

Privacy & Confidentiality Roundtable Annual Report for 2011-2012

2011-2012 Officers

Phoebe Evans Letocha, Chair
Elena Danielson, Vice-Chair/Chair Elect
Heather Dean, Immediate Past Chair
Laurel Bowen, Steering Committee Member
Amy Fitch, Steering Committee Member
Anne Ostendarp, Steering Committee Member
Linda Long, Representative to the Standards Committee
Brittany Bennett Parris, Web Liaison
Dennis Meissner, Council Liaison

i. 2012 Annual Meeting

Number of attendees: 50. The meeting agenda was publicized through the roundtable's regular communication channels (website, email, and conference program).

Election Results: In July 2012, the roundtable elected three new members: Menzi Behrnd-Klodt, who will serve as Vice-Chair/Chair Elect, and Erin O'Meara and Ryan Speer, who will serve as members of the Steering Committee. The roundtable would like to thank Heather Dean, Laurel Bowen, and Anne Ostendarp for their service. Special thanks to Heather Dean for overseeing the election.

Summary of Meeting Activities: Detailed minutes from the 2012 meeting can be found in the Appendix A. The roundtable would like to highlight this year's program which was a lively discussion challenging archivists to share ethical responsibilities for modern personal papers with researchers and donors. The program included four panelists, Laura Clark Brown, Nancy Kaiser, Aprille Cooke McKay, and Kelly Wooten, who presented several cases studies which they opened up for audience comments and discussion.

ii. Advocacy and Public Awareness

Completed Projects:

- **SAA 2012:** The roundtable received 4 session proposals for endorsement, and endorsed 2 session proposals. The program for our roundtable meeting was adapted from one of our endorsed sessions, which did not make it onto the SAA program. The roundtable initiated one SAA session proposal, which was endorsed by the P&C

roundtable as well as by the Science, Technology, and Health Care, and the Latin American and Caribbean Cultural Heritage Archives roundtables, and was accepted to the program. Phoebe Evans Letocha collaborated with Joan Echtenkamp Klein and Janice Goldblum of the Science, Technology and Health Care roundtable to shepherd a session proposal to examine medical privacy issues: Session 107 “From Hidden Collection to International Incident: The John Cutler Papers and the Guatemala Syphilis Experiments.” Joan Echtenkamp Klein (University of Virginia) chaired the panel. Papers were presented by Marianne Kasica (University of Pittsburgh), Robert Richards (NARA, Atlanta), and Paul A. Lombardo (Georgia State University). The audience for the session was standing room only. It provoked thoughtful questions and discussion throughout the meeting. A summary of the session is available in the roundtable’s newsletter, Appendix B.

- **SAA Leadership Orientation:** Roundtable leadership members provided feedback to our Council liaison regarding the SAA Leadership orientation. Elena Danielson and Amy Fitch attended the leadership orientation session at the 2012 SAA annual meeting and found it to be very helpful.
- **Choose Privacy Week:** Led by Immediate Past Chair Heather Dean, the roundtable submitted the Choose Privacy video it produced to SAA Council, which responded favorably in September 2011. SAA is now listed as a friend and ally to the ALA led Choose Privacy project at www.privacyrevolution.org. The video, which was loaded on Vimeo (<http://vimeo.com/30595392>), is available through the roundtable’s homepage and at ALA’s “Choose Privacy Week” video gallery. This short video provides an archival perspective to approaches to protecting one’s privacy in the online world.
- **“Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators” (HHS-OPHS-2011-0005):** Phoebe Evans Letocha submitted comments to SAA Council, which were used as it drafted the SAA comment in October 2011.
- **International Council on Archives:** Heather Dean and Elena Danielson submitted comments to SAA Council on ICA’s draft principles and guidelines for access to archives.

Ongoing Projects:

- **Privacy and Confidentiality Handbook:** Linda Long has continued to spearhead work on a proposed Privacy and Confidentiality Handbook. The Handbook is meant to be a guide for archivists on best practices for privacy and confidentiality issues. Linda has developed an outline and solicited feedback from roundtable members. She is

working on formalizing a publication proposal to submit for e-publishing of the handbook.

- **Privacy and Confidentiality Bibliography:** A bibliography of writings on privacy and confidentiality issues is accessible as a wiki at <http://privacybiblio.pbworks.com/w/page/18593383/FrontPage>. Roundtable member Ginny L. Kilander and members of the steering committee have continued to update the bibliography. Ryan Speer will be leading this effort in the future.

iii. Diversity:

The roundtable continues to work on developing a more diverse leadership team. Phoebe Evans Letocha will spearhead this initiative during the 2013 election process. The roundtable was unable to send a representative to the new SNAP roundtable because the time of its meeting conflicted with our own roundtable meeting, but we are interested in reaching out to this group.

iv. Technology

The roundtable is engaged in SAA's overall technology initiatives, including successfully conducting the roundtable's second online election and transitioning to the Drupal site. Special thanks to Brittany Bennett Parris for continued service as our Web Liaison. The roundtable, spearheaded by Elena Danielson, is adding an e-newsletter. (Appendix B)

Questions/Concerns for Council Attention: None at this time.

Respectfully submitted,
Phoebe Evans Letocha, Chair, 2011-2012
November 14, 2012

Privacy and Confidentiality Roundtable Meeting Notes
SAA Annual Meeting 2012, San Diego, CA
Wednesday, August 8, 2012
5:30-7:30 pm

1. Chair Phoebe Evans Letocha opened the meeting and welcomed approximately 50 attendees.

2. Immediate Past Chair Heather Dean announced P&C roundtable election results:

- Vice Chair/Chair-Elect, Menzi Berhnd-Klodt
- Steering Committee member, Erin O'Meara
- Steering Committee member, Ryan Speer

All current members of the roundtable leadership were introduced as well.

3. SAA Council liaison, Dennis Meissner, provided an update of Council's recent activities:

- Council decided that all roundtables must have bylaws. P&C will focus on that this year.
- The process by which SAA appoints representatives to external groups is being reviewed to reduce the overall number and to ensure relevance to SAA.
- The member-needs survey this year produced tremendous feedback. Council will subdivide the review into 7 or 8 groups to address the results. Dennis emphasized that this was a big effort and would be a big focus for Council this year.
- The advocacy strategic initiative has been reenergized, with Frank Bowles at the helm.
- Description given of NHPRC report to the Executive Branch/OMB on the state of documentary heritage of the U.S. It addresses the gaps in documentary programs.
- A question from the floor was asked: With Council's increase in focus on advocacy, would there be additional budget to support lobbying? Answer: No, no additional funds were discussed. Council was trying to cohere something quite nebulous, providing more advocacy supporting NHPRC, NEH, funding levels of NARA, etc.

4. Updates and Projects:

- As stated, bylaws are now required for all roundtables. Amy Fitch will lead the effort to develop bylaws for the P&C roundtable. They will be presented next year for a vote.
- HIPAA final regulations are expected to be released by HHS, perhaps very soon. It has been 2 years since the comment period closed. An announcement will be distributed to the P&C list as soon as they come out.
- Susan Lawrence, University of Nebraska--Call for Archivists:
Dr. Lawrence is a historian working on a project entitled "Privacy and the Past," which includes a chapter on archives. She is looking to interview archivists for a sense of how decisions are made with regard to privacy and confidentiality in providing access to information on the dead. This can include medical, financial, or sexual identity information. Her IRB-approved project will look at what historians should know about the decision-making process for such access.
- The P&C roundtable endorsed Session 107 on the John Cutler Papers and the Guatemala syphilis experiments. It is Thursday, August 9 at 10:00 a.m.
- Open Floor: Erin O'Meara is on the 2013 program committee for SAA in New Orleans, August 11-17, which is theme free and joint with COSA. Any types of topics are

welcomed. Lightning talks are an option. Sections can endorse 2 session proposals, which are due October 5. Presenters can speak at only one session.

- Julie Graham of the SAA Education Committee announced that SAA and IMLS have multiple scholarships available for the upcoming EAD-CPF workshops. The next one is in Princeton, NJ.
- Frank Bowles of the Government Affairs Working Group relayed a request from Council for volunteers to help monitor public policy issues of interest to the various roundtables. If anyone is interested in P&C topics, please contact him.

5. Introductions were made around the room, followed by a call for session ideas for SAA 2013. A session partnering Dr. Lawrence, other historians, and archivists to discuss P&C issues with regard to the deceased was suggested. Any additional ideas should be sent to the P&C leadership for endorsement.

6. Roundtable meeting program: "Reconciling Access and Privacy: Opening Archives of the Recent Past." Panelists Laura Clark Brown, Nancy Kaiser, Aprille Cooke McKay, and Kelly Wooten presented thought-provoking talks using case studies from their repositories (University of North Carolina at Chapel Hill and Duke University) to advocate for greater emphasis on open access to archives, particularly those containing modern personal and private organizational papers.

Minutes submitted by Amy Fitch, September 28, 2012.

9-12-12



[Photo by Thegreenj](#)

THE KEYHOLE

Newsletter of the Privacy & Confidentiality Roundtable, Society of American Archivists, September 2012

A LITTLE HISTORY: In the 1990s SAA meetings included an informal breakfast for people to discuss balancing privacy and access in archival practice. Ruth J. Simmons (Rutgers) convened the early morning discussions, promoted sessions on the topic, and eventually shepherded the group to achieve roundtable status. The discussions, panel sessions, and programs provided context for *Privacy & Confidentiality Perspectives* edited by Roundtable members Menzi L. Behrnd-Klodt and Peter J. Wosh (SAA, 2005). The sessions also provided substantial content for *The Ethical Archivist* by Elena Danielson (SAA, 2010). As of August 2012 there are 507 member/participants in the P&C Roundtable. SAA supports a Roundtable microwebsite and a listserv so that all the members have a forum for participation. The website includes a growing bibliography on privacy in archives; the steering committee welcomes additional citations as well as annotations. Roundtable meetings are well attended, but many members simply participate online. (More information on the P&C Roundtable history would be most welcome. Please contact Elena Danielson at elenad@stanfordalumni.org).

CURRENT LEADERSHIP

Elena Danielson, Chair (2012-2013), Hoover Institution Archives, Stanford University, retired
Menzi Behrnd-Klodt, Vice-Chair/Chair Elect (2012-2013), Klodt and Associates
Phoebe Evans Letocha, Immediate Past Chair (2012-2013), Johns Hopkins Medical Institutions
Amy Fitch, Steering Committee Member (2011-2013), Rockefeller Archive Center
Erin O'Meara, Steering Committee Member (2012-2014), Gates Archive
Ryan Speer, Steering Committee Member (2012-2014), Virginia Tech University
Brittany Parris, Web Liaison (2010-), Jimmy Carter Library & Museum
Linda Long, Representative to the Standards Committee (2010-2013), University of Oregon
Dennis Meissner, Council Liaison (2010-2013), Minnesota Historical Society

Previous past chair: Heather Dean, Yale

SAA ANNUAL MEETING IN SAN DIEGO

- 1) 2012 P&C Roundtable Meeting: The Privacy and Confidentiality Roundtable met Wednesday, August 8, 5:30 pm – 7:30 pm. The new steering committee was introduced followed by a lively program and discussion.
- 2) After the business meeting, the roundtable hosted “Reconciling Access and Privacy: Opening Archives of the Recent Past,” organized by Laura Clark Brown, Nancy Kaiser, Aprille Cooke McKay, and Kelly Wooten. They used case studies to advocate for greater emphasis on open access to archives. Phoebe Evans Letocha shepherded this program for the RT.
- 3) Report on SAA Session 107: Phoebe Evans Letocha also shepherded a 2012 session proposal to examine medical privacy issues “From Hidden Collection to International Incident: The John Cutler Papers and the Guatemala Syphilis Experiments.” Joan Echtenkamp Klein (University of Virginia) chaired the panel. Papers were presented by Marianne Kasica (University of Pittsburgh), Robert Richards (NARA, Atlanta), and Paul A. Lombardo (Georgia State University). Kasica described how the collection was acquired by the University of Pittsburgh and then the steps taken to inventory, process, describe, and create an online finding aid for it by 2002. She also explained the access restrictions imposed by Dr. Cutler when he donated the collection. Only after his death in 2003 did staff seek permission to make the collection available to historian Susan Reverby, who did not examine the papers in detail until 2009. Reverby revealed the secret experiments to the public in her 2010 article, which caused this to become an international incident. Richards described what happened to the collection when it was transferred to the National Archives as federal records. He discussed the steps that NARA took to digitize the collection to make it available online. Staff had to balance the need to protect the privacy of the subjects of the experiments while facing deadlines and pressure to assure transparency and access to content that is graphic in nature. Lombardo, who was a member of the Presidential Commission for the Study of Bioethical Issues, discussed its mandate to document what happened in the experiments. He showed how the Commission was able to trace through an examination of the records what happened to individual subjects of the experiments. The audience for the session was standing room only. It provoked thoughtful questions and discussion throughout the meeting.
- 4) Bylaws: SAA Council requires all roundtables to post bylaws. Amy Fitch will be looking at possible templates for creating a simple and flexible governing structure.

PROJECTS

- 1) Bibliography: P&C has a privacy bibliography that needs updating. Please contact Ryan Speer with suggestions for useful citations and annotations: rps@vt.edu
- 2) E-Manual: Linda Long is working on a privacy e-manual: llong@uoregon.edu.
- 3) Program Proposals: Erin O'Meara is on the 2013 Program Committee. As a committee member, she cannot make proposals herself, but she can help by advising on privacy-related proposals and strongly suggest proposers get in touch with the RT for endorsement: omeara.erin@gmail.com.
- 4) Website: Recommendations for the website should go to Brittany Parris: Brittany.Parris@nara.gov.

CALL FOR ARCHIVISTS

At the P&C Roundtable Meeting in San Diego, Dr. Susan Lawrence of the University of Nebraska issued a call for archivists' participation in a new project. Dr. Lawrence is a historian working on a book entitled *Privacy and the Past*, which includes a chapter on archives. She is looking to interview archivists for a sense of how decisions are made with regard to privacy and confidentiality in providing access to information on the dead. This can include medical, financial, or sexual identity information, among other things. Her IRD-approved project will look at what historians should know about the decision-making process for such access.

LEGAL UPDATES

Update on Regulations Concerning FERPA (Family Educational Rights and Privacy Act)

A December 1, 2011, U.S. Department of Education (DOE) press release (<http://www.ed.gov/news/press-releases/us-education-department-announces-new-measures-safeguard-student-privacy>) announced new regulations concerning the Family Educational Rights and Privacy Act (FERPA) to increase the DOE's "ability to hold those who misuse or abuse student data accountable and ensuring our taxpayer funds are invested wisely and effectively." The new regulations would give schools "the flexibility to pursue routine uses of information without getting prior consent while allowing them to prevent those who may misuse or abuse student information from accessing it," avoiding uncertainty "about where state sunshine laws left off and where FERPA picked up." The increased sharing is intended to facilitate the use of data in statewide longitudinal data systems (SLDS) by expanding the redisclosure authority in FERPA "to make further disclosures of personally identifiable information from education records, without the consent of parents or eligible students, on behalf of the educational agency or institution from which the PII was obtained." For example, "states will be able to determine which early childhood programs prepare kids for kindergarten. High school administrators will now be able to tell how their graduates did in college. And states will be able to enter into research agreements on behalf of their districts to determine how best to use limited education funding during tough economic times." The new regulations also aim to "fix the gap" in protection by extending accountability to institutions and entities without students in attendance, such as student lenders, which have access to student records protected by FERPA. An editorial compilation of CFR material and Federal Register amendments concerning FERPA, prepared by the U.S. Department of Education, may be found at <http://www2.ed.gov/policy/gen/reg/ferpa/index.html>

Few cases to date discuss the intersection of FERPA's protections with federal or state Freedom of Information Acts (FOIA). In a 2011 case, a federal judge in the Northern District of Illinois ruled that FERPA and the Illinois (FOIA) could not be used in concert to allow University of Illinois officials to refuse to release student admissions records in response to media requests. Commentators do not believe that this ruling will have a broad reach, however.

Citation: <http://www.insidehighered.com/news/2011/03/10/>

[federal_judge_rejects_u_of_illinois_attempt_to_use_privacy_law_to_shield_admissions_records](#)

Health Insurance Portability and Accountability Act (HIPAA)

The U.S. Department of Health and Human Services on May 31, 2011, announced proposed changes to the HIPAA Privacy Rule pursuant to the Health Information Technology for Economic and Clinical Health (HITECH) Act, which is part of the American Recovery and Reinvestment Act of 2009. The rule would give people the right to get a report on who has electronically accessed their protected health information. (See <http://www.hhs.gov/news/press/2011pres/05/20110531c.html> and <http://www.gpo.gov/fdsys/pkg/FR-2011-09-14/pdf/2011-23525.pdf> for more information.)

Menzi L. Behrnd-Klodt, September 3, 2012

THANK YOU: A BIG THANK YOU TO PHOEBE EVANS LETOCHA FOR SERVING AS 2012 CHAIR AND SPONSORING EXCEPTIONAL PROGRAMMING ON THESE KEY P&C ISSUES.

The *Keyhole* newsletter is emailed to all members signed up with the Society of American Archivists Privacy and Confidentiality Roundtable. The newsletter will be issued several times a year, basically whenever there is enough content worth reporting. If you wish to unsubscribe or for comments and questions about the newsletter and roundtable, please contact the chair, Elena S. Danielson, elenad@stanfordalumni.org.