## University of Alberta Research Records Policy – Work in Progress

Susan Babcock, Research Ethics Office Campus Data Summit

19 March 2013





- Universities document many things grades, grants, payroll, course descriptions, performance appraisals, budgets, codes of conduct, committee processes, purchasing, agreements, smoking (no), liquor consumption (limited), parking (expensive)
- We prize records and documents and data and work diligently to collect and/or generate them (knowledge production)
- All current UA policy and procedures speak exclusively to operational records

"uplifting the whole people"



- Solitary exception: Research & Scholarship Integrity Policy Section 3 – Responsibilities of the Principal Investigator
- a. Principal Investigators shall be involved both with the research design and with the supervision of research work, such as data acquisition, recording, analysis, interpretation, <u>and storage</u>.
- b. Principal investigators have the further responsibility for the research activities conducted by their students, research staff, and collaborators.
- c. Principal Investigators <u>shall retain original data for a minimum of 5 years</u> <u>after the work is published, or such period as required by funding agencies,</u> <u>or by University of Alberta policies respecting information and records</u> <u>management.</u>

"uplifting the whole people"



- All Canadian universities have policies about research funding, research requiring ethics review, research and scholarship integrity, patents, overhead, intellectual property, who can/cannot apply for research funding/conduct research
- Not one has policy on research records, although the University of Saskatchewan has published procedures for Stewardship of research records

"uplifting the whole people"

ARSHALL TORY, FOUNDING PRESIDEN

Context 3



- 2010 IAS audit of IT security in clinical faculties yielded
  2011 Report on IT Security Protection of Clinical
  Research Participants' Information
- Not surprisingly, the report identified gaps in research data management
- Note that all clinical research requires REB review and is governed by TCPS2 and, in Alberta, by the *Health Information Act*

"uplifting the whole people"

Catalyst



- VPR struck a working group involving representatives from Research Ethics Office, Information & Privacy Office, Northern Alberta Clinical Trials & Research Centre, VP-Information Technology and the Data Library to develop procedures that would fit under existing general Research Policy, including
- Research Records Guidance Procedure, with an appendix on Research Data Management Guidelines
- Reporting Information Privacy & Security Breaches Procedure
- Research Records Classification Procedure

"uplifting the whole people"

ARSHALL TORY, FOUNDING PRESIDENT, 1908



- First challenge define a research record
- Tendency to privilege records that identify individuals, especially health records – easy to create policy that dovetails with existing frameworks, eg TCPS, Health Information Act, FOIPP, contractual or funding obligations)
- Much harder to to design policy for research records for which there are fewer external or *a priori* requirements

"uplifting the whole people"



**Research information assets supporting both research and** operational needs. This includes administrative information and records produced for analytic or evidentiary purposes. Research records include those documents and records and materials captured by or for a researcher that are necessary to document, reconstruct, evaluate, and validate research results and the events and processes leading to the acquisition of those results. Research records may be in many forms including but not limited to laboratory notebooks, survey documents, questionnaires, interview notes, transcripts, machinegenerated data or performance outputs, recruitment materials, consent forms, correspondence, other documents, computer files, audio or video recordings, photographs including negatives, slides, xray films, samples of compounds, organisms (including cell lines, microorganisms, viruses, plants, animals) and components of organisms.

"uplifting the whole people"

MARSHALL TORY, FOUNDING PRESIDEN



- If there are no external requirements, why do you need institutional policy?
- To provide principle-based guidance for research records stewardship
- To advise on best practices in research records management and preservation
- To define key considerations in the production of research data and records containing identifiable information on human subjects
- To define key considerations and minimum requirements for research records retention

"uplifting the whole people"



- Different kinds of research records will require different standards for collection, maintenance, privacy and retention.
- In general, research records should be created, stored, used and retained in accordance with the highest standards of scientific and academic practice relative to the PI's discipline or field.
- Research records must be retained in sufficient detail to enable the researchers and the University to respond to questions about research methods, rigour, accuracy and authenticity, to demonstrate that the results are reproducible and to document the relative contributions of the research team.

"uplifting the whole people"

ARSHALL TORY, FOUNDING PRESIDER



- Technology today creates opportunities for data capture, data linkage, data sharing and data repositories and possibilities for research that were simply undreamed of as little as 10 years ago
- Most government and institutional policy is based on paper records
- Social media and social networking are being used to interact with patients, students, clients and research participants, to collect data and disseminate findings

"uplifting the whole people"



- Privacy, on the web, is poorly understood by many
- Move toward a more open sharing of information challenges traditional ideas about ownership, sharing and/or dissemination of data
- In many social networks, protection of confidentiality is not valued or relevant





- Draft materials are being slowly shepherded through the governance process
- Although none of the documents discuss ownership of research records, we anticipate some lively discussions on that issue
- In terms of day to day research, these procedures will not necessarily have a big impact
- However, there is value in establishing a starting point and is heightening awareness about issues in research records stewardship.

"uplifting the whole people"

MARSHALL TORY, FOUNDING PRESIDENT.



- The members of the Research Records Working Group are Richard Fedorak, Katharine Moore, Harry Davis, Gordie Mah, Carlos Miranda, Chuck Humphrey, Leah Vanderjagt, Lynn Penrod & Susan Babcock
- Bullets on social media from a presentation by Nancy Walton, Ryerson University, CAREB 2012
- Susan Babcock, Administrative Director, <u>susan.babcock@ualberta.ca</u> 780-492-6561

"uplifting the whole people"