Our Health, Our Data

Toward a Person

Group Members

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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.
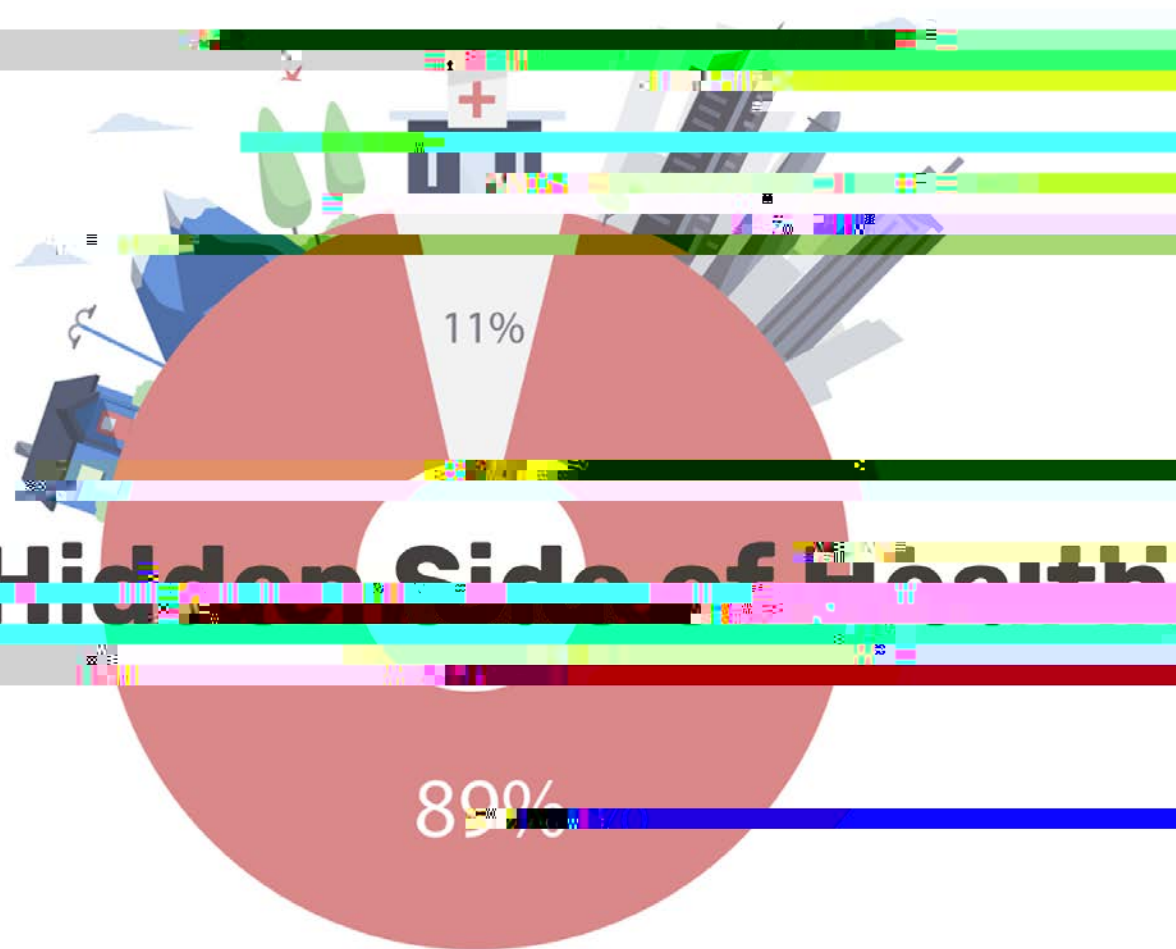
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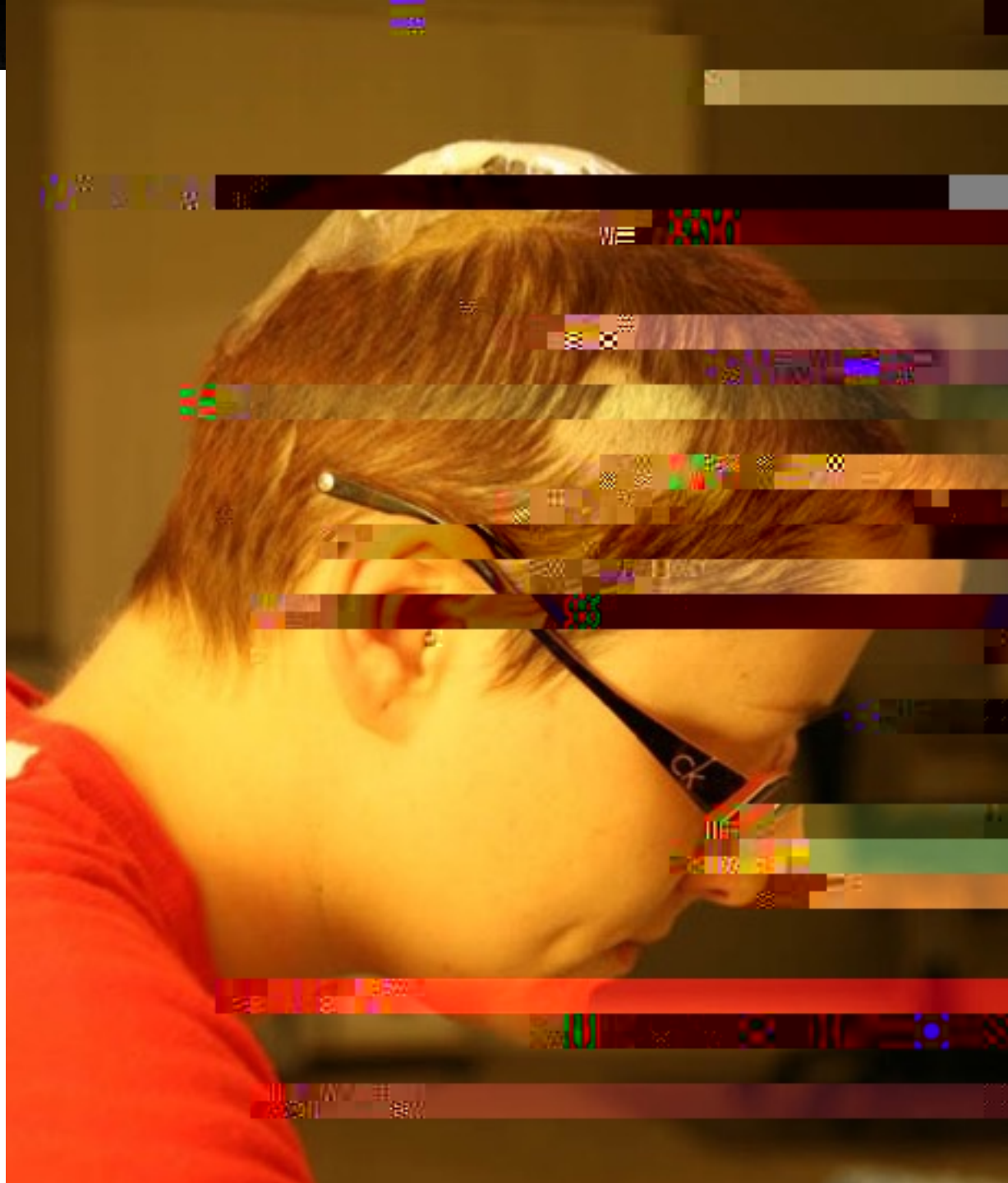
11%
Personal Health Information (PHI) covered by HIPAA

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

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Graphic:

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**

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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 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?