The Next Frontier – Big Data 2.0

Four Questions for Debate

• What does it mean to have data awareness and understanding in the new world of massive open online data and continuous participatory research programs?

• How can information specialists capitalize on their evolving data-related roles and competencies in the Big Data era?

• Where should librarians concentrate their efforts to create real value for the individuals and communities they serve?

• How can practitioners collaborate to make a big difference in our fast-moving data-rich society?
Libraries, Librarians, and Data

The Way We Were (2012) – An Evolving Landscape

• Social science data archives and geospatial data resources
  – local data libraries/support services established in the 1980s and 1990s (e.g., Edinburgh, Oxford, LSE)

• Networked data-intensive science and research data services
  – exploring data curation and storage, advising on data management plans (e.g., Georgia Tech, Purdue, MIT)

(Corrall, 2012)
Libraries, Librarians, and Data


New vocabulary, New roles, responsibilities, relationships

- Data centres/repositories
- Linked data
- Data analytics
- Data warehouses
- Data visualization
- Data journals/papers
- Data citation
- Text and data mining

Beyond Research Support

- Research data services
- Open data for collections
- Learning analytics projects
- Helping researchers to use data visualization tools
- Using data visualization in library assessment
- Metadata consultancy
- Facilitating research using text and data mining
RDM Tiered Service Delivery Model

From niche activity to mainstream service

1. **Basic RDM Service Providers**
   - All public-facing staff, general awareness

2. **Advanced RDM Service Providers**
   - Discipline-based knowledge (e.g., liaison librarians)

3. **Specialist RDM Service Providers**
   - Explicit data-related responsibilities, with in-depth competencies

(Mattern, Brenner & Lyon, 2016, p. 29)
Now with New Crime Data!
(Which comes with a handy guide.)

Browse our most popular datasets
156 datasets and growing

Groups/Topics
- Arts & Culture
- Civic Vitality & Governance
- Education
- Business & Economy
- Demographics
- Energy

Organizations
- Allegheny County
- Carnegie Library of Pittsburgh
- Healthy Ride
- BikePGH
- City of Pittsburgh
- Port Authority of Allegheny
Partners

The Western Pennsylvania Regional Data Center is built on partnerships with many organizations. The following organizations and people have been instrumental partners of the Data Center, and we would like to acknowledge their contributions:

- Allegheny County and the City of Pittsburgh have been our key partners from the start, and we’re excited to be working with so many committed staff and supportive elected officials.
- Our financial supporters include the University of Pittsburgh and the Richard King Mellon Foundation. The Data Center doesn’t happen without their generosity.
- University of Pittsburgh University Library System Digital Scholarship Services for their help with all things data management and metadata.

About

The Western Pennsylvania Regional Data Center supports key community initiatives by making public information easier to find and use. The Data Center provides a technological and legal infrastructure for data sharing to support a growing ecosystem of data providers and data users. The Data Center maintains Allegheny County and the City of Pittsburgh’s open data portal, and provides a number of services to data publishers and users. The Data Center also hosts datasets from these and other public sector agencies, academic institutions, and non-profit organizations. The Data Center is managed by the University of Pittsburgh’s Center for Social and Urban Research, and is a partnership of the University, Allegheny County and the City of Pittsburgh.
About

Exploring Data Worlds at the Public Library

Data literacy is new to the world of libraries and its meaning is still open to negotiation. Although many have advocated for the education of a data-literate population, there is little consensus on what such educational programs should look like, particularly in the context of informal learning at the public library.

The “Exploring Data Worlds at the Public Library” project will investigate youth data literacy in the context of technology-supported programs for young people at the public library. The project aims to increase awareness of the unique data literacy needs of youth as well as to develop strategies for training youth librarians so they can empower young people in our data-driven world.

By addressing gaps in the capacity of libraries to support the public's knowledge, skills, and practices surrounding data, the project will contribute to IMLS’s priority of building the social and technical infrastructure of libraries nationwide, and to the development of the National Digital Platform—the “combination of software applications, social and technical infrastructure, and staff expertise that provide library content and services to all users in the USA” (IMLS). This project was made possible in part by the Institute of Museum and Library Services. The project's grant number is RE-31-16-0079-16.
Pittsburgh libraries join initiative to protect data

JULIAN ROUTH
Pittsburgh Post-Gazette
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On the second floor of the Carnegie Library of Pittsburgh on Sunday, Priya Donti could be found hunched over a laptop, combing through government databases on monthly normal temperatures across different states.

The Carnegie Mellon University student’s participation in the first Data Rescue Pittsburgh event was driven by just as much a passion for open and transparent data as fear. Disturbed by reports that Donald Trump’s presidential administration might review Environmental Protection Agency climate data before it’s published, she joined more than 40 programmers,
The Next Frontier – Big Data 2.0

- Converging e-science, business intelligence, crowdsourcing, big data analytics, social media and Web 2.0 technologies
- Enabling broader and deeper applications of analytical tools
- Located in academic/research institutions, usually based on public participation and often involving commercial players
- Taking very large-scale data-intensive research to new levels of organizational and socio-technical complexity
- Raising ethical, legal and policy issues

Massive Open Online Data Studies (MOODS)
“The health care field generates an enormous amount of data every day. There is a need, and opportunity, to mine this data and provide it to the medical researchers and practitioners who can put it to work in real life, to benefit real people. Many organizations can fulfill part of this process, but none of them are equipped to begin with raw data, develop an idea and move that idea directly into a practice setting.”

What roles can libraries and librarians play in such endeavours?

Secondary data analysis
Defining digital medicine

“The patient is an enormous repository of information that needs to be harvested as a partnership not only in clinical care but in discovery.

It is the only way we will define wellness and its progression to disease, rather than traditional medicine that defines disease and its progression to death.”

(Ausiello in Elenko et al., 2015, p. 456)

Embodied information practices!
Precision Medicine Initiative

- Launched by President Obama in his January 2015 State of the Union address
- Aims to leverage advances in genomics, emerging methods for managing and analyzing large data sets, and health ICTs to accelerate biomedical discoveries — while protecting privacy
- Plans to enroll one million or more volunteers and may include children

“All of Us” Participatory research
Precision Medicine Initiative – issues...

“There’s privacy issues. We’ve got to figure out how do we make sure that if I donate my data to this big pool that it’s not going to be misused, that it’s not going to be commercialized in some way that I don’t know about.

And so we’ve got to set up a series of structures that make me confident that if I’m making that contribution to science that I’m not going to end up getting a bunch of spam targeting people who have a particular disease I may have.”

(Obama, 2016, February 25)

Ethical, legal, and social implications?
Values
documentation

PMI Cohort Program announces new name: the All of Us Research Program

The Precision Medicine Initiative® (PMI) Cohort Program will now be called the All of Us Research Program and will be the largest health and medical research program on precision medicine. A set of core values is guiding its development and implementation:

- Participation is open to all.
- Participants reflect the rich diversity of the U.S.
- Participants are partners.
- Participants have access to their information.
- Data will be accessed broadly for research purposes.
- Security and privacy will be of highest importance.
- The program will be a catalyst for positive change in research.

The name change reflects these values. We will invite people from all across the U.S. to raise their hands to be one of a million or more participants who will contribute their health information. This information will form the basis of a data set that researchers will be able to analyze to identify better ways to prevent and treat diseases that are based on individual health, environment, and lifestyle.

To truly reflect the far-reaching nature of the program, NIH developed a name that would convey the inclusivity and openness that are hallmarks of PMI research.
Harvard PGP is “an open science research project...designed to create public scientific resources that everyone can access by bringing together genomic, environmental, and human trait data donated by our participants”

- Founded at Harvard Medical School in 2005, now a Global Network involving Canada (University of Toronto), the UK (UCL) and Austria (Austrian Academy of Sciences)
- Harvard PGP is staffed by a small, largely volunteer group of researchers, engineers, and ethicists who are all pioneers in their fields
- Members of the Global Network follow a common set of guidelines, but the quantity and quality of information on national sites varies significantly

“Privacy, confidentiality and anonymity are impossible to guarantee in a...research study where public sharing of genetic data is an explicit goal”

Personal Genome Project
Guidelines of the Global PGP Network

a) **Public Data.** Participants are invited to share genomic and trait data using a CC0 waiver

b) **Non-anonymous.** Risks of participant re-identification are addressed upfront as part of the consent and enrollment process
   - Neither anonymity nor confidentiality of their data is promised to participants

c) **Equal access.** Participants are given timely and complete access to their individual data i.e., raw data and not just summary results “where feasible”

d) **Oversight.** Each member must maintain current Institutional Review Board [Research Ethics] or local equivalent approval

e) **Not for profit.** Managed or sponsored by a non-profit organization (or local equivalent).
   - A member shall not sell or license participant data or tissues except for purposes of “reasonable cost recovery”

Pretty Good Privacy?
biobank uk

“A major national health resource”

• Registered charity
• Est. by Wellcome Trust, MRC, Dept. of Health, Scottish Gov., and NW Regional Dev. Agency; funded by Welsh Dev. Agency, BHF and Diabetes UK
• Hosted by U. Manchester, supported by NHS
• Open to *bona fide* researchers anywhere in the world, including those funded by academia and industry

**Background**

• Aims to improve prevention, diagnosis and treatment of life-threatening illnesses
• Recruited 500,000 people aged 40-69 in 2006-2010
• Participants have undergone measures, provided blood, urine and saliva samples, and detailed personal information – and agreed to have their health followed

“...to help scientists discover why some people develop particular diseases and others do not”
UK Biobank wants to be “a model not only for best science but for best ethical practice too, in relation to these big biobank projects”

Professor Roger Brownsword, Chair (2011-2015)
UK Biobank Ethics and Governance Council (UKEGC)

http://www.ukbiobank.ac.uk/ethics/

So, what are the ‘best science’ and ‘best ethical practice’ lessons to be learned from UK Biobank?
Researchers wanted to use UK Biobank to identify people to invite into a separate study.

They asked UK Biobank to send an introductory email to its participants pointing to the website of the new study.

Offering such a recruitment mechanism could benefit the research community.

- But take time and resources that could be used elsewhere.

In what circumstances would it be acceptable for Biobank to divert resources in this way?

- How should *ad hoc* third-party re-contacts be accommodated?

UKBEGC proposed two options:

- Create a dedicated webpage to provide neutral information about (approved) studies.
- Provide a withdrawal category allowing Biobank participants opt-out from email invitations.

The project was approved as a pilot subject to fitting with Biobank’s timetable of re-contacts and will be used to draw up a framework for future requests.

UK BIOBANK ETHICS AND GOVERNANCE COUNCIL ANNUAL REVIEW 2015
Sage Bionetworks developed and maintains the **Participant-Centered Consent (PCC) toolkit**.

The goal of the PCC toolkit is to transform the concept of consent from a signature on a legal form to a process that educates, and to allow as many people as possible to engage in consented studies. The PCC toolkit is openly licensed and may be used in any context, by any user, for any purpose, as long as attribution is provided back to Sage Bionetworks.

The PCC toolkit contains a variety of resources for developing a consent process:

- PCC visual dictionary of icons and concept animations
- eConsent workflows
- Design documents and templates
- FAQ

“...from a signature on a legal form to a process that educates”
Issues arising from **Big Data 2.0 projects**

**Legal compliance**
- Privacy laws
- Data protection legislation
- Right to be forgotten
- Genetic information laws
- Freedom of information
- Intellectual property  
  e.g., patenting human genes (cf. EU and US case ruling)
- Licensing/contractual issues
- Publishing

**Ethical challenges**
- Privacy
- Anonymity  
  – protection from bad actors  
  e.g., cybercriminals, hactivists
- Monetization  
  – selling of health data
- Conflicts of interest
- Informed consent
- Solicitation of donors for participation in other studies
Policy questions arising from Big Data 2.0

- How and by whom will health data/big data be preserved and made retrievable for and by future stakeholders?
- What guidelines and requirements are needed for publishing related to health data/big data?
- Who needs to have a voice in policy-setting and policy-making, and who should craft the governing policies and codes of ethics?
  - Given the pace of change, how often should policies and codes be reviewed and updated?
- What oversight and enforcement mechanisms are needed to ensure compliance?
  - What are the penalties for piracy of health data or malfeasance, negligence, willful blindness, and harmful impacts on human subjects?
  - What protections are available or need to be developed and codified for whistleblowers who report lapses and breaches of compliance?
Big Data 2.0 – Potential roles for info pros

Global megaprojects
➢ Very large scale
➢ Interdisciplinary
➢ Human subjects
➢ Inter-state/international
➢ Multiple jurisdictions
➢ Cross-sector partners
➢ Different cultures

Advancing knowledge to benefit society, but raising multiple issues of concern...

• **Data ethics** – monitoring practices and advocating or contributing to *policy* for data protection and research integrity

• **Data literacy** – extending education to cover personal, social, professional and scholarly *contexts* of data creation, sharing and use

• **Digital curation** – applying repository and RDM know-how (e.g., *metadata* advice and consultancy)

• **Interdisciplinary facilitators** – helping multidisciplinary teams navigate unfamiliar *territory*
Conclusion – Critical roles for LIS

- Mainstream data literacy and adopt holistic approaches to include data handling in education, work, and everyday life
- Raise awareness of ethical, legal, and social implications (ELSI) of large-scale participatory data-intensive projects
- Work proactively across professional and sectoral boundaries to share and transfer essential know-how (e.g., metadata)

Provide a human-centred perspective – The conscience of the big data world

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