

Wearables in Research: Ethical Considerations

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Objective

- Consider the ethical implications of incorporating wearable devices into research design and highlight the promise of blockchain technology and privacy-preserving innovations to facilitate participant ownership of data



Wearables

- Computing devices that are worn on (or in) our persons
- Key features: continuous data collection, transmission & analysis
- 3rd party consumer electronics, and some medical devices

To “wear”

1. To carry or have on one's person as covering, adornment, or protection. *"wearing a jacket; must wear a seat belt."*
2. To carry or have habitually on one's person, especially as an aid. *"wears glasses."*
3. To display in one's appearance. *"always wears a smile."*

Or:

the damaging, gradual removal or deformation of material at solid surfaces

Three key modalities

Tracking (GPS + Bluetooth)

- Smartphone apps
- Ankle/wrist bracelets
- **Geolocation**

Biometric Surveillance

- Oura Ring, Fitbit, Apple watch
- Chemosensors, e.g. glucose monitor
- **Biological data**

Video/Image Capture

- Body cameras
- Smart glasses
- **Sociological context & behavioral data**

Ethics By Design

Key considerations

- Privacy & autonomy
- Embedded bias
- Power asymmetries

Design features

- Invasive & passive by nature
- Who/what it was built for
- How/why data ownership defined

Medical device or consumer electronic?



Is the device available by prescription?



Whose standards for safety & efficacy?



HIPAA, Common Rule, Conv. on Human Rights & Biomedicine vs. FTC



Traditional health data protections do not apply



Limited transparency and regulatory oversight

Limits to Informed Consent

- Impossibility of self-managing ToS for myriad devices, platforms, etc.
- The challenge of data aggregation, triangulation, secondary use
- Potential the impact on 3rd parties
- “Accepting the cookies” vs. truly informed consumers/participants
- The role of conferring benefits to offset burdens imposed

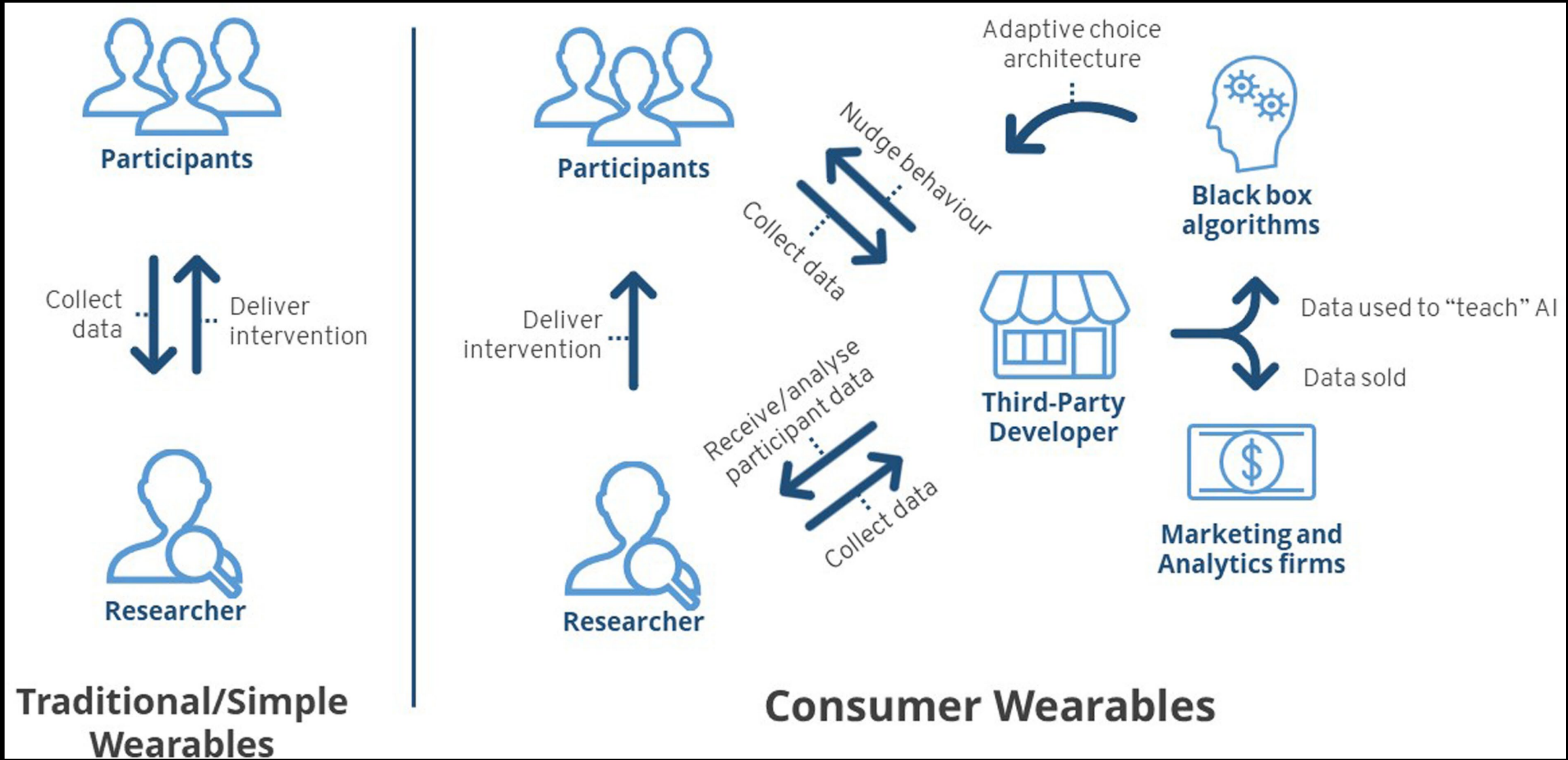
Impact on Disparities & Discrimination

- Example: Body temperature monitoring for COVID surveillance vs. pregnancy and ovulation status
- Example: Oxygen saturation and race differences
- Example: Political activity and geolocation

- Who/what were the technologies created and validated for?
- Does the study rely on individuals' personal devices?

Who owns the data?

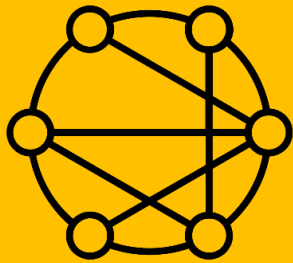
- Unique context for these modalities which capture and allow study of unprecedented level of intimate data
- Who has access to the data? Who controls its use? Who can profit?
- Critical to separately consider the identity of the individual researcher, their employer, and the manufacturer or owner of the devices



Alternatives & Future Directions

Potential Technology Solutions

Blockchains



A new computing platform with unique assurances of trust

Zero-knowledge proofs

- For the value of x ;
- I know secret value w ;
- Such that condition D holds on x and w .

Proving knowledge of secrets without revealing the underlying data

Trusted execution environments



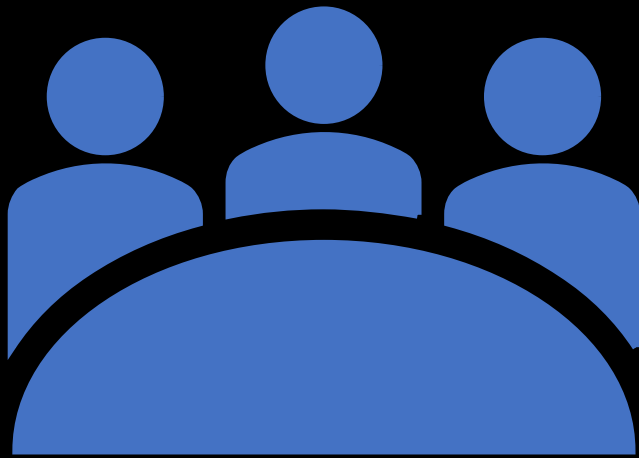
Hardware with integrity and privacy guarantees

Federated Learning



Distributed AI/ML

Design for Inclusion and Shared Governance



- Consider mechanisms for implementing ongoing oversight and input from the study population
- Role for “data unions” and similar structures
- Transparency of data use does not compromise security and privacy
- Distributed access to individual data outputs and aggregate findings
- Data transparency and accountability for diversity

Three takeaways re: Ethics of Wearables

- Consider wearables as an invasive research methodology, with implications for privacy, autonomy, and heavy reliance on trust
- Commercially available wearables are designed and built for specific purposes, populations and endpoints—do not assume alternative applications are valid
- Power asymmetries are created and exacerbated by business models and practices regarding ownership and access to wearable data

Thank you!

Any questions?

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