To Restrict or Not to Restrict

Balancing Access, Privacy and Confidentiality in the STOP AIDS Project Records

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Society of California Archivists
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• Community-based HIV prevention non-profit based in San Francisco

• 1 year NHPRC Detailed Processing grant
Typical workshop folder contents
• Workshops designed to target specific groups within the Gay/Bi/Trans community
• Invasion of privacy to link personally identifying information to these programs?
Resources for determining restricted material

1. Donor Agreement
2. Law
3. Institutional Policies
4. Context
5. Donor
Donor Agreement

During the archival processing, the Records will be screened by or under the supervision of staff competent to determine files of a sensitive or confidential nature. Donor access to these files during this process will be determined by the Libraries in consultation with the donor and in accordance with University policies and procedures.
Law

• HIPAA Privacy Rule
  – Prohibits “covered entities” (health care providers, plans and data clearinghouses) from disclosing personally identifiable health info without patient permission
Institutional Policies

- Safeguard the health privacy of individuals
- Staff or donors may identify materials containing restricted information
- Researchers may access materials if they follow specified procedures
CONFIDENTIALITY AGREEMENT

By signing your name you are agreeing to hold confidential all comments made by participants in this discussion. Specifically, you agree not to disclose the names of any of the group participants. You may discuss the statements made by participants (and your reaction to their statements) as long as you do not identify the specific individual.

[Signature]

(Sign Here)
Donor

- As creator, most knowledgeable about individuals represented in collection and their expectations during participation
- Want to protect safety and privacy of participants in order to maintain their trust and the trust of the communities they serve
• Separate personally identifiable information while retaining anonymous material
Tradeoff

– Privacy of third parties maintained
– Donor confidence

– The complete context of the workshop files will be restricted for a period of time
HATE MUST STOP AIDS ISN'T OVER