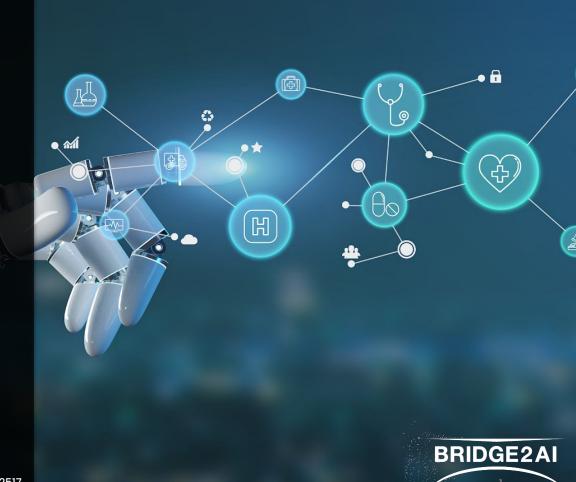
Bridge2Al Face-to-Face Meeting Science Talk

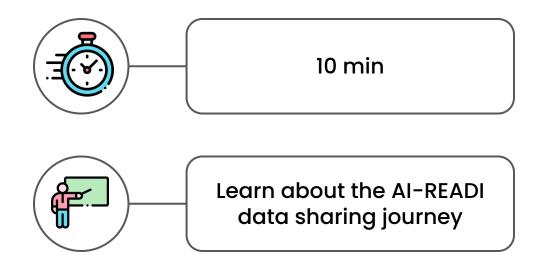
# Open Data Sharing in the Era of AI: Challenges and Opportunities

Wednesday, May 21, 2025

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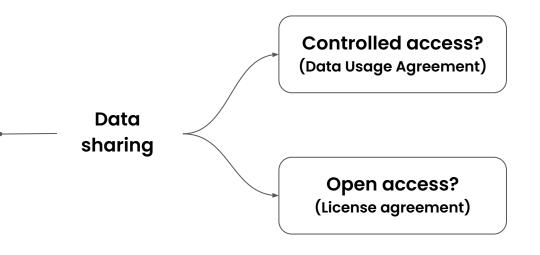
#### **About This Presentation**



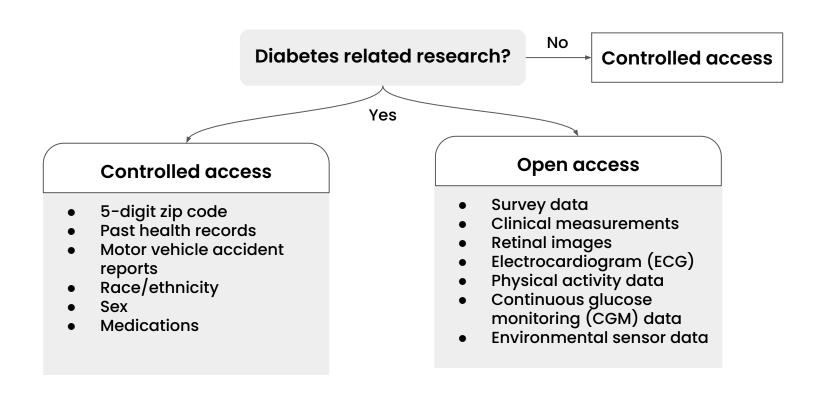
#### How to share the AI-READI data?

### Lots of data types and variables being collected

- Surveys
- Clinical measurements
- Retinal images
- Electrocardiogram (ECG)
- Physical activity data
- Continuous glucose monitoring (CGM) data
- Environmental sensor data
- And more



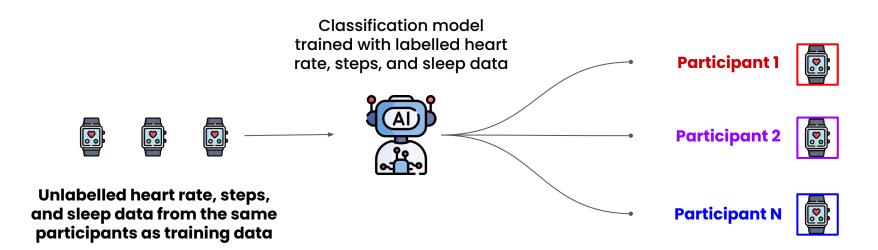
#### We looked at the informed consent



#### Physical activity data

#### Al models can be trained to

identify physical activity data at an individual level



#### Other data types

Literature suggests AI models can be trained to identify many data types at an individual level → pseudo-reidentification



Physical activity data (up to 99% accuracy)



Continuous glucose monitoring (CGM) data (86% accuracy)

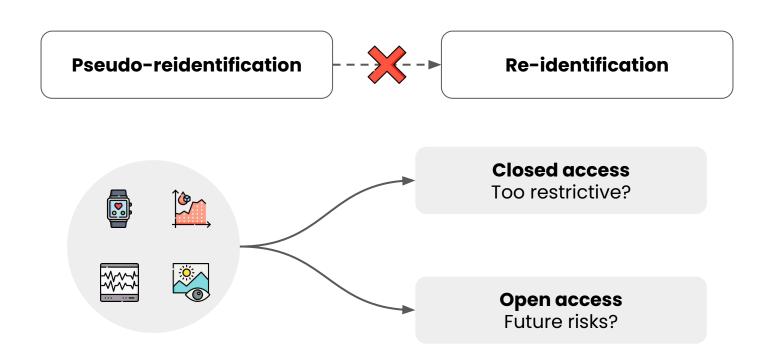


Electrocardiogram (ECG) data (up to 100% accuracy)



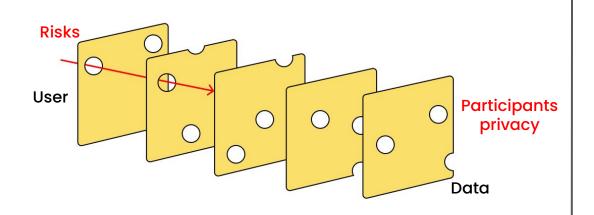
Retinal imaging data (up to 99% accuracy)

How to share pseudo-reidentifiable data?



We developed a new open data access model

Swiss-cheese model of open data sharing implemented in a new data sharing platform called FAIRhub

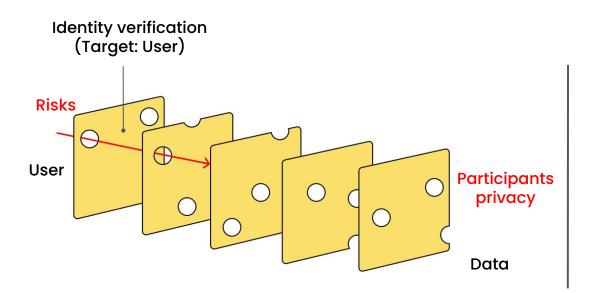


Multiple steps to access the data

Each designed to help minimize risks to participants privacy and prevent misuse

Not foolproof individually but stronger when used together

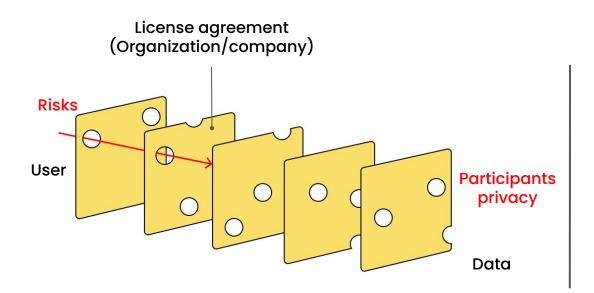
Layer 1: Identity verified data access





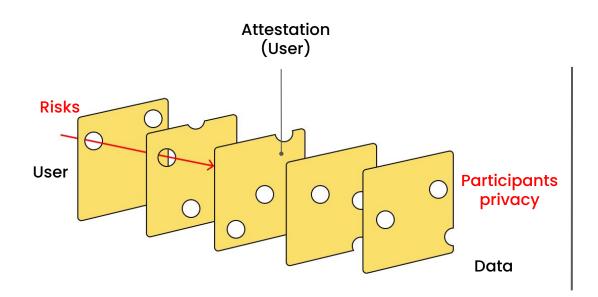
Anyone accessing the data needs to login through an identity verification system using their institutional email

#### Layer 2: New license agreement



- Re-identification of study participants or harm
- Distribution of the data
- Distribution of models that "memorize" the data
- **Commercial** use

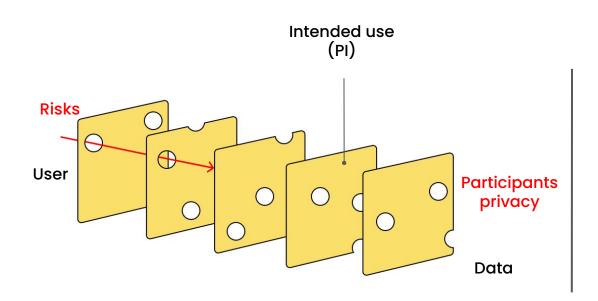
#### Layer 3: Attestation





Users must type out character by character and attest to the main conditions of the license

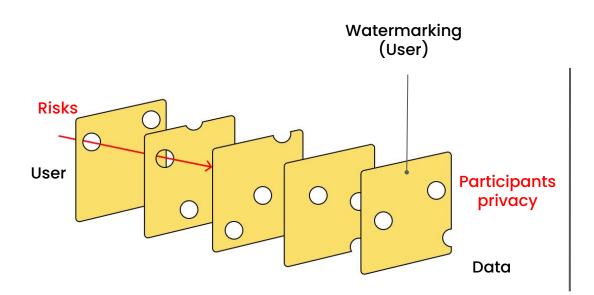
Layer 4: Intended use of the data (publicly shared)





Users must describe their intended use of the data which is shared publicly with their name

Layer 5: Data watermarking for each user



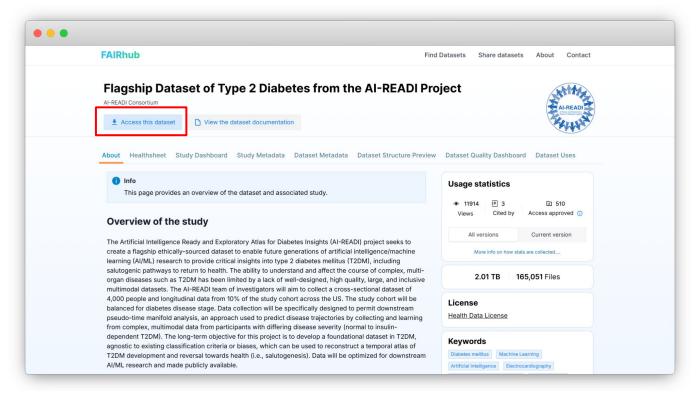




Each user gets a uniquely watermarked dataset tied to their identify

If the dataset appears online we can track who leaked it

#### Implemented in FAIRhub (fairhub.io/datasets/2)



## Closing remarks

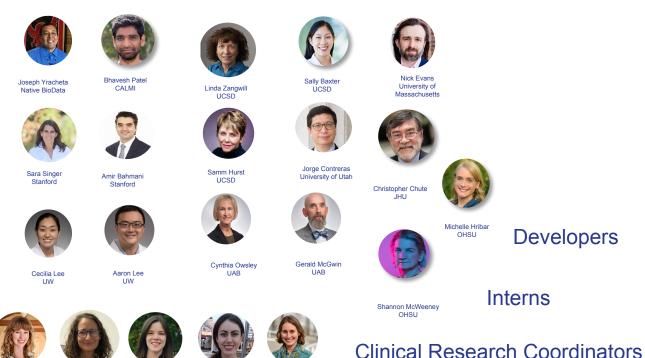
#### Summary

Challenges Some data types considered safe for open sharing are identifiable at an individual level (pseudo-reidentification)

Opportunities We developed a new swiss cheese model of open data sharing to minimize risks to participants privacy and misuse

Check it out! You can check out this data sharing model for the AI-READI dataset at fairhub.io

#### **AI-READI Team**



**Program and Project Managers** 

#### **Thank You!**





