

Civic Hall Ethical Data Collection: Resources

Compiled by Arlene Ducao, arlduc@nyu.edu

Introductory References and Resources (Most will be discussed today)

- The Belmont Report: https://videocast.nih.gov/pdf/ohrp_belmont_report.pdf
- The Belmont Report website: <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>
- The Menlo Report: https://www.caida.org/publications/papers/2012/menlo_report_actual_formatted/
- Protecting Human Subjects (archived course materials): https://humansubjects.nih.gov/sites/hs/phrp/PHRP_Archived_Course_Materials.pdf
- More Human Subjects Resources from HHS.gov: <https://hrsa.gov/publichealth/clinical/HumanSubjects/training.html>
- UN Declaration on Human Rights: <http://www.un.org/en/universal-declaration-human-rights/index.html>
- NIST.gov Cybersecurity Framework: <https://www.nist.gov/cyberframework>
- NIST.gov Definition of Personally Identifying Information: <https://nvlpubs.nist.gov/nistpubs/Legacy/SP/nistspecialpublication800-122.pdf>
- EU Data Privacy and Ethical Guidelines (2009): http://ec.europa.eu/research/participants/data/ref/fp7/89827/privacy_en.pdf
- Simple Guidelines from the European Data Protection Board (who created GDPR): https://edpb.europa.eu/guidelines-your-rights_en
- Toolkit for Visualizing Data for Human Rights Advocacy: <http://visualizingrights.org/kit/>
- Wikipedia's User Account Structure: https://en.wikipedia.org/wiki/Wikipedia:User_account_security
- The Engine Room's Responsible Data Mailing List: https://lists.theengineroom.org/lists/info/responsible_data
- One Data Generator: <http://generatedata.com>

Some Sample Policies

(Chosen for general relevance to nonprofits)

- [Constant Contact](#)
 - [Why You Need a Privacy Policy | Constant Contact Blogs](#)
 - [GDPR: What You Need to Know and How Constant Contact Helps ...](#)
- [Mailchimp](#)
 - [Mailchimp and GDPR](#)
- [Salesforce](#)

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- https://www.salesforce.com/company/privacy/full_privacy/
- [Zoho](#)
- [Indeed](#)
 - <https://www.indeed.com/legal/applicant-privacy>
- [National Council of Nonprofits](#)

Additional Reading & Resources

(Including Wikipedia image credits not mentioned above)

- Tuskegee Syphilis Experiment: https://en.wikipedia.org/wiki/Tuskegee_syphilis_experiment
- WWII and Nazi Experiments: <http://www.un.org/en/sections/history/history-united-nations/index.html>
- Stanford Prison Experiment: https://en.wikipedia.org/wiki/Stanford_prison_experiment
- Cambridge Analytica, Facebook, 2016 Elections: <https://www.theguardian.com/uk-news/cambridge-analytica>
- Data Types (computer science): https://en.wikipedia.org/wiki/Data_type
- Data Types (IOT/ICT): Arlene Ducao's Data Visualization Toolbox: <https://drive.google.com/file/d/0B1KM70jIEfvpT3FSZzEzVkFaMDA/view>
- Data Types (Human Rights): <http://visualizingrights.org/kit/data/index.html>
- Data Types (Customer Relationship Management): https://en.wikipedia.org/wiki/Customer-relationship_management
- Information Silos: https://en.wikipedia.org/wiki/Information_silo
- Business Models in Consumer Technology: <https://www.slideshare.net/JanDawson2/business-models-in-consumer-technology>
- Resource Constraints in Project Management: <https://www.scholar99.com/triple-constraints-project-management/>
- Levels of IRB Review: <https://oprs.usc.edu/files/2017/04/levels-of-review.png>
- Types of Informed Consent: http://www.med.uottawa.ca/sim/Data/Serv_Ethics_e.htm
- "Toss out that old stakeholder review process:" <https://www.slideshare.net/jillchrist/toss-out-that-old-stakeholder-review-proceess>
- Quantitative Methods for Public Administration (book): <https://www.waveland.com/browse.php?t=525>
- ACM Conference on Fairness, Accountability, and Transparency: <https://fatconference.org>

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Next Level Tactics and Tools

(201-level tools for developing your own data collection policy)

- <https://privacytools.seas.harvard.edu/differential-privacy>
- <http://ukanon.net/wp-content/uploads/2015/05/The-Anonymisation-Decision-making-Framework.pdf>
- <https://mediainpactfund.org/a-holistic-approach-to-operational-and-digital-security/>
 - <https://mediainpactfund.org/reports/global-media-philanthropy-what-funders-need-to-know-about-data-trends-and-pressing-issues-facing-the-field/>
- <https://www.internews.org/resource/saferjourno-digital-security-resources-media-trainers>
- <https://safetag.org>
- <https://www.fordfoundation.org/media/3334/digital-security-grantcraft-guide-v10-final-22317.pdf>
- <https://rarenet.github.io/DFAK/en/SecureCommunication/>
- <https://freedomhouse.org/program/lifeline#.U8HUGvldXAM>
- <https://holistic-security.tacticaltech.org>
- <https://alidade.tech/>
- <https://huridocs.org/2017/03/community-discussion-holistic-security-in-practice/>
- <http://www.integratedsecuritymanual.org>
- <https://iapp.org>
 - <https://iapp.org/resources/article/sample-data-protection-policy-template-2/>
 - <https://iapp.org/news/a/whats-a-nonprofit-to-do-the-best-privacy-program-on-the-cheap/>
 - <https://iapp.org/resources/article/introduction-to-privacy/>
 - <https://iapp.org/news/a/looking-to-comply-with-gdpr-heres-a-primer-on-anonymization-and-pseudonymization/>
- <http://dataforpolicy.org/about/>
- <https://www.onetrust.com/gdpr-applies-charities-non-profit-organizations/>
- <https://nptechforgood.com/2019/02/01/5-ways-to-protect-your-nonprofits-data/>
- <https://www.hurwitassociates.com/liability-risk-management-insurance/ma-data-security-law-requirements>
 - <https://www.mass.gov/files/documents/2016/07/qr/sec-plan-smallbiz-guide.pdf>
- Last minutes additions (May 1 2019)
 - <https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html#standard>
 - <https://iapp.org/news/a/looking-to-comply-with-gdpr-heres-a-primer-on-anonymization-and-pseudonymization/>

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- <https://www.caida.org/projects/predict/anonymization/>

Legal Resources

- NY Legal Referral Service. They provide a set of referrals based on your legal needs, and then the initial 30-minute phone consultation with each lawyer is \$35.
<http://www.nycbar.org/get-legal-help/>
- The Legal Aid Society “exists for one simple yet powerful reason: to ensure that no New Yorker is denied the right to equal justice because of poverty. For over 140 years, we have protected, defended, and advocated for those that have struggled in silence for far too long - working on the front-lines and behind-the-scenes to offer our clients the exceptional legal services they deserve.” <https://www.legalaidnyc.org/>
- The City Bar Justice Center Neighborhood Entrepreneurship Program regularly holds free clinics around the city, where you can get a free in-person consultation:
<https://www.citybarjusticecenter.org/get-help/>