

# Digital Trade and Health: Data Flows and Data Governance

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# About ITIF

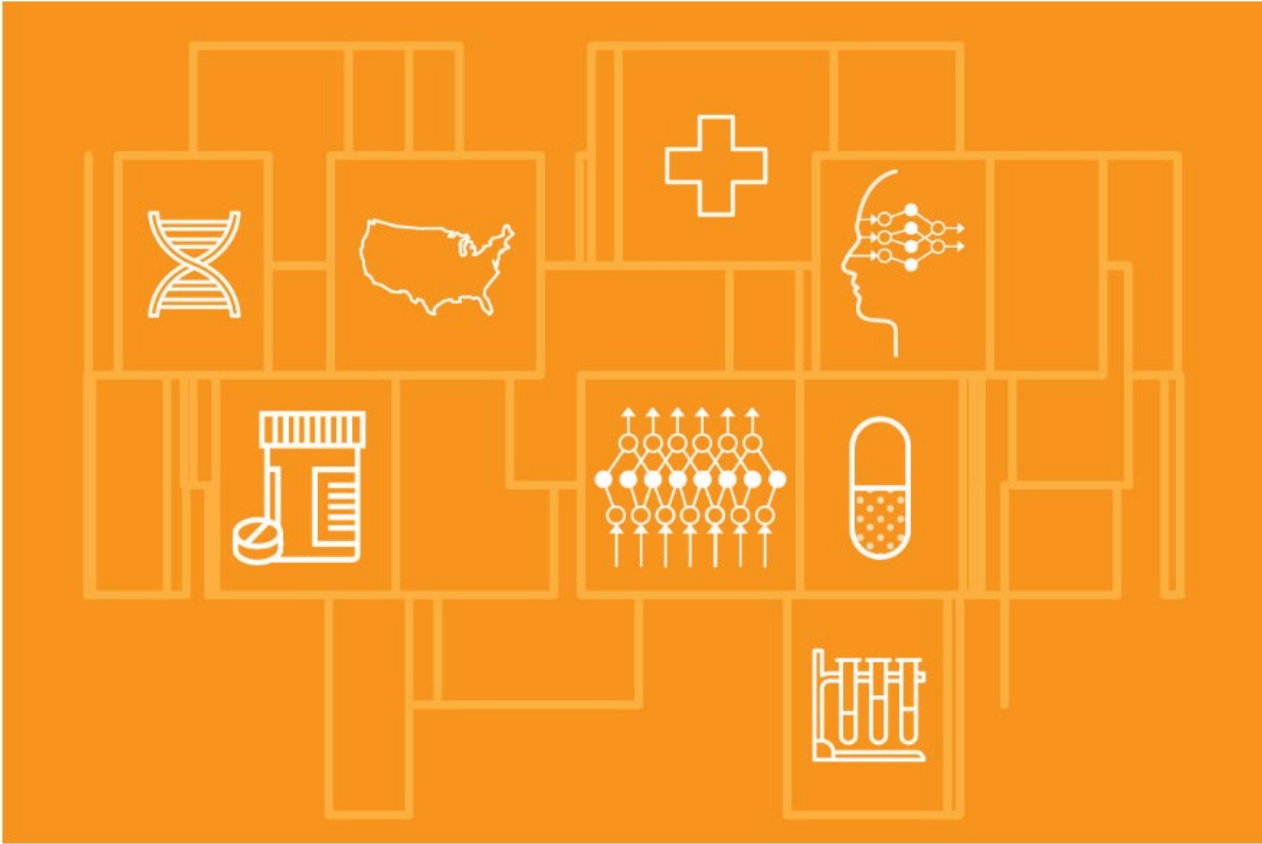
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- Independent, nonpartisan research and education institute focusing on intersection of technological innovation and public policy, including:
  - Innovation and competitiveness
  - IT and data
  - Trade and globalization
  - Life sciences, agricultural biotech, and energy
- Formulates and promotes policy solutions that accelerate innovation and boost productivity to spur growth, opportunity, and progress
- World's top think tank for science and technology policy, according to the University of Pennsylvania's authoritative *Global Go To Think Tank Index*

# Recent Report: Promise of Data-Driven Drug Development

## The Promise of Data-Driven Drug Development

by Joshua New | September 18, 2019



# Benefits of Data-Driven Health Services and Research

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- Lowers costs and provides better and quicker diagnosis, drug discovery, and treatment.
  - E.g. High-throughput screening.
  - E.g. Clinical trials: use of AI for candidate selection and ICT for follow up
- Better healthcare outcomes: personalized medicine.
  - In part, due to rapid drop in cost and time for genome sequencing.

# Related Global Trends: “Real World Data” & Data Poverty

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- Proliferation of ICT devices can aid drug/health service development.
  - E.g. Smart phones; smart watches and fitness trackers; & air-quality monitors.
- Data Poverty\*
  - To benefit, people must have data about themselves/their communities.
  - Policymakers should include efforts to address the “data divide” as part of holistic health system strategies.

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\* Daniel Castro, “The Rise of Data Poverty in America” (ITIF, 2014).

# Health Data Should Flow Freely Across Borders

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- Improves the quantity, quality, and diversity of data.
  - Improved drug and health service development, design, and delivery, as well as access.
  
- Data flows and data protection\*
  - Focus on firm accountability (not the location of data storage).
  - Data protection rules should flow with the data.

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\* Nigel Cory, Robert Atkinson, & Daniel Castro, “Principles and Policies for “Data Free Flow With Trust” (ITIF, 2019).

# Restrictions on Health Data Flows

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- Explicit local data storage: “data localization.”\*
  - E.g. Australia, Canada, China, Russia, and UAE.
- De facto barriers to data flows:
  - Explicit consent for transfers and opaque “white lists” of approved countries for data transfers.
- Which trend prevails globally?
  - Local vs. global - trapped vs. free flowing health data.

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\* Nigel Cory, “Cross-Border Data Flows: Where Are the Barriers, and What Do They Cost?” (ITIF, 2017).

# Impact of Restrictions on Flows of Health Data

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- Preventing involvement in development of new drugs and health services.
- Cutting off access to improved health services and outcomes.
  - Firms are not going to setup local facilities in every country.
  - Reducing attractiveness for foreign clinical trials.
- Reduced, and slower, drug discovery.
  - At best, leads to inefficiencies. At worst, leads to missed discoveries.



# Approaches to Supporting/Protecting Health Data Flows

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- Data Aggregation, Sharing, and Transfers
  - Create ways for people to share their data.
  - Data trusts, federated data systems, and international data registries.
- International Initiatives
  - Global Alliance for Genomics and Health – Focuses on standards/framework.
- Trade Agreements
  - USMCA, CPTPP, and other bilat agreements allow free flow of data.
  - WTO e-commerce negotiations will hopefully do the same.

# Conclusion

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- Enormous benefits to data-driven health services and research.
  - But many challenges to overcome to improve, and protect, the free flow of health data.
- Obviously, need to manage data privacy and protection concerns.
  - However, this is not mutually exclusive to greater data-driven drug discovery and design and delivery of new health services.
- New trade rules on data flows have an important role to play.

# Thank You!

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