Big Data in the Life Sciences: Multimedia Resources

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Description

This collection includes TED Talks, recorded lectures, and documentaries by scholars and others engaged in the scholarly conversation on the ethics of Big Data, including applications in healthcare, concerns over privacy, and challenges in interpretation. The list was compiled in Spring 2018 by Michelle Sullivan Govani to go with the Big Data Resource Collection developed by Valerie Racine.

Body

Bernholz, Lucy. "Behind and Beyond Big Data - Stanford PACS." 2016. https://pacscenter.stanford.edu/video/lucy-bernholz-digital-civil-society/.

- Privacy is incredibly valuable to us as individuals, but it also serves a critical role for society and democracy more broadly, says Lucy Bernholz. She is the co-director of Stanford's Digital Civil Society Lab.

Bernholz, Lucy. "Using Data for Good: The Potential and Peril of Big Data." FSGImpact. 2017. https://www.youtube.com/watch?v=hDs1g871bV8.

- Lucy Bernholz, Visiting Scholar, Center on Philanthropy and Civil Society, Stanford University at the Next Generation Evaluation Conference. Dr. Bernholz discusses the impact of big data on power imbalances, personal privacy, and civil society.

Bernholz, L., and Tracey Lauriault. "Transform the Sector: Doing Data Ethically." Vimeo. 2017. https://vimeo.com/220701693.

- Data isn't a silver bullet. It doesn't solve every problem facing the sector and beyond that, it can actually introduce new risks — especially when dealing with marginalized or vulnerable populations. This session, led by one of the world's leading thinkers on the ethics of digital data, will connect participants with the latest resources for safe, ethical and effective digital data governance and provide guidance on how you can address your own data challenges.

Boyd, Danah. 2017. Global Ethics Forum: The Ethics of Big Data with Danah Boyd. Carnegie Council for Ethics in International Affairs. https://www.youtube.com/watch?v=SZjjnsI2Tjo.

- How do we analyze vast swaths of data and who decides what to collect? For example, big data may help us cure cancer, but the choice of data collected for police work or hiring may have built-in biases, explains Microsoft Research's danah boyd. "All the technology is trying to do is say, 'What can we find of good qualities in the past and try to amplify them in the future?' It's always trying to amplify the past. So when the past is flawed, it will amplify that."

Crockett, Molly. "Molly Crockett: Beware Neuro-Bunk." TED Talk. 2012. https://www.ted.com/talks/molly_crockett_beware_neuro_bunk.

- Brains are ubiquitous in modern marketing: Headlines proclaim cheese sandwiches help with decision-making, while a "neuro" drink claims to reduce stress. There's just one problem, says neuroscientist Molly Crockett: The benefits of these "neuro-enhancements" are not proven scientifically. In this to-the-point talk, Crockett explains the limits of interpreting neuroscientific data, and why we should all be aware of them.

Cukier, Kenneth. 2014. Big Data Is Better Data. https://www.ted.com/talks/kenneth_cukier_big_data_is_better_data.

- Self-driving cars were just the start. What's the future of big data-driven technology and design? In a thrilling science talk, Kenneth Cukier looks at what's next for machine learning -- and human knowledge.

Curran, A., Levy, J., McDonald, S., Lucy Bernholz. "Data Dilemma: Shared AND Secure? - Stanford PACS." 2017. https://pacscenter.stanford.edu/video/data-dilemma-shared-and-secure/.

- Digital data are a double-edged sword for civil society: a valuable source of insights and learning, and a potential liability for under-resourced organizations to manage and protect. How can the social sector navigate this data dilemma? Can data be shared and secured at the same time? Who owns donated data and who is responsible for protecting it? This conversation will highlight three efforts to make the most of shared digital data, to enhance the sector's security practices, and to develop governance models purpose-built for the digital age.

Etlinger, Susan. "Susan Etlinger: What Do We Do with All This Big Data?" TED Talk. 2014. https://www.ted.com/talks/susan_etlinger_what_do_we_do_with_all_this_big_data.

- Does a set of data make you feel more comfortable? More successful? Then your interpretation of it is likely wrong. In a surprisingly moving talk, Susan Etlinger explains why, as we receive more and more data, we need to deepen our critical thinking skills. Because it's hard to move beyond counting things to really understanding them. (12:23)

Grace, Justin. "Ethical Quandary in the Age of Big Data." TEDxUCL - YouTube. 2015. https://www.youtube.com/watch?v=mVZ78kdduyY.

- Data is now everywhere. The 'internet era' has now passed and we are entering the era of data. Data use and misuse can lead to both powerful positive change or disaster. Here I discuss the questions we should ask about data and present three case studies where organisations have generated controversy from their data practices. I finish by touching on what we can do to take ownership of our data.

Kohane, Isaac. "Isaac Samuel Kohane Makes a Case for Genomic Data Sharing at the Risk of Reduced Security. - YouTube." 2014. https://www.youtube.com/watch?v=yKAFbixq2tY.

- 2014 Bio-IT World Keynote. Kohane explores, is there a threat to privacy? How does that threat inform our expectations for privacy? Is any expectation of privacy reasonable? How can we best preserve privacy and autonomy while accelerating medical progress?

O'Neil, Cathy. "Cathy O'Neil: The Era of Blind Faith in Big Data Must End." TED Talk. 2017. https://www.ted.com/talks/cathy_o_neil_the_era_of_blind_faith_in_big_data_must_er

- Algorithms decide who gets a loan, who gets a job interview, who gets insurance and much more -- but they don't automatically make things fair. Mathematician and data scientist Cathy O'Neil coined a term for algorithms that are secret, important and harmful: "weapons of math destruction." Learn more about the hidden agendas behind the formulas.

Polonetsky, Jules. 2014. Ethical Insights: Big Data and Privacy, Navigating Benefits, Risks and Ethical Boundaries. University of St. Thomas | Minnesota. https://www.youtube.com/watch?v=KJmqiwNjfMI.

- Jules Polonetsky – executive director of the Future of Privacy Forum, explores what is "big data" and how is it evolving, challenges "big data" presents for privacy, best practices in balancing benefits and risks, and who decides how "big data" is used. Ethical Insights is hosted by Ron James, president and CEO of the Center for Ethical Business Cultures (CEBC).

Rockefeller Foundation. "Rockefeller Foundation: Ethics of Big Data on Vimeo." 2016. https://vimeo.com/148018894.

- How can data help communities in times of upheaval? How can it hurt them? A group of key innovators in the fields of data and computer science, the arts, and the humanitarian and ecological spheres collaborated on a fresh approach that emphasizes ethics as a central — and often overlooked — factor in building community resilience.

Stryker, Charlie. "Big Data Will Impact Every Part of Your Life." TEDxFultonStreet - YouTube. n.d. https://www.youtube.com/watch?v=0Q3sRSUYmys.

- Dr. Charles W. Stryker is the Founder and President of a professional advisory firm, Venture Development Center, Inc. (VDC), and he has been recently recognized as the Data Innovator of the Year 2013. His business has a focused practice of assisting "Big Data" firms in creating, developing and commercializing Information Services properties.

Tozzi, Alberto. 2017. Ethics in Innovation: The Role of Big Data. Asset Project. https://www.youtube.com/watch?v=jMCTccs1ObE.

- Video Clip: The growing role of Big Data in medicine raises an ethical issue for Responsible Research and Innovation: what about privacy and a possible misuse of such information? During "Shaping the Future of Pediatrics" congress in Rome, ASSET met Alberto Tozzi, Research area coordinator and Head of Digital Medicine and Telemedicine Unit at Ospedale Pediatrico Bambino Gesù, Rome. He suggests that technical solutions can help, but they are not enough, without a cooperation among all the actors (patients, family, hospital, authorities, and so on). This is a very brief introduction to the types of ethical questions you could ask around big data.
- ASSET (Action plan on Science in Society related issues in Epidemics and Total pandemics) is a 48 month project that combines public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media, in order to develop an integrated, transdisciplinary strategy, which will take place at different stages of the research cycle, combining local, regional and national levels. Learn more at: http://www.asset-scienceinsociety.eu/.

Wallace, Marie. 2014. "The Ethics of Collecting Data." https://www.ted.com/talks/marie_wallace_the_ethics_of_collecting_data.

- One big ethical question looms over the excitement about the potential of big data: how do we maintain privacy while gleaning insight from all of this collected information? Marie Wallace offers some fresh thinking on the topic, such as radical transparency on how retailers use ads to target certain demographics. (10:18)

Woopen, Christine. "Oviedo Enhanced Interview." 2017. https://vimeo.com/239074149.

- In this video, Christine Woopen, a professor of ethics and theory of medicine at the University of Cologne, discusses the importance and impact of big data. She covers its potential benefits as well as the possible harmful consequences. Big data poses many challenges, particularly in regard to human rights. Woopen discusses the need for the Convention of Human Rights to address big data and its impact at the Oviedo Convention.

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Resource Type

Bibliography

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Big Data in the Life Sciences Collection

Topics

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