Our Health, Our Data

Toward a Person-Centered Model of Information Exchange
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“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.
11%
Personal Health Information (PHI) covered by HIPAA

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
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.
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?