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SCHOOL *of* PUBLIC HEALTH

Privacy and Confidentiality

Anant Bhan, MBBS, MHSc

Ethical Social and Cultural Program for the Grand
Challenges in Global Health Initiative

Objective of this Session

- Explain and elucidate the differences between privacy and confidentiality
- Describe how requirements for confidentiality and privacy may vary with the setting, research topic, or individual
- Understand mechanisms to protect privacy and the confidentiality of data



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Section A

Introducing Privacy and Confidentiality

Privacy

- It can be defined as control over the extent, timing, circumstances of sharing oneself (physically, behaviorally, intellectually) with others
- Right to control access to ourselves and our personal information
- Access: socio-economic status, age, circumstances

Confidentiality

- Confidentiality has been defined as the principle of maintaining the security of information elicited from an individual in the privileged circumstances of a professional relationship
 - Cross, Susan, & Sim, Julius. (2000).
- Respecting other people's secrets

Confidentiality

- The treatment of information an individual has disclosed in a relationship of trust and expectation that it will not be divulged to others
- Information disclosed voluntarily: protected from disclosure
- Prior agreement with subjects, through the consent process—if and how the information provided will be protected
- Refers to information/data about a person and limiting access to private data about a person

Why Is Confidentiality an Issue?

- A study by General Medical Council (GMC) in UK in 1998 found that breaches of confidentiality was considered by the public as the worst offence by researchers
 - O' Brien and Chantler. (2003).

Privacy Versus Confidentiality

- Privacy is about persons
- Confidentiality is about data or information

Why Do We Need Privacy in a Research Setting?

- In biomedical research it is a requirement of the relationship between the researcher and the participant
- To respect the participant's dignity and personhood
- To obtain valid data
- To ensure that research in general can continue without losing credibility as an enterprise that gives benefits

Why Do We Need to Maintain Confidentiality of Information?

- It is a contract between the researcher and the subject of research
- To maintain the dignity, welfare, and privacy of subjects
- The possibility of stigma and other social problems if not maintained
- Research as an enterprise could lose its credibility

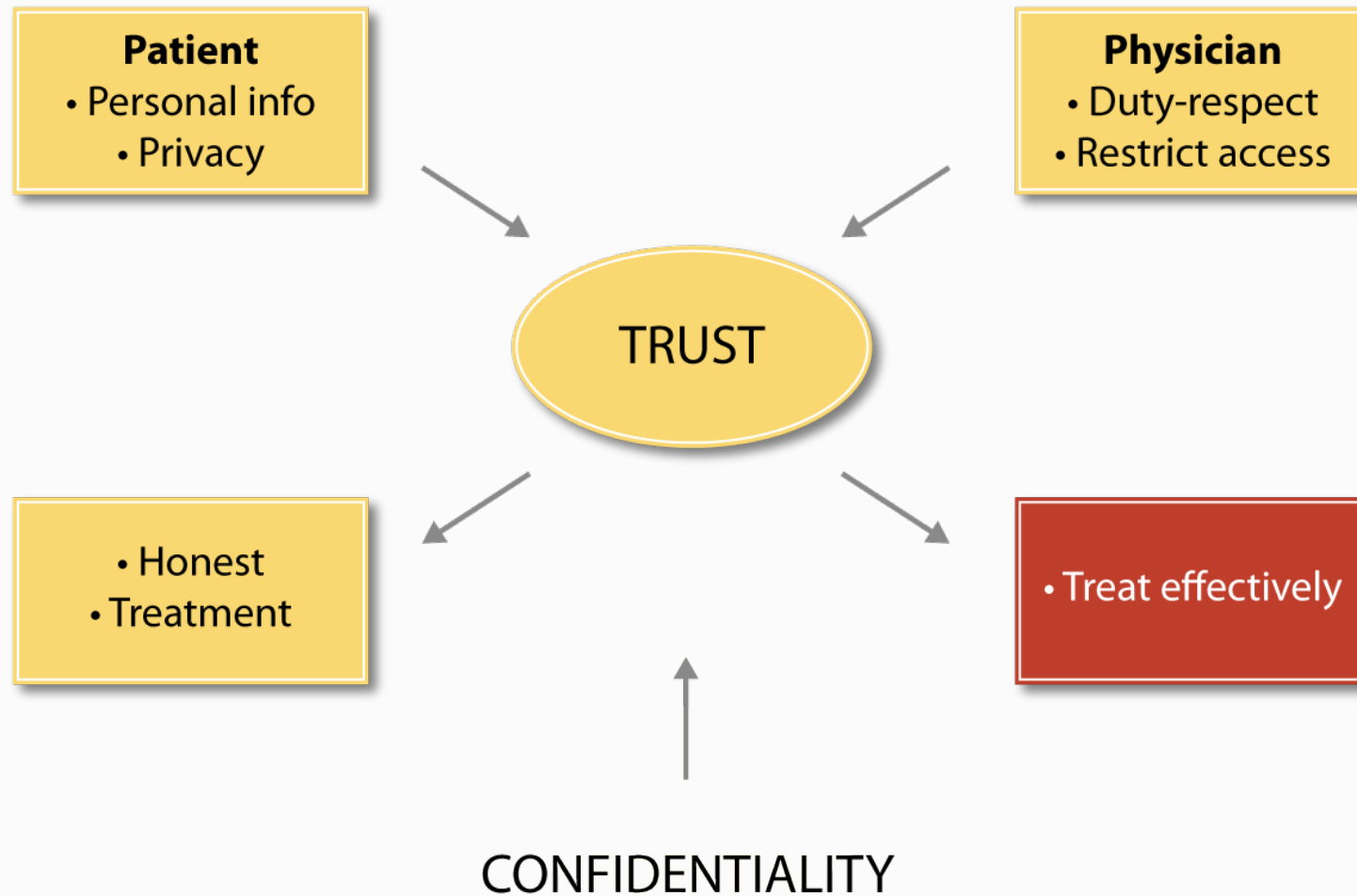
Privacy

- At what stage of the process does one accommodate the need for privacy?
 - These needs should be taken into account even in the planning stages of the study so as to make provisions for privacy during the various research process where ever the subject is approached
 - Privacy is based on the perspective of the participant, not the evaluation of the IEC or the researcher

Confidentiality

- At what stage of the research process does confidentiality need to be considered?
 - It is a pre-requisite for undertaking research and needs to be addressed at all stages of the research process, from design of the study, data collection, compilation, analysis, and even reporting

Doctor-Patient Relationship



Researcher-Subject Relationship

