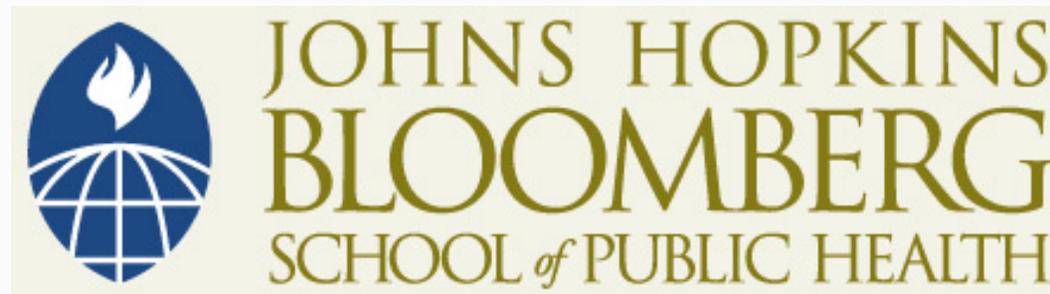


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Section C

Challenges in Maintaining Privacy in Our Settings;
Mechanisms to Address Challenges to Privacy and
Confidentiality

Inequity: Power Hierarchies



Source: Picture courtesy of Dr. S.P. Kalantri.

Lower Levels of Literacy and High Levels of Trust in Health Care Providers



Source: Picture courtesy of Dr. S.P. Kalantri.

Overcrowding: Lack of Space, Especially in the Public Sector



Source: Picture courtesy of Dr. S.P. Kalantri.

Challenges to Maintaining Privacy in Developing Country Settings

- In biomedical research: in overcrowded hospital settings, overworked medical personnel undertake research
 - One needs to provide for space and time for informed consent
 - One needs to maintain privacy for procedures that keep the dignity of the participant
 - One needs to address issues of privacy with respect to compliance, follow up procedures if any
 - Issues relating to medical hierarchies and power structures in health care delivery system

Mechanisms to Overcome These Challenges to Privacy

- Biomedical context:
 - Treat the research context as different from the treatment context
 - Create space and time for a meaningful dialogue with participants
 - Seek institutional and funding support
 - Train all the researchers in these requirements
 - Use IEC review as an empowering process

Challenges to Maintaining Confidentiality in Developing Country Settings

- In biomedical research:
 - Using of patient records due to the overlap in the researcher role and the health provider role
 - Medical records have universal access through out the particular system
 - Lack of a culture of ethical review and the need to maintain confidentiality

Mechanisms to Overcome these Challenges to Confidentiality

- Delink research data from usual access through the health system
- Alternative storage mechanisms
- If electronic data, make sure access is restricted by use of codes, passwords
- Delink the data on a computer from network access
- Limit the number of people who have access to the data

Mechanisms to Overcome these Challenges to Confidentiality

- Anonymise data
- Pseudonymised data
- Encrypted data

Mechanisms to Overcome these Challenges to Confidentiality

- What do we mean by anonymise data?
 - This means removing the information in the data that would help to identify the person uniquely
 - This does not mean just name and address, it could mean remove names of villages in some contexts, removing names of the other diseases that the person has, or any other information that could be used to identify the person
 - Consult other researchers who have worked in the field on similar studies and IEC members

Mechanisms to Overcome these Challenges to Confidentiality

- What is pseudonymised data?
 - Describe the issue by using a nickname for the person or institution etc.
- What is encrypted data?
 - Use alternative codes for persons' unique identifiers in such a way that only those who are part of the research process can actually de-code and work with

Mechanisms to Overcome these Challenges to Confidentiality

- Prevention methods
 - Only collect data that you will use
 - If you do not need some information that can be used to identify the individual, do not collect such information
 - Store the identifiers separately, if you collect them

Do We Always Have to Respect Privacy and Confidentiality?

- Not if the event or study is based on public events, such as the behavior of persons in the carnival/mela
- Not if it involves data already in the public domain
- Not if it does not have the potential to identify or harm any of the participants
- These studies still need to be cleared by the IEC, you alone cannot judge these matters!

Summary

- Privacy and confidentiality; distinction
- Why these are important/what the guidelines say
- Situations in research context where care needs to be exercised
- Practical suggestions in a research setting

References

- Cross, Susan & Sim, Julius. (2000). Confidentiality within physiotherapy: Perceptions and attitudes of clinical practitioners, *Journal of Medical Ethics*, 26, pp. 447-453.
- Khan, Murad. (2003). Confidentiality in research. Presentation made at the workshop on ethical issues in health research, Aga Khan University, Karachi.
- O'Brien, J. & Chantler, C. (2003). Confidentiality and the duties of care. *Journal of Medical Ethics*, 29, pp. 36-40.
- Ethical guidelines for social science research in health, NCESSRH, CEHAT, Mumbai. (2000).
- ICMR. (2006). Ethical guidelines for biomedical research on human subjects. New Delhi.

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