# **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. CDC: 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
- 4. UF "HOW TO: DE-IDENTIFY DATA", with very useful checklists

# Tools for Anonymizing Data (Note: be very careful doing this on your own)

#### With R

- 1. Martin Monkman's link to R packages for Anonymizing Data
- 2. Blog Post / Tutorial
- 3. R package Anonymizer

#### With other tools, including stand-alone software and online tools

- 1. list of free tools
- 2. ARX (open source, free)
- 3. Amnesia (open source, free)
- 4. De-identification Tools from NIST
- 5. 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
- 4. The European Institute for Gender Equality's GEAR Tool (Gender Equality in Academia and Research)
- 5. UN "Methods for gender data collection and estimation" Training Materials.
- 6. Colaço, R., and Watson-Grant, S. (2021). A Global Call to Action for Gender-Inclusive Data Collection and Use. RTI Press Publication No. PB-0026-2112. Research Triangle Park, NC: RTI Press. https://doi.org/10.3768/rtipress.2021.pb.0026.2112

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

- 1. 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