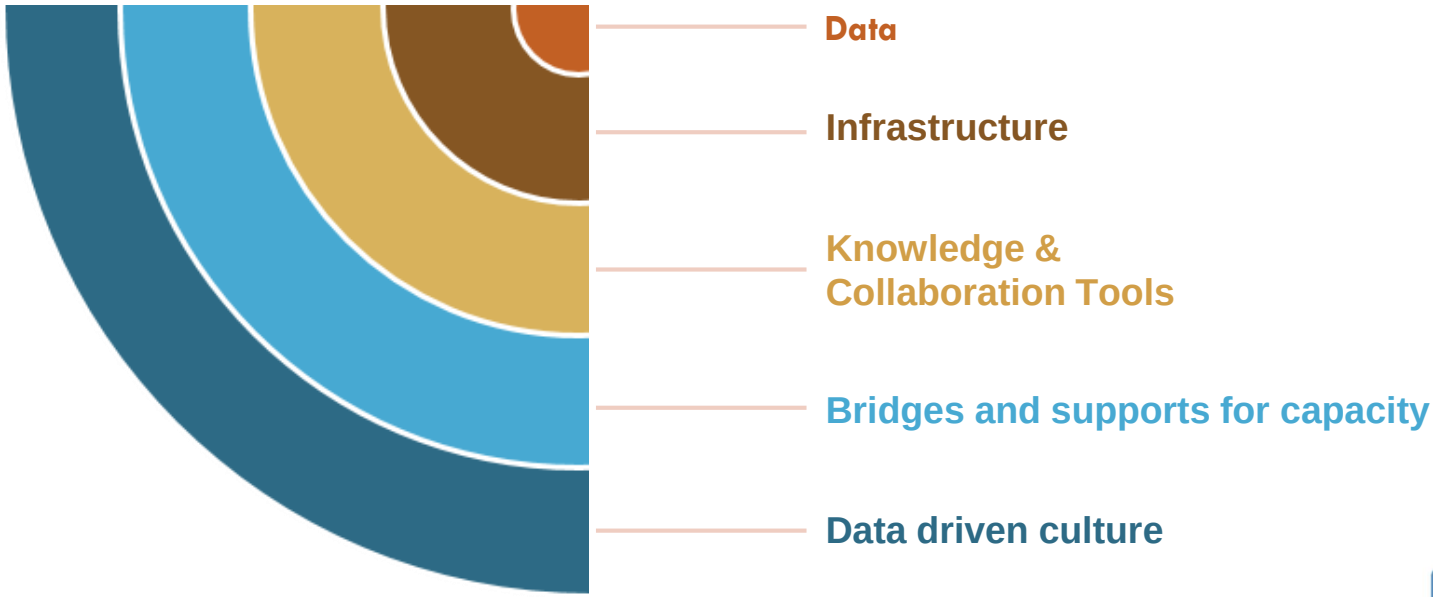
4. Investment Needed in **Research & Discovery**

Data innovation research and implementation: Support test beds and R&D projects to drive sector-wide change throughout the data ecosystem

Impact investing: Identify and invest in leading enterprises that will increase ecosystem health and impact



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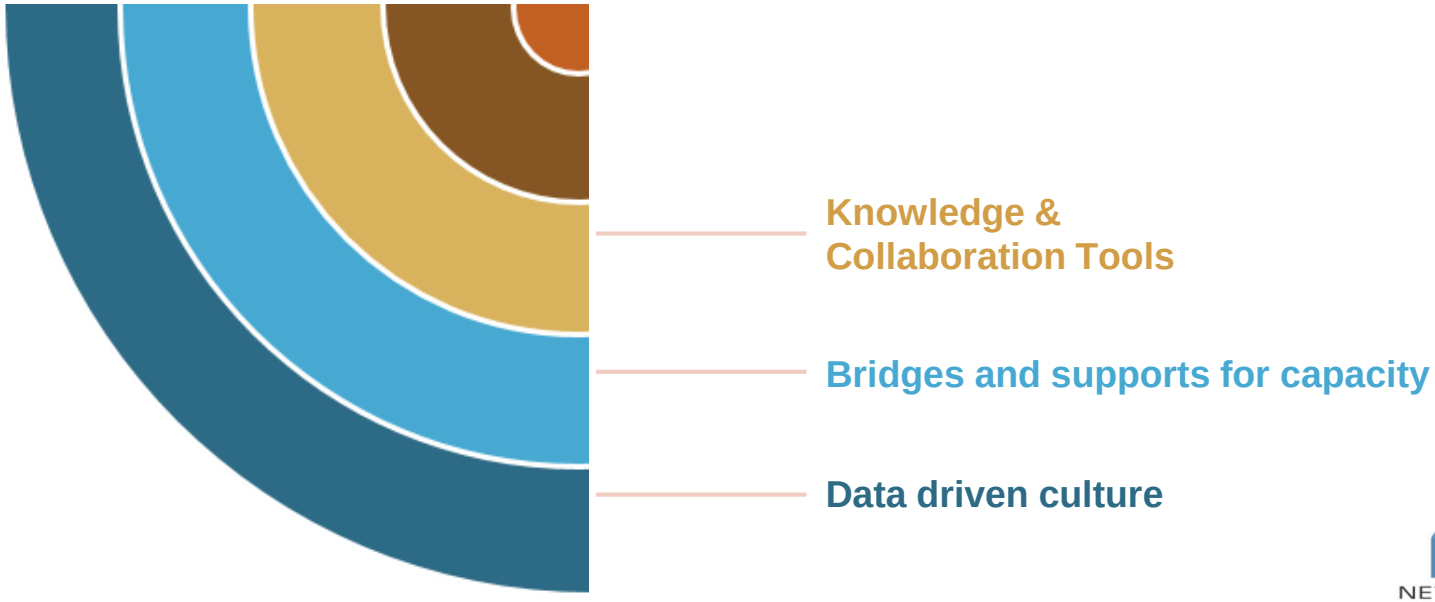
4. Investment Needed in **Research & Discovery**

Data Innovation Research and Implementation Example

HHS's Idea Lab *is supporting the Market R&D challenge, where participants are early stage startups that have a product that's ready to be tested. HHS is pairing them up with clinical partners to pilot their product to help companies make those connections with future customers and help build the evidence base for health IT and mobile health for consumers getting technology to help increase patient engagement.*



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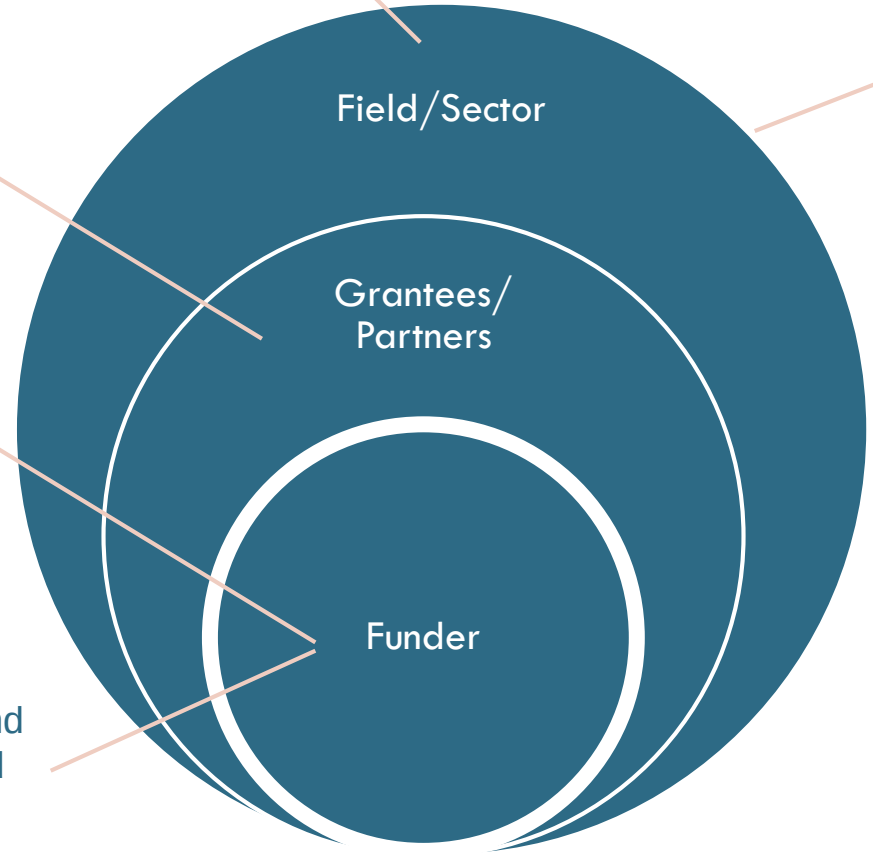
Exert Philanthropic Leadership for a Data-Informed Culture

Support grassroots advocacy on this work: Engage communities proactively to help set an agenda for data collection and use

Change Investment strategies: Use lean grantmaking for software and tech development. Make grants to maintain as well as use technology, make grants to orgs that use data and tech effectively.

Advocate to Advance this Work: Use bully pulpit to create demand for a stronger data infrastructure, ethical standards, and open government efforts

Walk the Walk: Use data in decisionmaking, share data, develop and deploy grant requirements for using and sharing data, engage in and encourage data philanthropy



Data-informed culture

- Decision makers, policies, attitudes, behaviors

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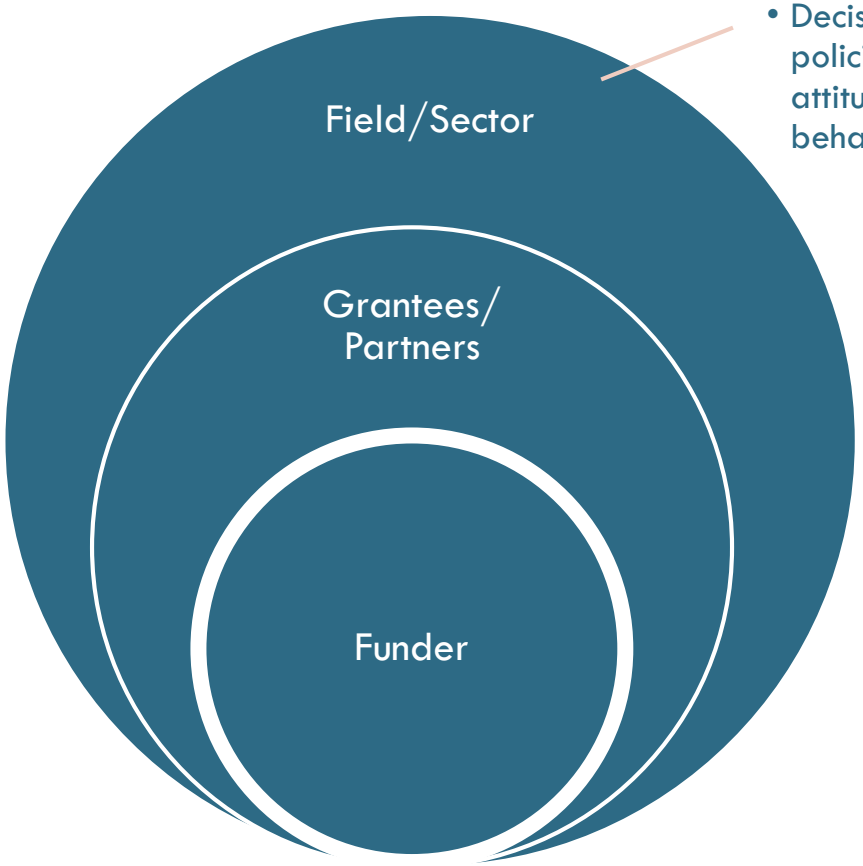
Exert Philanthropic Leadership for a Data-Informed Culture



Change Investment Strategies Example

Google used lean grantmaking approach to fund an upgraded version of Ushahidi. Grant was structured as a "product build" grant, and process involved finding five partners that Ushahidi wanted to work with to consider as target users. Expectation was not that they would reach a million people, rather to deliver a product to five people, and then a finished product was complete and available.

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Technology Innovations That Help Answer Key Questions

Key Questions

- What can data tell us about conditions on the ground?
- What can data tell us about what works/will have impact?
- How can data surface unexpected correlations that spark innovation, which leads to new solutions?
- What can data tell us about where and how we can do better?

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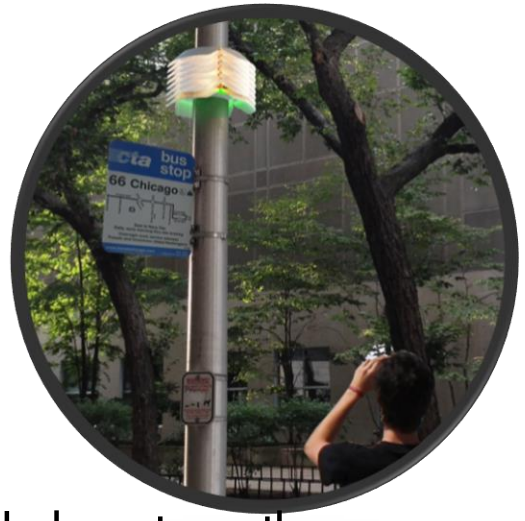
What can data tell us about conditions on the ground?

Innovation

Sensors and sensor networks; alternative data sources

Example



What: Chicago's *Array of Things* project

Sensors on lampposts gather data on air quality, sound, heat, precipitation; a "fitness tracker for the city"

Who: Cross-sector partnership: the U of Chicago's Urban Center for Computation and Data, Argonne National Laboratory, the Computation Institute and the City of Chicago

Results: The data will help make Chicago a truly "smart city," - operate more efficiency, save money by anticipating and proactively addressing potential problems like urban flooding.

Open access to data will support development of innovative applications, such as a mobile application that allows a resident to track their exposure to certain air contaminants.

https://arrayofthings.github.io/

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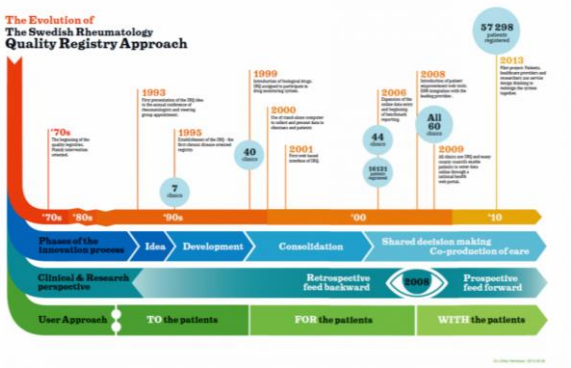
What can data tell us about conditions on the ground?

Innovation

Crowdsourcing
Integration



Example

- **What:** The Swedish Rheumatology Quality Register (SRQ) - Patients and doctors provide data on treatments outcomes and side effects in real-time online or via apps
- **Who:** Swedish Ministry of Health, physicians and patients
- **Results:** SRQ includes 84% of their patients with rheumatoid arthritis. Has played a role in improving the efficient use of expensive medications, reducing inflammation, and reducing total hip joint replacements by 90% in patients with arthritis

http://srq.nu/en/2014/09/11/lagandring-for-personer-med-nedsatt-beslutsformaga/

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What can data tell us about what works/will have impact?

Innovation

Predictive analysis; risk and asset modeling

Welcome to Kaggle's data science competitions.

Competition Name	Reward	Teams
 **West Nile Virus Prediction** Predict West Nile virus in mosquitos across the city of Chicago	$40,000	1306

Example

- **What:** Predicting West Nile Virus in mosquitos across Chicago by using weather, location, testing, spraying data to more accurately predict outbreaks and allocate resources towards preventing transmission.
- **Who:** Cross-sector partnership between the Robert Wood Johnson Foundation, the City of Chicago Department of Public Health and Kaggle, a global community of data scientists that compete to solve problems
- **Results:** 1,306 teams competed for $40,000 in prize money. Competition results will be available in fall, 2015.

https://www.kaggle.com/c/predict-west-nile-virus

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How can data surface unexpected correlations that spark innovation, which leads to new solutions?

Innovation

Combining unlikely datasets; algorithm development to uncover unexpected correlations and new approaches to problem solving

UNIVERSITY INNOVATION ALLIANCE

Example

- **What:** University Innovation Alliance, using diverse, previously unconnected data sets to pinpoint interventions that increase graduation and retention rates for low-income students and students of color.
- **Who:** Six foundations and 11 public research universities.
- **Result:**
  - Arizona State University's eAdvisor program helped it's four-year graduation rate for lower-income students increase from 26% to 41%
  - Georgia State University increased retention rates by 5%, and African-American and Latino students now graduate at a higher rate than white students.

http://www.theuia.org/

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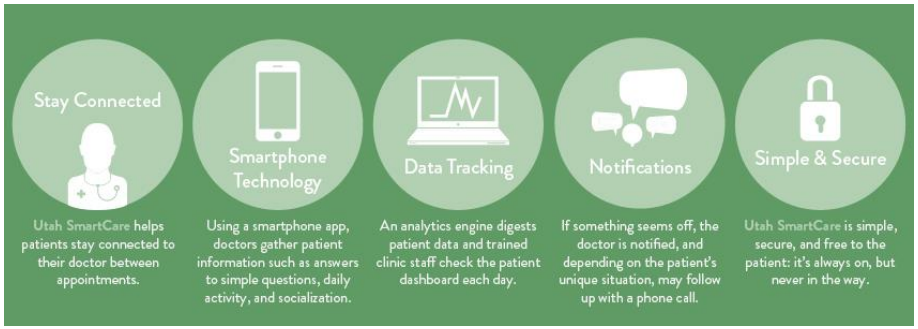
What can data tell us about where and how we can do better?

Innovation

Strategic real-time data and feedback loops; Individual data from cell phones, health monitors, activity trackers



Example

- **What:** Utah SmartCare, uses cellphone data and self-reported information to identify a person's behavioral signature, then looks for variations in real-time that might suggest mental health issues/need for help. App then connects the user to a provider.
- **Who:** A cross-sector partnership between Ginger IO (the smartphone app provider), five healthcare organizations and the Cambria Healthcare Foundation.
- **Results:** The pilot program is targeting 500 patients with co-morbid conditions, nearly 80 percent of whom live at or below the poverty line.

http://auch.org/programs-services/utah-smartcare

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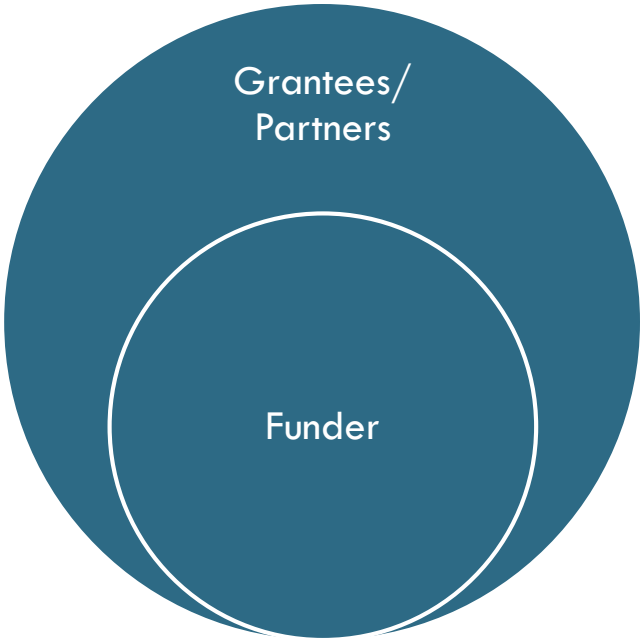
Cautionary Tale! Stakeholder Involvement

Learn from Glorious Failures

Stakeholders
Individuals
Communities



inBloom *was a student data nonprofit that streamlined student information online in nine states so teachers could track their progress, and increase personalization of lessons.*

- *Received $100 million in seed funding from the Bill and Melinda Gates Foundation and the Carnegie Corporation of New York,*
- *Project was unable to reassure parents that children's information would be safe with a third party vendor.*
- *Negative public reaction led to the closure of inBloom, and passage of laws that now cripple the ability to implement future student data and personalized learning efforts*

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Tools and Technology Supports

Key Research Finding

- Research identified hundreds of tools and examples of tool use
- Compared to known innovations in tools and technology, the social sector is slow to adopt new tools and does not fully leverage existing tools
  - Use tends toward tools that only require entry-level skills
  - Use tends toward established practices, rather than innovation

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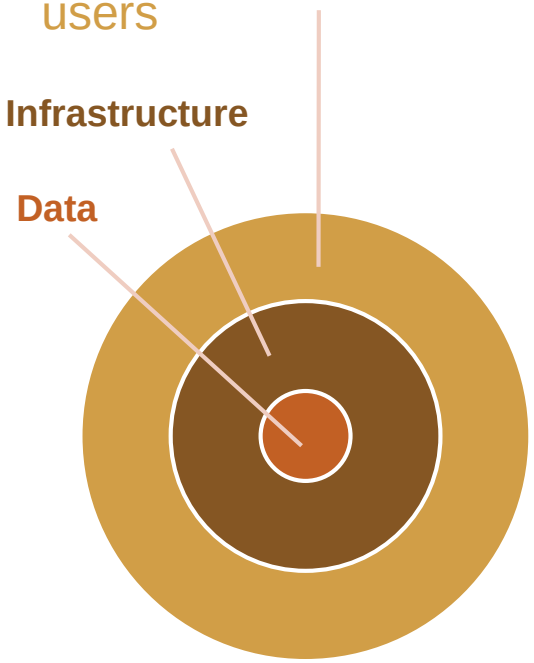
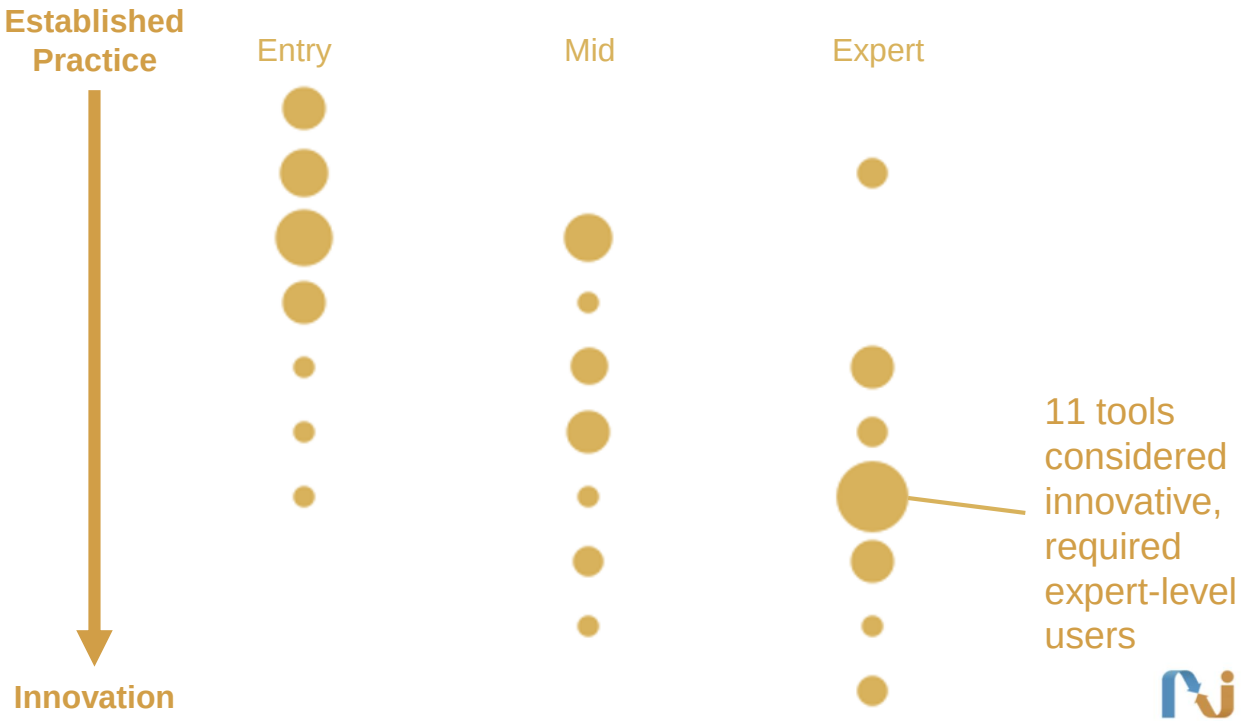
Innovative Tools Require Expert Level Users

Knowledge & Collaboration Tools
Tools on the innovative end of the spectrum tended to require expert-level users





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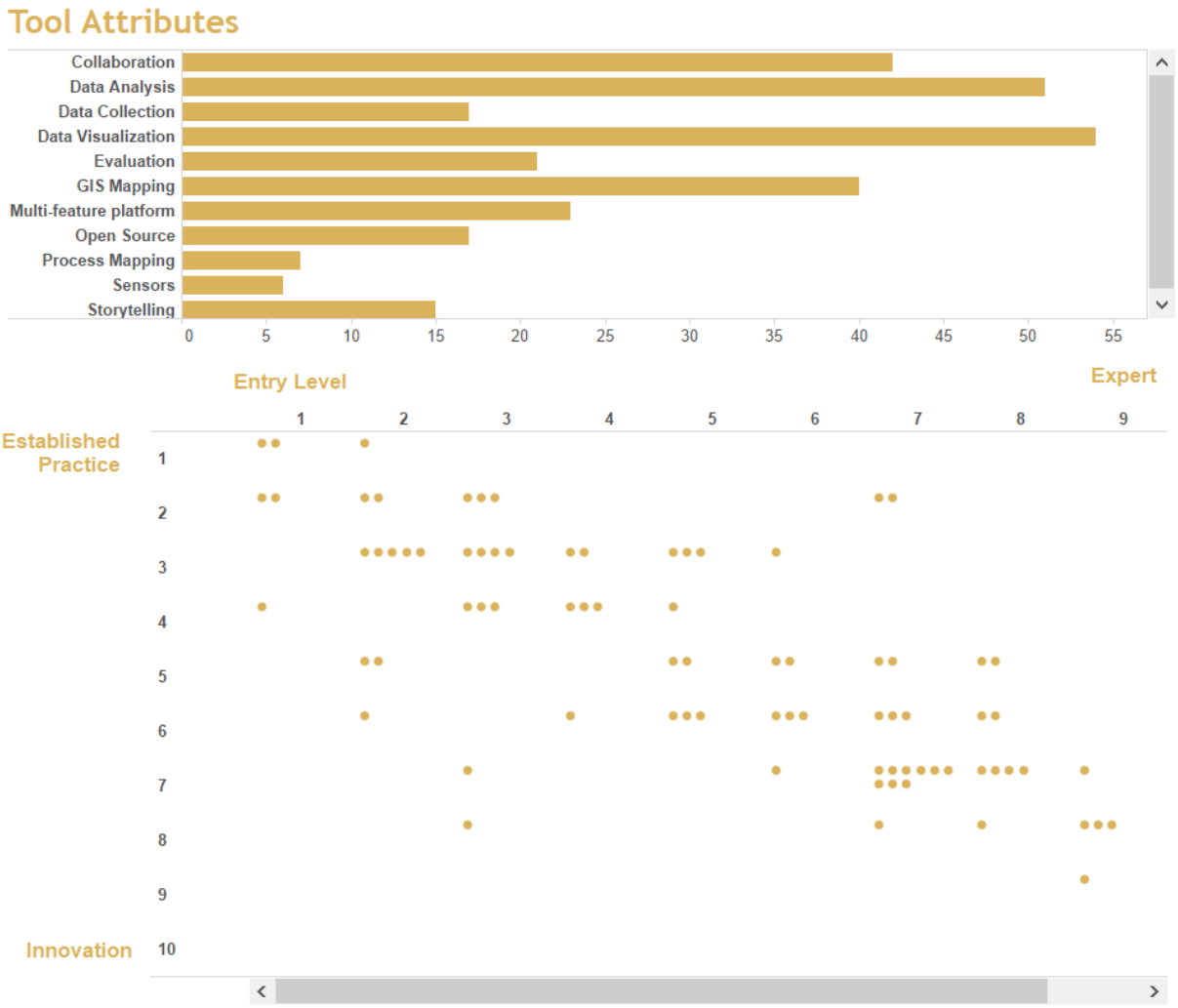
Sector Doesn't Have Capacity to Use Existing Tools



Diving In

Building a Data Informed Culture: Internal Organizational Checklist

Questions to keep in mind during discussions with colleagues:

- Are IT, program and evaluation departments connecting around the use of data to drive impact at an enterprise level?
- Do internal advocates for using data to inform or drive decisionmaking exist?
- Is there budget allocation to support data integration, analysis and visualization to support foundation strategy?
- Are efforts to pilot the use of data to inform and drive strategy planned or do they already exist?
- Are incentives and reward structures in place to encourage data-informed decision making and data sharing?
- Is there capacity internally for data analysis, integration and visualization? If not, where will that capacity come from?

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Building a Data Informed Culture: External Partner Checklist

- Do grantees or partners understand the value of using data to inform and drive strategy?
- Are there requirements for partners to use data in reporting to establish impact or share data sets?
- Is there budget allocation to support data integration, analysis and visualization to support foundation strategy?
- Are efforts to pilot the use of data to inform and drive strategy planned or do they already exist?
- Are incentives and reward structures in place to encourage data-informed decision making and data sharing?

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Tool Development & Funding Readiness Checklist

- Is there a demonstrated need for this tool?
- What role will this tool play in bolstering a healthy data ecosystem?
- What parts of the ecosystem does the tool support or interact with?
- How will you avoid duplicating efforts or reinventing the wheel?
- Is the tool's development using human-centered design to ensure that target end users can fully leverage the technology?
- Realistically, who has the capacity to use this tool to its full potential? If it's not a majority of the people that you are trying to reach, how will you bridge that gap?
- How will you know that the tool is making a difference for target users?

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About the Research Team: Network Impact

- **Network Impact** (NI) provides advice, research and tools to support social change networks, foundations and the emerging field of network builders. NI's practice draws on years of experience assessing civic tech, social change networks, public health and communications and advocacy.
- From 2012-2014, the NI team provided consulting support for the Knight Foundation's Technology for Engagement initiative, including evaluation support for existing grantees and the creation of consistent approaches for evaluating future Technology for Engagement grants. Past projects also include consulting support and evaluation of regional and national policy networks such as RE-AMP, an upper Midwest network of funders and nonprofits working on climate change and energy policy; the Urban Sustainability Directors Network; and rural policy networks developed by the W.K. Kellogg Foundation's "Rural People, Rural Policy" Initiative.
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