### ELAINE SEDENBERG I JOHN CHUANG I DEIRDRE MULLIGAN DESIGNING THERAPEUTIC ROBOTS FOR PRIVACY PRESERVING SYSTEMS, ETHICAL RESEARCH PRACTICES, & ALGORITHMIC TRANSPARENCY



# PRIVACY-PRESERVING PRACTICES (FIPS)

- Transparency (no secret systems)
- Access (to individuals' records and their uses)
- **Privacy Controls** (ability to prevent information about oneself from purposes without consent)
- Integrity (ability to correct or amend)
- Data Use Protections (prevent data misuse)

## ETHICAL FRAMEWORKS

ROBUST RESEARCH & INFO SHARING THROUGH BELMONT AND MENLO REPORTS

#### Belmont Report

- Respect for persons (individuals should be treated as autonomous agents; operationalized through voluntary informed consent)
- **Beneficence** (obligation to maximize benefits and minimize harm)
- Justice (distribute benefits of research fairly and carefully select research subjects to avoid undue burden from underserved groups)
- Special ethical considerations for vulnerable populations (children, elderly, handicapped, or very sick)

#### Menlo Report

- Respect for Law and Public Interest (legal compliance and methods/ findings transparency)
- Existing legal/policy guidelines (privacy laws and regulation)

#### IMPLEMENTATION RECOMMENDATIONS FOR THERAPEUTIC ROBOTS

#### Access to Data

 Users should have options to prevent archiving, delete, & dispute/edit inaccurate data over lifespan of information system. Special considerations for choices of disabled/vulnerable persons.

#### General Practice & Algorithmic Transparency

 Notify users of all research practices (including algorithmic & product development), and provide notice of data inputs & algorithmic outputs that impact user

#### Universal Informed Consent

- Embrace dynamic informed consent models for all data uses (not just those required by law)
- Design for Privacy-Preserving Data Sharing
  - Utilize technical solutions (e.g., remote data access or open PDS models) to share data
- Anticipate New Knowledge & Unintended Consequences
  - Promote diversity in review process and build flexible information systems

#### Questions? Comments?

ELAINE@ISCHOOL.BERKELEY.EDU