



October 26-28, 2020

Maternal & Infant Health in the Digital World:

Patient-Centered Care During COVID and Beyond

VIRTUAL CONFERENCE

hmhbga.org/event/beyondcovid2020

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Responsible Data Sharing During (and after) a Pandemic

Healthy Mothers Healthy Babies GA Conference 2020

Maithri Vangala, Director of Community Engagement, BrightHive

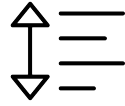
Sam Levy, Community Engagement Manager, BrightHive



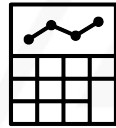
brighthive

BrightHive helps organizations, networks and communities securely and responsibly link their data to enhance their impact, empower individual and collective decision making, and increase equity of opportunity.

For years, organizations, networks, and communities have sought to **collect, integrate, and share data.**



To **align thinking** and make more informed decisions.



To gain broader and **more precise insights** into their individual and collective work.



To measure and achieve the greatest **individual and collective impact** possible.

But **it's not easy**, and that's a problem.

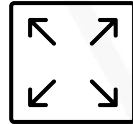
It's been **too hard** for organizations to collaboratively **share their data** with other organizations inside and outside of their network.



Institutional and legal constraints prevent organizations from reaching consensus and sustaining it over time.

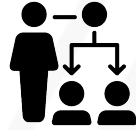


Fragile bilateral agreements are too transactional, adversarial, and are not designed to adapt to changing needs.



Limited capacities and incentives—and overall risk—discourage organizations from collaborating.

It's been **too hard** for organizations to collaboratively **share their data** with other organizations inside and outside of their network.



Top-down data mandates dominate with little control or benefit for the organizations providing data.

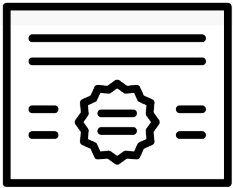


Variations in organizational data and technology do not easily align or integrate.

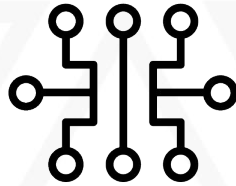
What if ... ?

What if each of these data challenges could be **addressed simultaneously**, allowing organizations, networks and communities to **unlock the power** of their combined data?

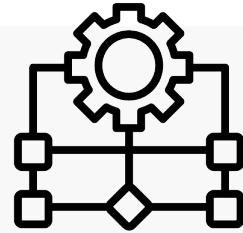
A BrightHive Data Trust provides the **legal, technical, and governance** framework that empowers a collective of organizations to securely connect their data sources and create new, shared data resources.



Legal and Ethical
Framework

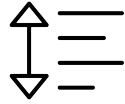


Technical
Standards and Tools



Data Governance
Process

BrightHive Data Trusts empower organizations to ...



Better **align and coordinate** their work.



Enhance and appropriately **measure their impact**.



Effectively **address challenges**—both immediate and emerging.



Be more responsive to the current and future information needs.



Allow their data to be used and enhanced.



Bay Area Workforce Data Trust

Use case

Which programs and credentials meet employers' skill needs and help prepare job seekers for specific occupations available in their region?

BrightHive's work

The Project Signal Workforce Data Trust unlocks the value of existing data, making it easier for low-income Bay Area residents to discover training and credential programs in their area as well as access information about program effectiveness and success.

State of Colorado



My Colorado Journey

Use case

Satisfying state-level WIOA reporting requirements while also providing residents with information about career and training opportunities throughout the state.

BrightHive's work

Working to connect a previously disconnected ecosystem of data in order to create new datasets that help provide personalized, timely, and relevant information to individuals, allowing them to make better informed education and career planning decisions.

What is data governance?



A collection of practices and processes which collectively describe how decisions are made, monitored and enforced regarding the management of an organization's data.

(derived from DAMA International)

Traditional data sharing governance is often limited and under-resourced

Short-Sighted



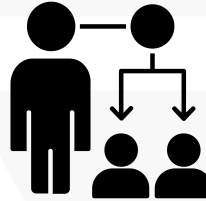
Addresses immediate needs using limited bilateral agreements without a plan for sustainability.

Isolated



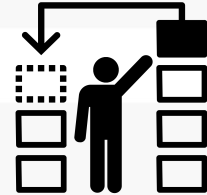
Often sustained by a single champion, but can fail due to changes in leadership or isolated engagement.

Imposed



Imposed on organizations which lack the capacity to participate on equal footing.

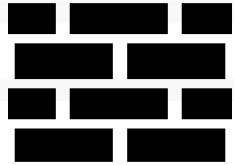
Self-interested



Lawyers engage to protect interests and eliminate liability at the expense of value to stakeholders.

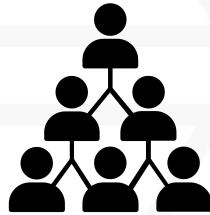
Data sharing governance should be equitable, sustainable

Sustainable



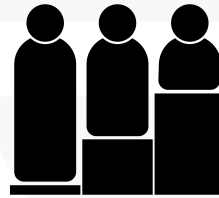
Addresses immediate needs while supporting the potential for long-term growth.

Coordinated



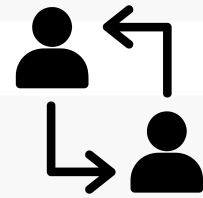
Supports shared decision-making for trust-managed data resources and organizational data ownership.

Empowered



Levels the playing field for all data sharing members, regardless of size, capacity, or incentives to participate.

Group-oriented



Eliminates liability while creating value for communities and individuals who should benefit most from the data sharing.

Data governance: define the collective

Identify a **neutral convener** to guide the collective.

Identify the **key stakeholders** for your collective who represent the **cross-section** of data owners, subject matter experts, technical advisors, data users, and those whose data is being collected.

Establish **internal trust** within the collective.

Rally around a shared vision that outlines a common set of **values** and **motivations**, sets **specific goals** for the partnership, and considers how various barriers to sustainability can be overcome.

Data governance: identify a use case

Identify the **problem** or **policy issue** data sharing can address,

Understand **what** data is being shared, and **why**.

Define **success**--having a clear idea of how you can achieve impact informs what data and metrics you might need,

Leverage existing legal agreements, knowledge, relationships, and collaborations.

Data governance: establish a robust framework

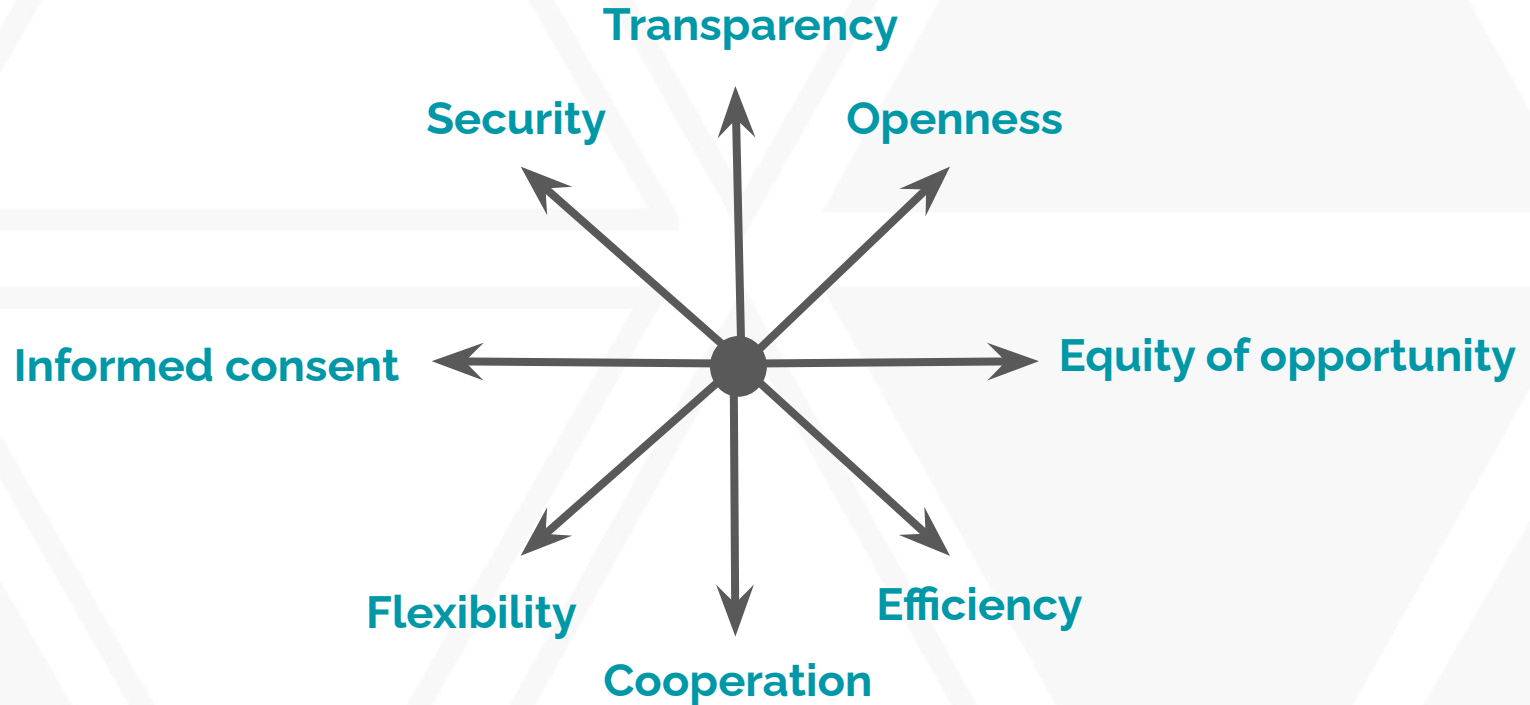
Define **roles and responsibilities** of each stakeholder involved in the collective.

Establish minimum **data** and **technical** specifications for how data will be shared.

Identify and agree on data sharing **expansions**, including new **use cases**, new members, new **pooled resources**, and third party users.

Ensure agreed upon changes are **managed through amendments** rather than renegotiation to meet the expanding and evolving needs of the collaborative and its beneficiaries.

A foundation of ethical principles is key



“Now, more than ever...”

The need for responsible data sharing

Suddenly, responsible data sharing is on everyone's mind

wttw

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SCIENCE & NATURE

Tech Giants' Plan to Track COVID-19 Raises Concerns

Dan Andries | April 23, 2020 8:23 pm

Stopping COVID-19 will include monitoring and sharing personal data

"In a plague, civil liberties have to be suspended. There are good reasons for that."

UNEMPLOYMENT CHECKS ARE BEING HELD UP BY A CODING LANGUAGE ALMOST NOBODY KNOWS

States have been starved of modernization funding for years

By [Victoria Kelly](#) | [Macquinn](#) | Apr 14, 2020, 8:00am EDT
Illustration by [Alex Chen](#)

COVID-19 could have its own PATRIOT Act, but we need privacy guarantees

Heather Federman @FedHeds / 4:15 pm CDT • April 16, 2020

Comment

Technology

Pandemic Data-Sharing Puts New Pressure on Privacy Protections

By [Ben Brody](#) and [Naomi Nix](#)
Apr 15, 2020, 5:00 AM CDT

HEALTH TECH STAT+

Major health-record company drops opposition to federal data-sharing rule

By [CASEY ROSS](#) @caseymoss / APRIL 23, 2020

“We are used to telling people that we can either share data rapidly **OR** responsibly.

COVID-19 is forcing us to figure out how we can share data rapidly **AND** responsibly.”

Data sharing in a crisis: digital contact tracing

Digital contact tracing applications as a means to:

- **track** cases
- **identify sources** of transmission
- inform people who may have been exposed to **take precautions** that can **prevent further transmission**
- share information about **testing protocols** and locations
- measures you can take to **protect yourself and others**

Contact tracing challenges and opportunities

Ensuring stakeholders are **fully engaged** to achieve maximum benefits from contact tracing

Clarifying and communicating **regulatory and legal expectations** to invite interpretation and promote shared understanding

Establishing trust between all involved parties, including data users, app developers, public health agencies, government officials, and data contributors

Implementing **accessible design**--contact tracing apps shouldn't reinforce or further discriminatory outcomes

Designing **privacy and security standards** to protect the sensitive, medical, personally identifiable information collected through contact tracing ranging from infection status to location data to contacts names and whereabouts

Governance enables other uses and disposal of contact tracing data

Post-pandemic, there may be **requests to use the data** for other reasons

- Scientific research
- Public interest historical use
- deleting or de-identifying, both **physically and electronically**
- **what, how, when, and in what circumstances** will data be disposed

Check out these resources if you want to learn more about data governance

[Sharing Data for Social Impact: Guidebook to Establishing Responsible Governance Practices \(Beeck Center for Social Impact and Innovation\)](#)

The Data Sharing Governance Guidebook, which includes a thorough list of resources throughout

[NNIP's Resource Guide to Data Governance and Security \(National Neighborhood Indicators Partnership\)](#)

A resource guide on responsible data governance practices; see pages 18–30 for a discussion of good data security practices.

[7 Tools to Help Build Sustainable Data Governance \(Earley Information Science\)](#)

A toolkit with guides and resources on how to build a sustainable data governance model

[MITA Governance Charter \(Medicaid\)](#)

A template for a team governance charter

[Responsible Data Use Playbook for Digital Contact Tracing](#)

Equips public health authorities and app developers with information and protocols for preserving privacy and ensuring the ethical use of data within contact tracing efforts.

Continue the conversation

Join our [Responsible Data Sharing slack community](#) to connect with others working on data collaborations, access tools and resources, and participate in events.

Sign up for our [newsletter](#) to stay connected to resources, news and stories to help organizations responsibly use and share data to increase collective impact.

Thank you!

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