

Breakout Session 7: Track B

Patient-Centric Federated Learning: Automating Meaningful Consent to Health Data Sharing with Smart Contracts

Dr. Kristin Kostick-Quenet

Assistant Professor, Baylor College of Medicine

Tools for Balancing Big Data Discovery with Patient Privacy and Consent

Award title: “Ethical Perspectives Towards Using Smart Contracts for Patient Consent and Data Protection of Digital Phenotype Data in Machine Learning Environments” (3R01MH125958)

(PI) Kristin Kostick-Quenet, PhD¹

(MPI) Eric Storch, PhD¹

(MPI) John Herrington, PhD²

¹Baylor College of Medicine (Houston)

Children’s Hospital of Philadelphia (CHOP)²

Problem Addressed:

How to make data widely available while also protecting intellectual property and data privacy?



Image: Bleuewire.com

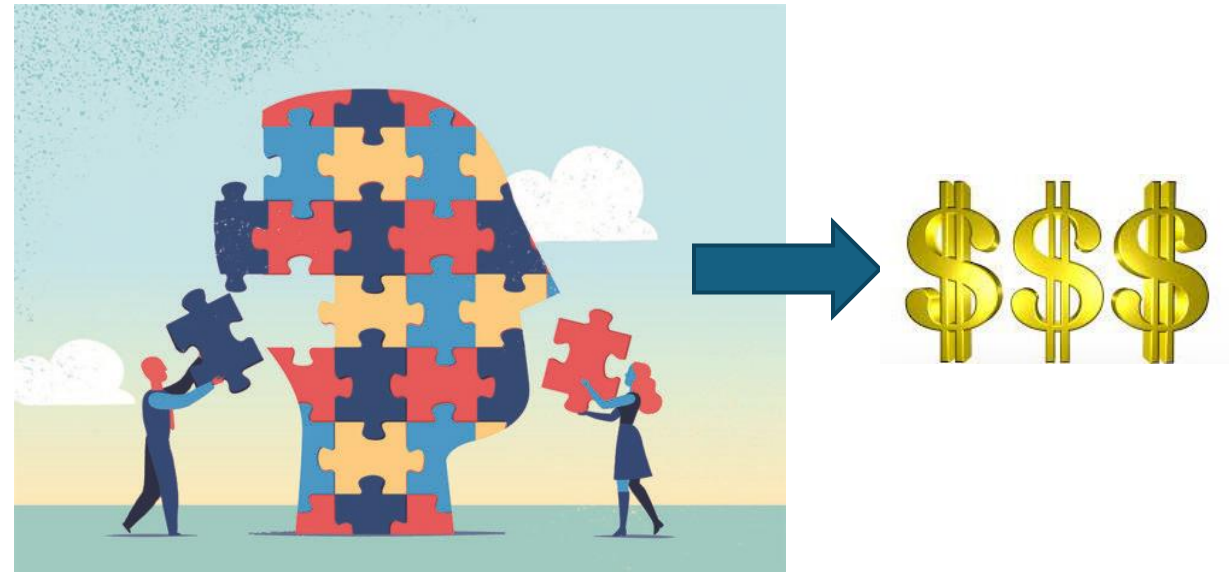
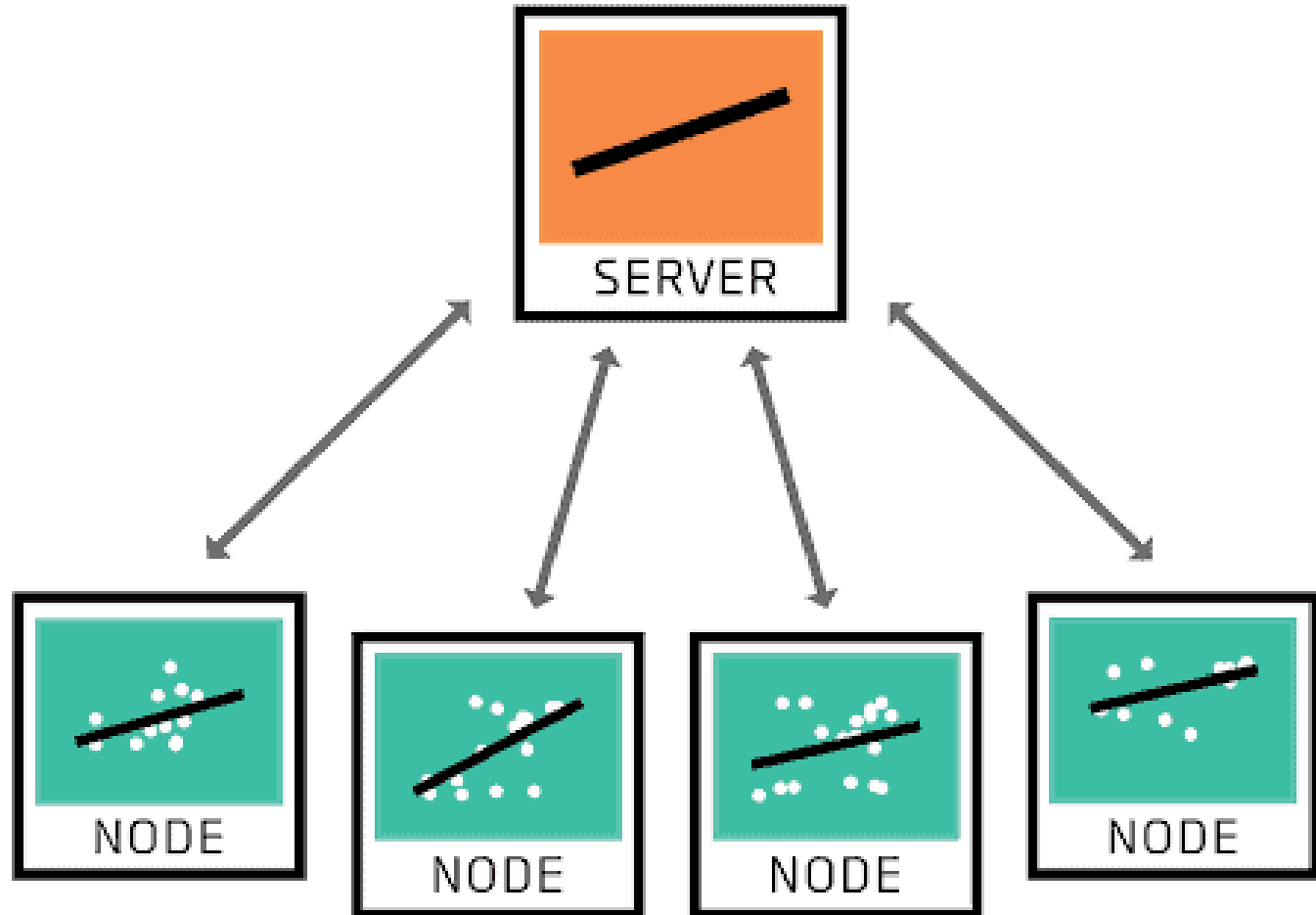


Image: Adobe Stock

AI-enabled Federated Learning



Whose interests does Federated Learning protect?



Image: Investopedia.com

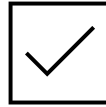


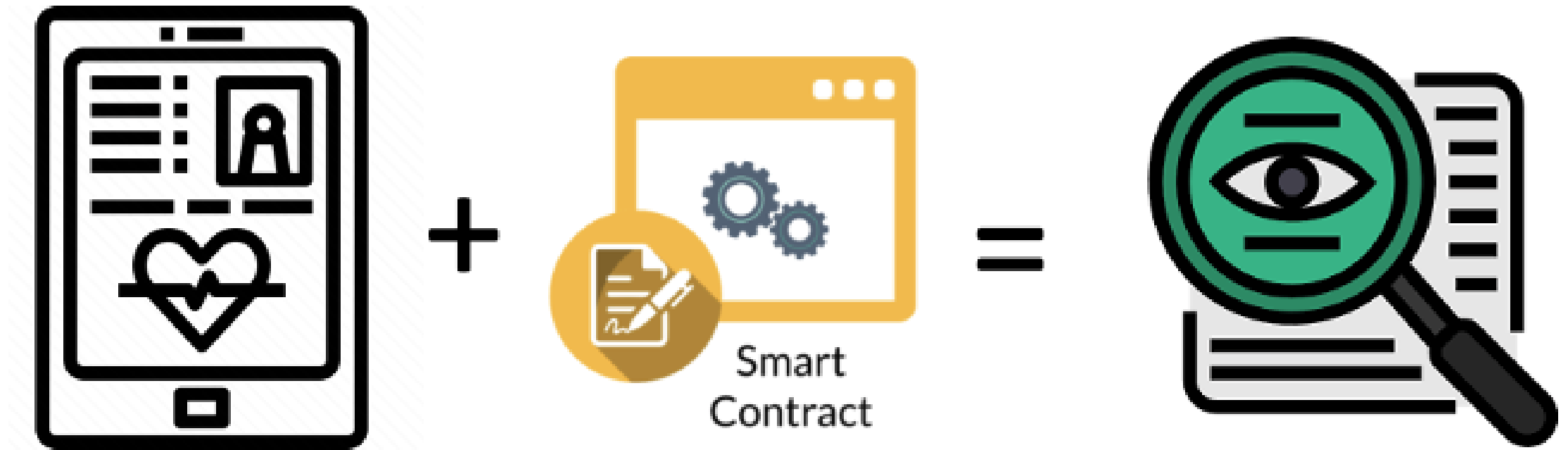
Image: trainingexpress.com

The problem of broad consent

Consent to secondary uses stretches what counts as “informed consent”



Filling the consent gap with Smart Contracts



Filling the consent gap with Smart Contracts

Science

Current Issue First release papers Archive About ▾

HOME > SCIENCE > VOL. 375, NO. 6580 > HOW NFTS COULD TRANSFORM HEALTH INFORMATION EXCHANGE

🔒 | POLICY FORUM | DATA



How NFTs could transform health information exchange

Can patients regain control over their health information?

[KRISTIN KOSTICK-QUENET](#), [KENNETH D. MANDL](#), [TIMO MINSSEN](#), [I. GLENN COHEN](#), [URS GASSER](#), [ISAAC KOHANE](#), AND [AMY L. MCGUIRE](#) fewer [Authors Info &](#)



CHAINLINK RESEARCH REPORTS

How NFTs and Smart Contracts Could Transform Health Information Exchange.

📅 APRIL 29, 2022
📺 /CHAINLINK



Dr. Kristin Kostick-Quenet
Assistant Professor
Center for Medical Ethics & Health Policy, Baylor College of Medicine

42:11

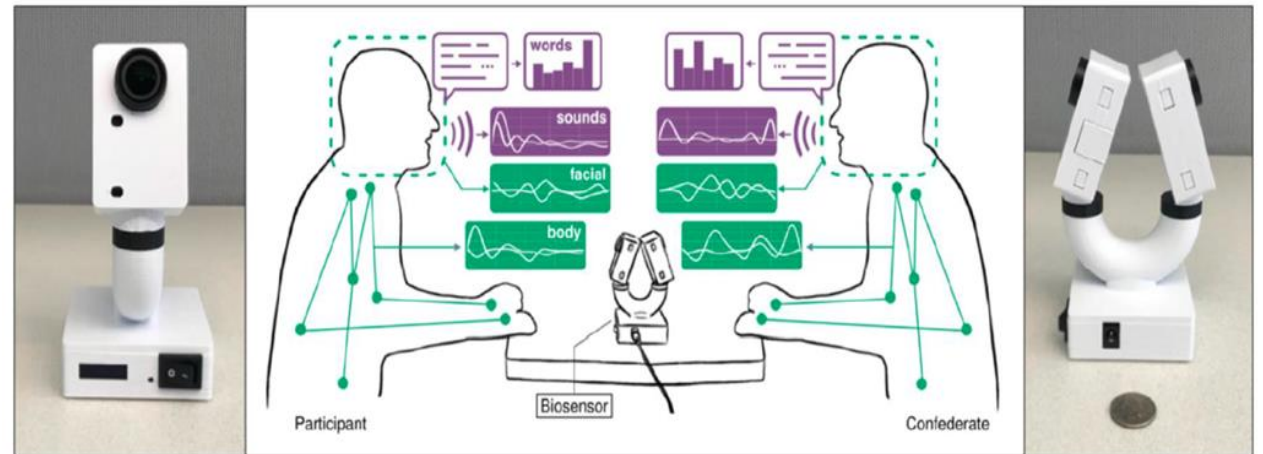
Chainlink

Project Aims & Methods

Primary Aim: Identify stakeholder perspectives towards integrating SCs in machine learning environments

N= 40 in-depth stakeholder interviews

- Patients
- Caregivers
- Clinician Researchers
- Technical Experts
- Ethical/legal Experts
- Industry Reps (e.g. EHR)



Our tabletop Biosensor collects synchronized, high-resolution audio and video data from social interactions.

PARENT STUDY: (NIH R01MH125958)

Optimized Affective Computing Measures of Social Processes and Negative Valence in Youth Psychopathology

MPIs: Herrington, Storch

Research Outputs: Papers

nature
machine
intelligence

Nat Mach Intell. 2023 May ; 5(5): 480–482. doi:10.1038/s42256-023-00658-w.

Ethical hazards of health data governance in the metaverse

Kristin Kostick-Quenet[✉],
Vasiliki Rahimzadeh

Center for Medical Ethics and Health Policy, Baylor College of Medicine, Houston, TX, USA.

Am J Bioeth. 2023 November ; 23(11): 42–44. doi:10.1080/15265161.2023.2256258.

The American Journal of
BIOETHICS

Computational Ethics Tools to Audit Corporate Self-Governance in Data Processing

Christine R. Deeney,
Kristin Kostick-Quenet
Baylor College of Medicine

Research Outputs: Presentations



NFT Your Health Data: What are the Ethical Implications?

Kristin Kostick-Quenet, PhD¹

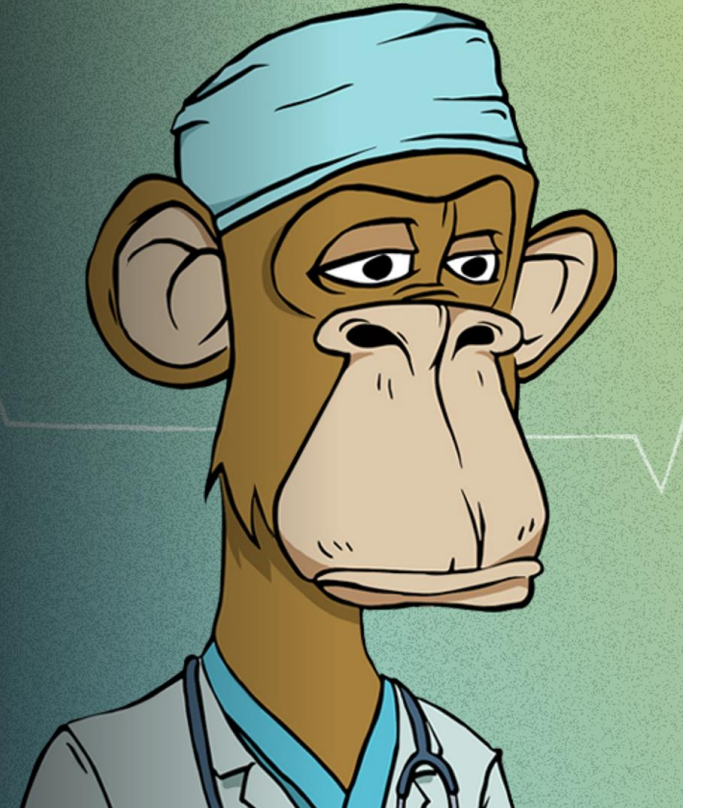
Christine Deeney, BA¹

Eric Storch, PhD¹

John Herrington, PhD²

¹Baylor College of Medicine (Houston)Children's

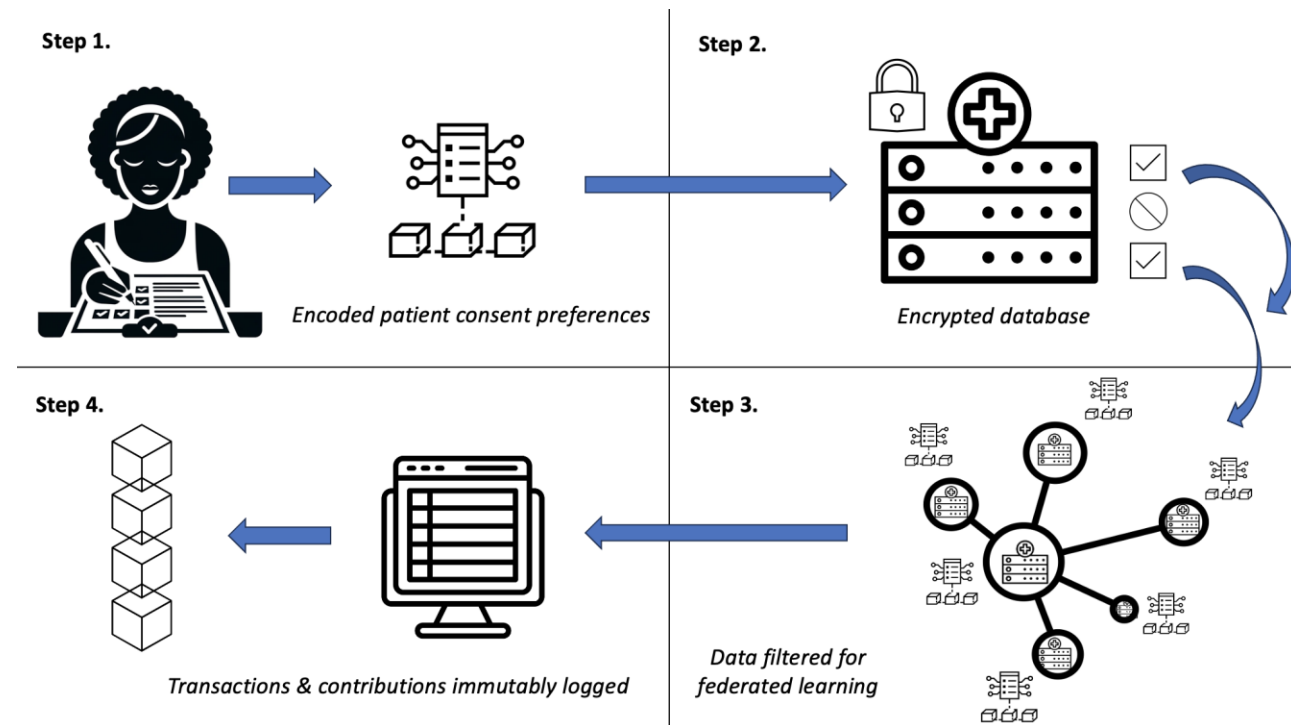
²Hospital of Philadelphia (CHOP)



Research Outputs: Under Review / Upcoming

“Patient-Centric Federated Learning: Automating Meaningful Consent to Health Data Sharing with Smart Contracts.” Under review by *International Journal of Medical Informatics*

Kostick-Quenet, K; Compagnucci, M;
Riobo Aboy, M; Minssen, T.



Research Outputs: Under Review / Upcoming

“Sensitive Bytes: Beyond Checkboxes in Protecting Digital Phenotyping Data”

To be submitted to: *Big Data & Society*

Christine Deeney & Kristin Kostick-Quenet

1.78

0.8

0.8

1.78



Thank you!

Kristin.kostick@bcm.edu

@kkostick 

