Cutting Edge

COMBINING ACCESS AND BEST PRACTICE IN A LARGE MEDICAL COLLECTION

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Background: Archives Service Center

- University and local history archives
- Approx. 1,000 collections and 35,000 linear feet of material
- A lack of history of medicine collections; Thomas Parran Papers, but not much more
Background:
Dr. Thomas E. Starzl

• Performed the world’s first successful human liver transplantation in 1967
• Advocated cyclosporine use as an anti-rejection drug, which helped make organ transplantation more feasible on a large scale
• Advanced new theory of immunosuppression
• Very active in lobbying for organ procurement, and in professional organizations
• “Retired” in 1990, but is still publishing and active (at 88!)
Background: Dr. Starzl’s Papers

- An ongoing accession from an active office
- 450 linear feet of material
  - Mainly correspondence, but also speeches, articles, reviews, photographs, schedules, VHS and cassette tapes, IRB and grant applications, PR material, memorabilia and- yikes- patient research material
- Finished collection: 327.62 linear feet
Getting Started

- Familiarizing ourselves with best practice
  - Top 25 NIH-funded institutions survey
  - Reading, reading, and some more reading
  - Talking with colleagues
- Noticing some major privacy concerns
  - Obviously, the patient research files
  - Ubiquitous PHI in the correspondence
Working Up the Chain

- Library administration is involved
- University Legal Counsel
- Reaching out to the IRB
Guidance from the Institutional Review Board

- Review of three categories of material:
  - IRB and grant applications
  - PHI in the correspondence
  - "Research files"

- Setting up policies and procedures to access truly restricted material through the IRB

- Tweaking our "Access Restricted" form to cover access to correspondence
Working with Researchers

- Basic information and limited documentation available on Dr. Starzl website
- Two PhD candidates working on researching large medical institutions
- No concerns about accessing “research files”
- Making use of extended reference interviews to allow limited access
Looking Ahead

- Waiting on final University Legal Counsel approval
- Once finding aid is published, we’ll examine how well the policies and procedures are working for the researchers - changes can be made as necessary
- This certainly won’t be our last medical collection - we need to make sure these policies will be applicable to currently incoming and future accessions
- Confidence knowing we’ve moved forward by following examples from expert institutions and by getting institutional backing at the highest levels
Questions? Thoughts?

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Learn more about Starzl at:
http://starzl.pitt.edu
And the Archives Service Center at:
http://www.library.pitt.edu/archives-service-center