# **Tools & Resources: Ethics & Legal Compliance**

#### **Data / Research Ethics & Compliance for UF Researchers**

- 1. UF Research Misconduct Homepage: Policy, Training, Reporting, and Best Practices
- 2. UF Office of Research Integrity and Compliance (Research Integrity & Compliance)
- 3. Info for UF Researchers regarding Risk Assesment for International Collaborations and Export Control
- 4. UF IACUC
- 5. UF IRB
- 6. UF Privacy Office

#### **Intro: Privacy**

- 1. NIH: what is HIPPA?
- 2. What is the EU General Data Protection Regulation (GDPR)? (link 1), (link 2), (link 3 UF)
- 3. What is FERPA?

#### **Anonymizing Data: Introduction**

- 1. Intro to Anonymization
- 2. Overview by Martin Monkman
- 3. EDUCASE Guidelines for Data De-Identification or Anonymization

## **Tools for Anonymizing Data**

- 1. With R
  - Martin Monkman's link to R packages for Anonymizing Data
- 2. With other tools, including stand-alone software and online tools
  - list of free tools
  - ARX (open source, free)
  - Amnesia (open source, free)
  - De-identification Tools from NIST
  - AirCloak (paid)

## **Data Protocols for Working with Indigenous Communities**

- 1. Indigenous peoples and responsible data: an introductory reading list
- 2. CARE Principles for Indigenous Data Governance
- 3. Carroll, S.R., Herczog, E., Hudson, M. et al. Operationalizing the CARE and FAIR Principles for Indigenous data futures. Sci Data 8, 108 (2021). https://doi.org/10.1038/s41597-021-00892-0

#### **Data Collection, Privacy, and Gender**

- 1. How to Ethically and Responsibly Identify Gender in Large Datasets
- 2. Clair A Kronk et al. 2022. Transgender data collection in the electronic health record: Current concepts and issues. *Journal of the American Medical Informatics Association* 29(2):271–284 https://doi.org/10.1093/jamia/ocab136
- 3. Heidari, S. et al. 2016. Sex and Gender Equity in Research: rationale for the SAGER guidelines and recommended use. *Res Integr Peer Rev* 1,2 (2016). https://doi.org/10.1186/s41073-016-0007-6

### **Emerging Issues resulting from Technological Advancements**

- Automated Data Collection: The Big Picture and Legal Issues
- 2. Are transcription services HIPPA compliant?
- 3. Di Minin, E. et al. 2021. How to address data privacy concerns when using social media data in conservation science. *Conservation Biology*, 35:437-446. https://doi.org/10.1111/cobi.13708

### **Text Mining, Copyright, and the Law**

- 1. Text and Data Mining of In-Copyright Works: Is It Legal?
- 2. The plan to mine the world's research papers
- 3. Copyright and the Progress of Science: Why Text and Data Mining Is Lawful
- 4. Copyright's impact on data mining in academic research
- 5. Text and Data Mining at Springer Nature
- 6. UF Library Guide: Copyright on Campus: Essentials
- 7. UF Library Guide: Data Sharing & Copyright

# **Ethics of Data Sharing**

- 1. Commit to transparent COVID data until the WHO declares the pandemic is over
- 2. NIH issues a seismic mandate: share data publicly