THE VALUE OF RESPONSIBLE DATA SHARING FOR RESEARCH

Sharing data for research can provide benefits and opportunities to many stakeholders. It can be used to develop new and innovative research, strengthen public confidence in technology, and better understand societal trends. But we know there are also concrete risks associated with shared data, particularly personal data, including privacy risks, equity risks, and risks associated with commercialization of research.

With a better understanding of the environment that implicates data sharing for research, including established responses to risk as well as the varied participants involved in data sharing decisions, we can create a data sharing ecosystem that greatly impacts the world around us—for the good.

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WHO IS INVOLVED?

Different stakeholders have interests in shared data, each with their own goals and needs. Developing strong relationships between stakeholder groups is key to defining common interests and preventing misalignment, inefficiencies, and other more serious data dangers.

RESEARCHERS

Current challenges
Difficult administrative restrictions, competing usage rights, and costs

Goal
Streamlined access to the best data, enabling creation of new knowledge and transfer of information

ORGANIZATIONS & BUSINESSES

Current challenges
Protecting personal and proprietary data, meeting individual expectations, protecting the brand

Goal
Use of data to support and substantiate research that is valuable for the organization, its users, and society

RESEARCH INSTITUTIONS

Current challenge
Aligning research with institutional mission and goals

Goal
Mission-driven research that creates opportunities for the institution to achieve better visibility and increase academic standing

INDIVIDUALS

Current challenge
Lack of control or insight into sharing and use of personal data

Goal
Understanding that data will be used in ways that benefit individuals while limiting additional exposure to risk

GOVERNMENT

How is data sharing shaped by legislation?

Governments play a key role in shaping the data sharing for research environment. Although not a primary recipient of data, the government can create legislation that influences or mandates data sharing for research and defines appropriate safeguards. Government bodies also often benefit from the outputs of the research conducted with shared data.

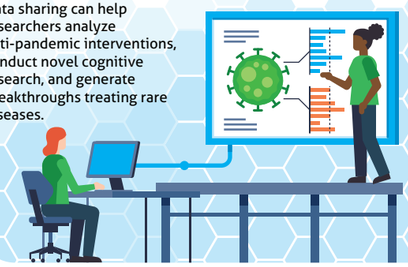
THE BENEFITS, CHALLENGES, AND OPPORTUNITIES OF DATA SHARING FOR RESEARCH

Data sharing for research is complex. Responsible data sharing can lead to research that benefits individuals, communities, and society as a whole. However, ensuring that data sharing for research is conducted ethically, equitably, and with proper respect for privacy represents a major challenge. Certain strategies and practices can help ensure that these challenges are addressed properly, but they must be utilized appropriately and with an understanding of their benefits and limitations.

1. Responsible data sharing for research creates benefits

MORE EFFECTIVE RESEARCH

Data sharing can help researchers analyze anti-pandemic interventions, conduct novel cognitive research, and generate breakthroughs treating rare diseases.



INDEPENDENT ANALYSIS AND ACCOUNTABILITY

Data sharing can provide insight into how tech platforms operate, how algorithms impact kids' mental health, and whether original research is replicable.

BETTER CRISIS RESPONSE

Data sharing can help governments and NGOs respond to disasters more quickly.

2. Challenges to data sharing for research may serve as barriers

DATA FITNESS

Good data fitness ensures that data in a data set, along with its attributes, are accessible, compatible, and usable, facilitating the understanding and ready use of data by researchers.

RE-IDENTIFICATION

Collaboration and ongoing risk analysis helps parties fully understand and, when possible, mitigate threats of re-identification while retaining data utility. Re-identification threats often arise from linking research data to other data sets.

RESEARCH MISCONDUCT

Certain behaviors, like fabrication or falsification, raise questions about the propriety of data sharing and undermine research results. Post-fabrication review can necessitate further data access by investigators.

3. Opportunities exist to address data sharing challenges

ACCESS CONTROLS

Technical or physical safeguards can reduce the risks of sharing particularly sensitive data sets.

DATA SHARING AGREEMENTS

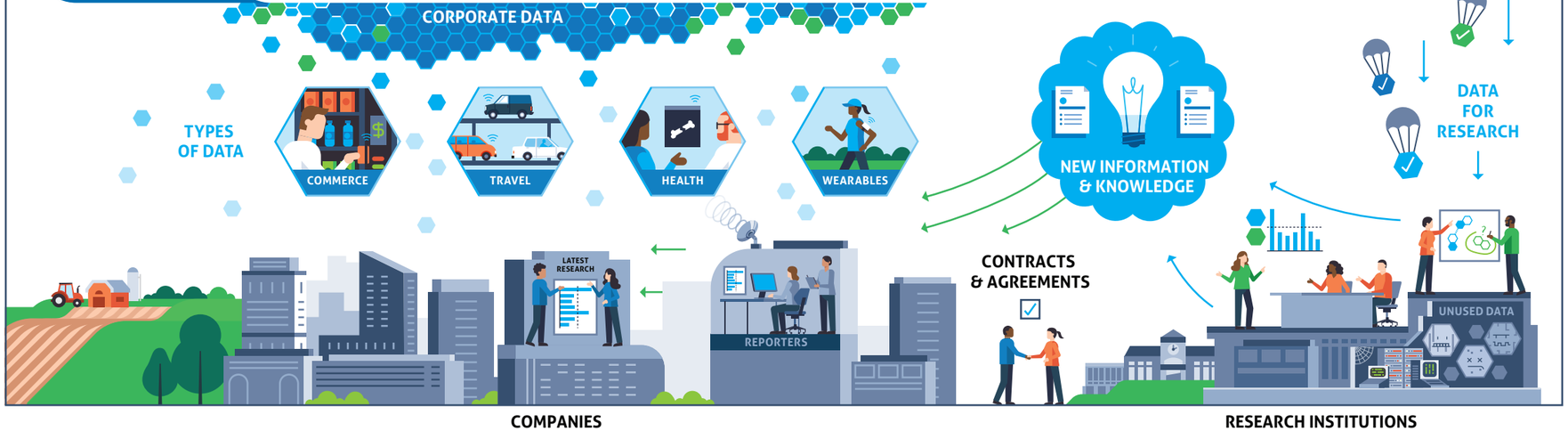
When clear and detailed, agreements governing data sharing relationships can establish common expectations, provide important performance indicators, and serve as an instrument for oversight.

ETHICS REVIEW BOARDS

Lessons learned from ethics review boards provide important guidance for ongoing review of research using personal data.

DATA DISCLOSURE LIMITATIONS

When disclosure or use of data poses a particularly high risk to individuals, organizations may choose to limit the scope of shared data, share only with trusted researchers, or decline to share altogether.



PREPARING FOR ACTION

We all have a role to play in the future of responsible data sharing for research. Here's what you can do next.

FACILITATE COMMUNICATION

Organizations, researchers, and research institutions should invest in policies and processes around communication for programs and projects that share personal data. They should ensure mutual understanding and expectations once a data sharing relationship is initiated.

ASSESS AND BUILD CAPACITY

A decision to transmit or receive personal data requires a comprehensive understanding of the data itself, the costs and legal requirements around accessing and/or protecting that data, and investment in structures to address any shortcomings.

EVALUATE PRIVACY SAFEGUARDS

Organizations should ensure that data sharing activities are in line with individual expectations and protect privacy to the extent possible while serving the intended purpose. Researchers and research institutions must also commit to providing ample privacy protections, including securing the data against unintended access.

EXECUTE ON RESEARCH

Researchers should conduct the relevant research, remain mindful of the expectations of data subjects and the sharing organization, and work consistently with organizational policies and values.

EMBRACE OVERSIGHT MECHANISMS

Internal and external oversight can provide mechanisms for all parties to ensure that data sharing research activities meet expectations and limit risk.