

Privacy and Confidentiality Roundtable Meeting Notes
SAA Annual Meeting 2013, New Orleans, LA
Wednesday, August 14, 2013
5:15-7:15 pm

Chair Elena Danielson opened the meeting and welcomed approximately 75 attendees.

In introductory remarks, Danielson noted that the Roundtable (RT) membership now stands at 508, with 118 voting in the online elections for chair and steering committee. She noted that more voted online than can attend RT meetings. In 2012, attendance was about 50 or 10% of the membership, so the challenge is to engage the other 90%. A recent Oral History Section online chat on the Boston College oral history case with more than 100 attendees might provide a good model.

In the past year, the Roundtable developed and adopted

Elena announced the RT election results:

Steering Committee member, Nancy Kaiser
RT leadership members also were introduced.

Danielson asked the attendees to introduce themselves.

SAA Council liaison Dennis Meissner provided a brief update on recent Council activities. He also spoke about the possible virtualization of future meetings. As Dennis term ends with this annual meeting, Tim Pyatt will take over as Council liaison to the RT.

Most of the meeting was devoted to the two presentations scheduled.

Phoebe Evans Letocha, Alan Mason Chesney Medical Archives, Johns Hopkins Medical Institutions, presented an update on the changes that the HITECH Act, passed by Congress, has made to the Privacy and Security Rules of the Health Insurance Portability and Accountability Act (HIPAA). These changes, effective in March 2013, took into effect testimony of Nancy McCall and other archivists. As a result of the revisions, many more archives likely are covered by HIPAA, falling into the category of "business associates." HIPAA places responsibility on archives to determine they must comply with HIPAA. The law also changed the definition of "Protected Health Information" (PHI) which no longer applies to protect (close) records of those deceased 50 years or more. Letocha noted that although HIPAA's changes allow more information to be made available, archivists' decisions may be more difficult as they must know dates of death and review state statutes, which may define "medical records" (as HIPAA does not) or define the term differently, or protect patient records for longer or different time periods. She has developed a decision tree that factors in the age of the subject at the date of creation of the records. Institutions cannot authorize publication of protected health information. She advised consulting with legal counsel for these gray areas and differences in the laws. The burden of protecting patient information and privacy falls on both researchers and archivists. Although HIPAA requirements must be met, Phoebe also reminded archivists not to forget ethical standards when they consider collections. Finally, there are likely to be more negotiating of individual business associate agreements between archives and medical institutions and donor agreements, as well as more restrictions on medical records. For more information about HIPAA, there is a link on the RT webpage to the Science, Technology & Health Care Roundtable page.

Mark Greene, American Heritage Center, University of Wyoming, gave a presentation on development of a privacy survey, planned for distribution to archivists before year end with responses to be anonymous. The goal is to gain a reasonable indication of how the profession views privacy and the ethics of confidentiality. He noted that anecdotally it seems as though the opinions of the profession have shifted, but more data is needed to understand how archivists review records and make decisions on privacy and access. Greene hopes to restart the conversation to help the profession coalesce around a core of privacy and confidentiality policies or principles and develop decision trees, and norms and boundaries. Some of the issues discussed included the desirability of developing policies to protect third party privacy rights, but should such policies have such a bias? Will donors continue to donate if archivists can impose restrictions on their own initiative? What about potential breach of contract claims if archivists impose restrictions to protect third party privacy when donors want no restrictions? Should privacy policies be written? How can institutional policies be crafted to take the onus (and burden) of this decision-making off of individual archivists? Mark also answered questions from the audience and provided and solicited comments from attendees about the draft document. Suggestions included adding categories for "not applicable" and additional gradients in the responses, as well as space for comments. There is concern that the survey is too long and Greene asked the audience how many might likely take such a survey. Greene welcomes suggestions from archivists about the survey.

At the conclusion of the Roundtable meeting, Elena Danielson relinquished the chair and the traditional "keyhole and key" to incoming Chair, Menzi Behrnd-Klodt

Minutes submitted by Menzi Behrnd-Klodt, September ____, 2013