



# Our Health, Our Data

Toward a Person-Centered Model of Information Exchange



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# Origin Story

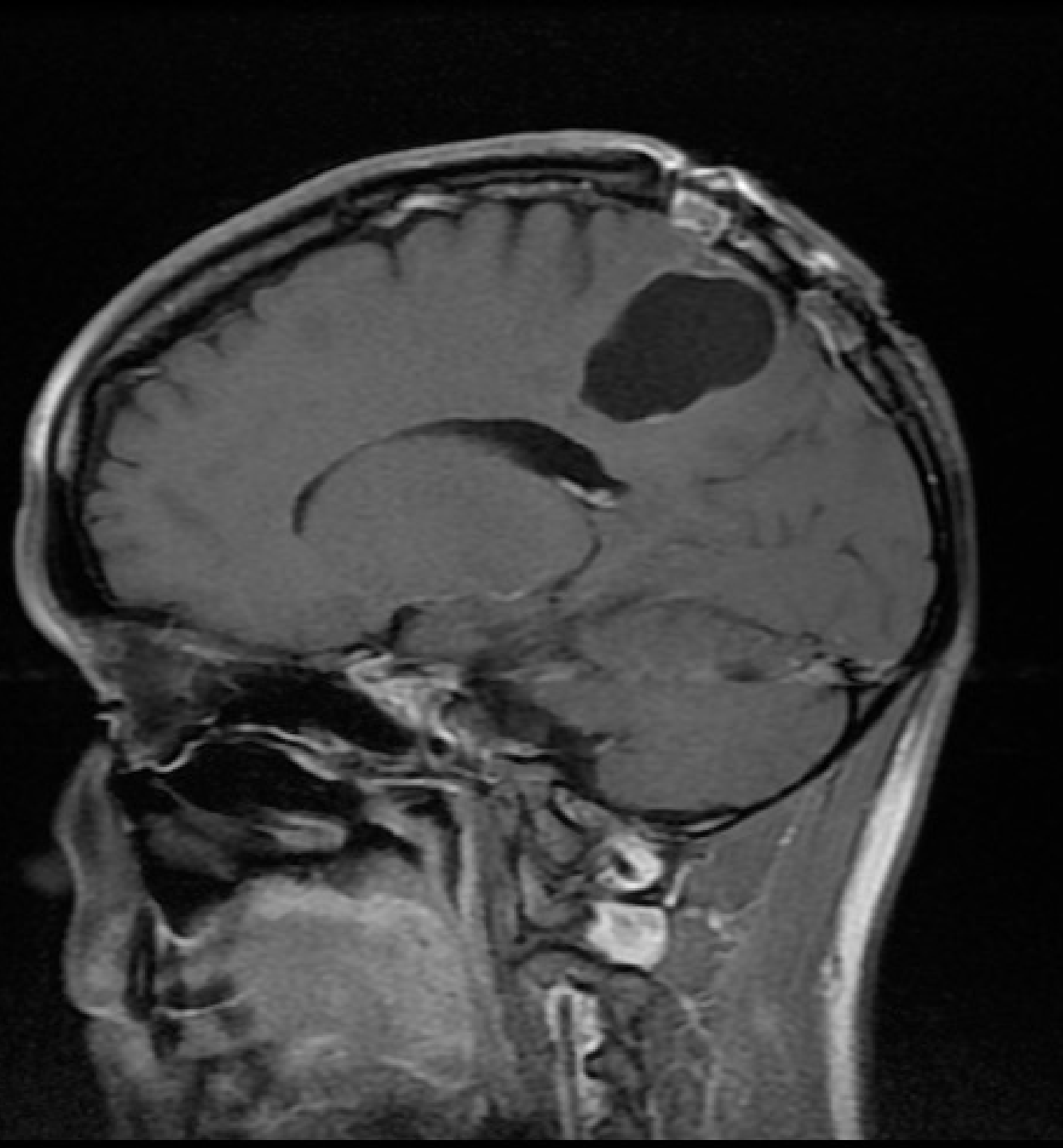
- “Technologies to enhance activation” include wearables, personalization of service delivery, clinical decision support tools, predictive analytics, precision medicine, etc.
- Thus, health tech innovation is increasingly **data-driven**, but ethics around data collection and ownership lag behind implementation.
- SDOH makes it clear that *personal data from outside the health system* are key to unlocking health activation potential and population health improvements, but we know that misuses of data can actually *increase* disparities.

**All personal data is health-relevant data.**



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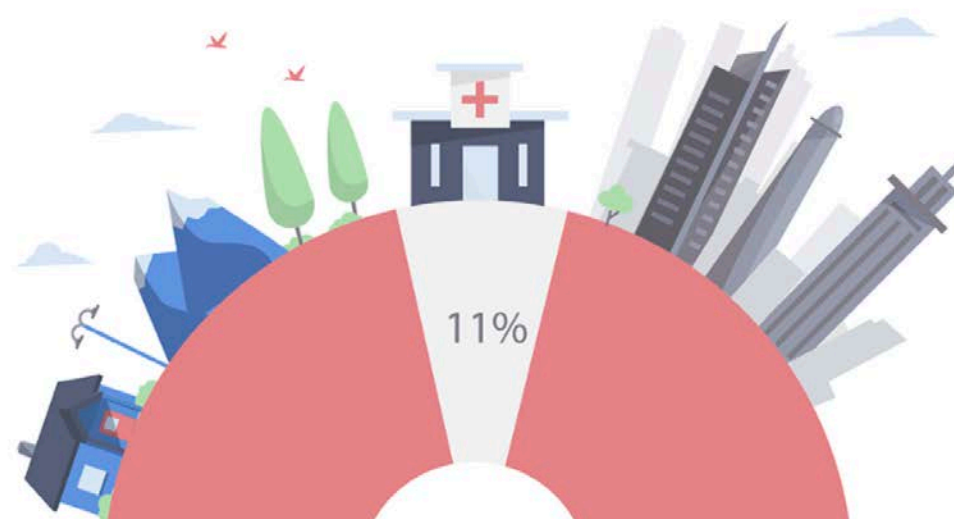
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**11%**

Personal Health Information (PHI)  
covered by HIPAA



# The Hidden Side of Health

**89%**

Not covered by HIPAA:

- Google searches
- Online medical purchases
- Personal device data (e.g., Fitbit, Apple Watch)
- Social media posts
- Personal health records on mobile apps



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Graphic: HealthDataBasics.org



# Assumptions & Hypothesis

- Health systems are a central zone for the collection, integration, and use of personal data to impact both individual- and population-level outcomes.
- *However*, health systems are *far* from the **only** zone where personal (health-relevant) data is being collected, analyzed, and monetized.
- There is a large gap between the way personal data is handled and regulated within the health system and outside of it -- but *neither approach serves the people whose data is being collected, monetized, and analyzed.*

**To realize the promises of health tech,  
uses of personal data across sectors should be broadly governed by a  
“person-centered” approach.**



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# Questions for Consideration

- **Who is our target audience?** Multiple stakeholder groups (i.e., providers, practitioners, payers, patients, CEOs, developers, entrepreneurs, etc.) OR hone in on 1-2?
- **How prescriptive should we be** in advocating for a “person-centered” approach to personal health data governance?
- **Person-centeredness:** How might we honor the personal nature of health disparities/inequities while providing guidance for stakeholders focused on the technical details?

