MANAGEMENT OF INFORMATION DURING RESEARCH IMPLEMENTATION

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LEARNING OBJECTIVES

- By the end of this presentation you should be able to:
- Know why it is important to keep research data/information securely
- Understand the various ways of keeping research data;
- Share experiences on keeping and challenges of storing research data

Layout

MAGING INFORMATION :-

- PRE-STUDY
- DURING THE STUDY
- AFTER THE STUDY

Reflect on….

ACTIVITIES INVOLVED IN RESEARCH IMPLEMENTATION

P-People

R-Resources

A-Activities

I-Information

S-Self

E-Environment

MANAGING –INFORMATION (DATA)

- Refer to PRAISE

Guidelines to manage information

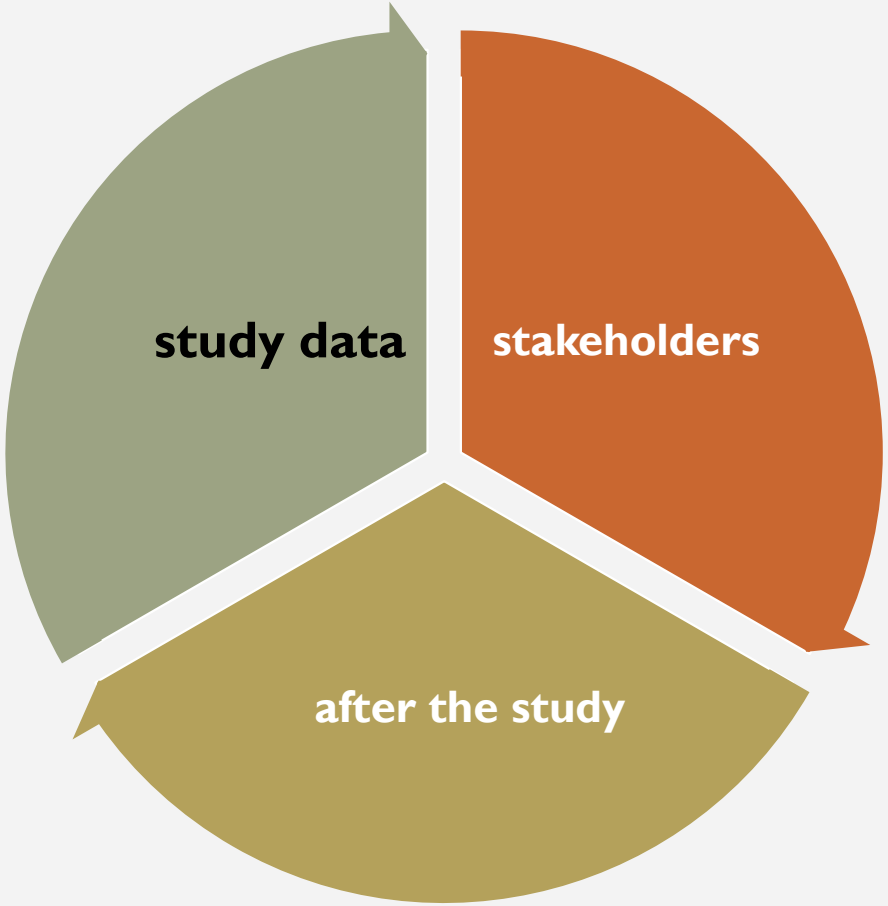
- Before the study – At proposal stage

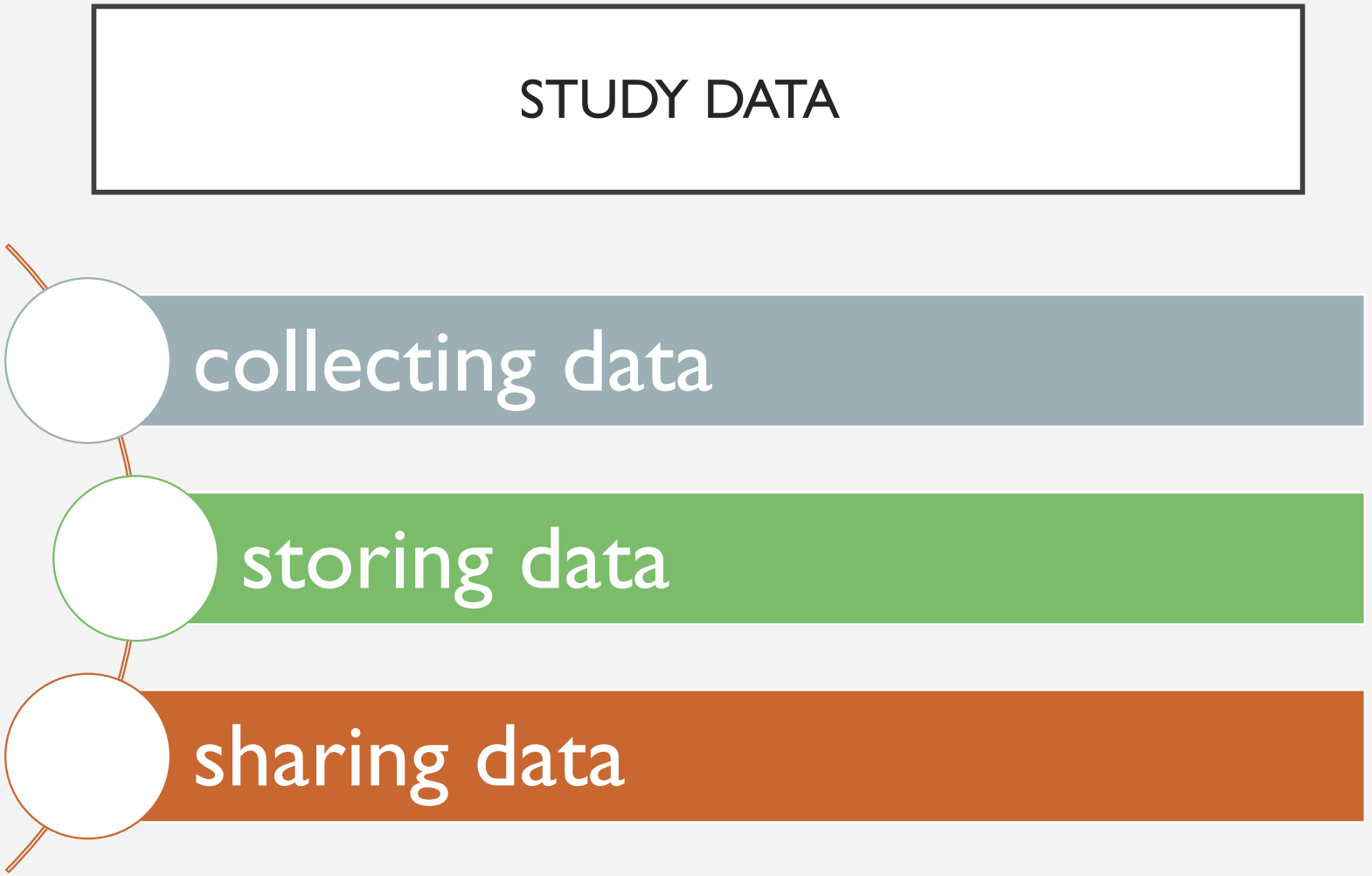
- During the study- during implementation of the research project

- After the study- Dissemination and publication

Management of information should be clear at the on-set at all stages

MANAGING INFORMATION




STUDY DATA
collecting data
storing data
sharing data

COLLECTING DATA

- Paper based vs electronic data collection
- Clear procedures on how to collect data
- Checklists for study visits
- Standardize the data (measurements, dates, number of decimal places
- Phrasing of questions

- Maintaining privacy of participants and their data

Quality control (double entry or visual checks)

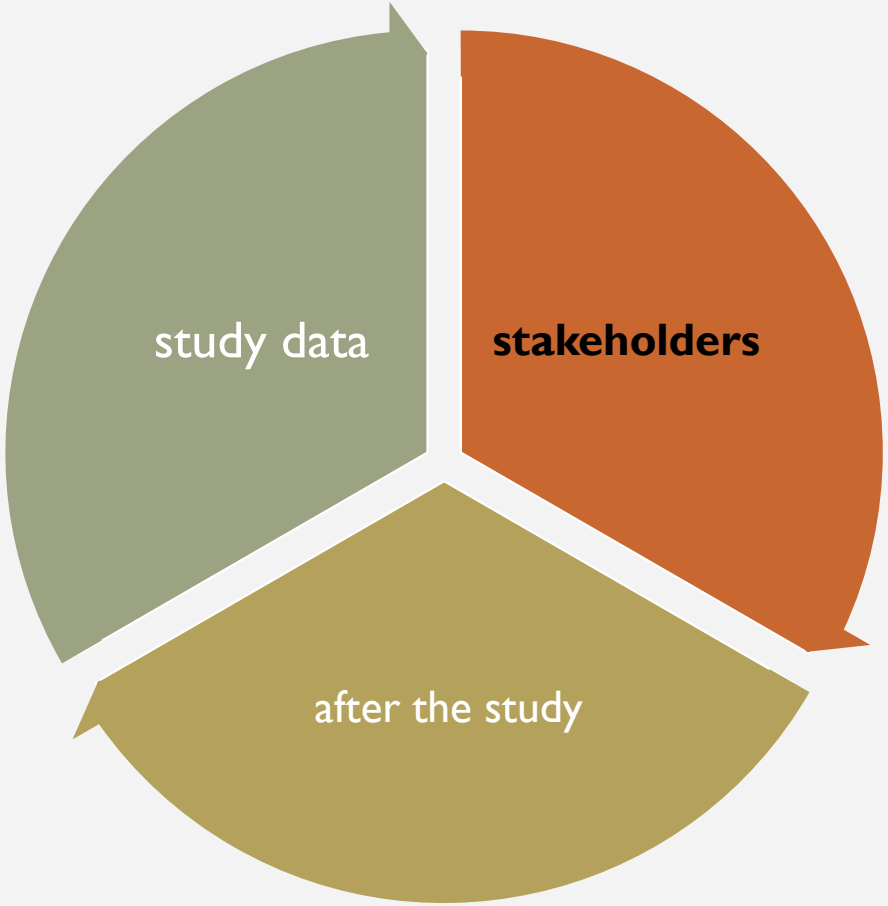
STORING DATA

- Filing system
- Locked cabinets, locked office, accessible only by investigator and research coordinator
- Cloud based storage
- Databases-password protected

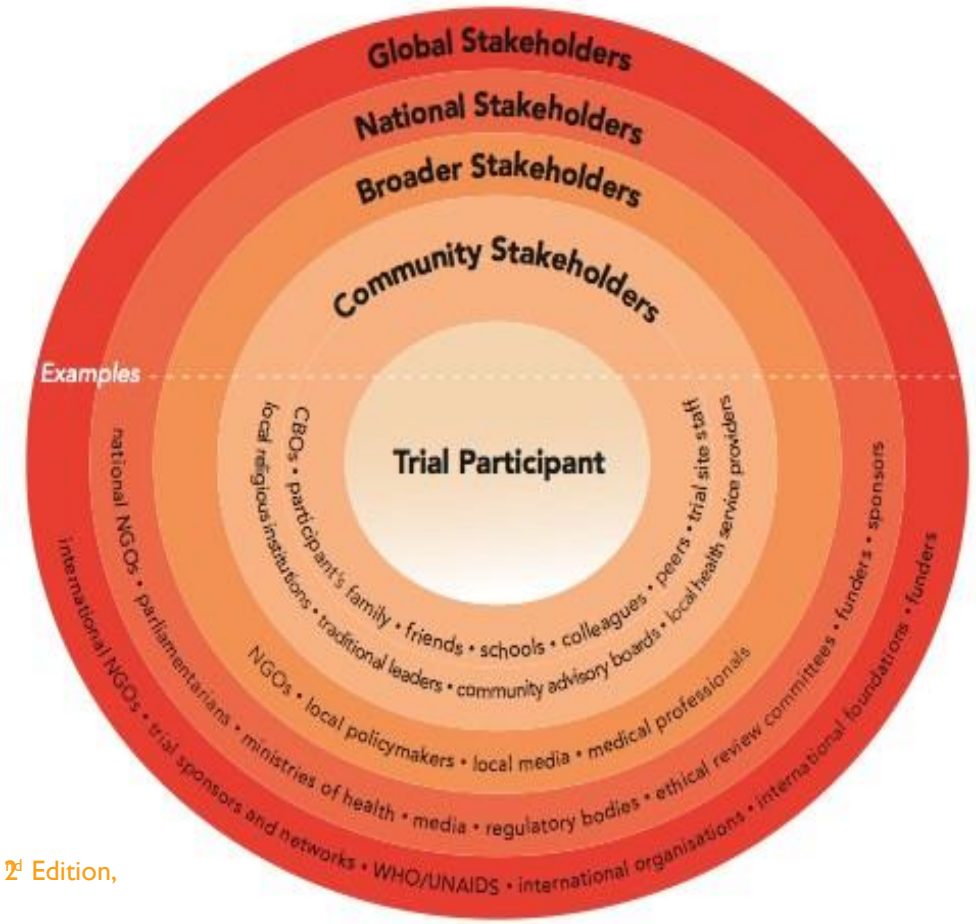
SHARING DATA

- Data ownership in a consortium
- Who is allowed access to the data for:
  - Quality control
  - Analysis
  - Future use
- Assure data is de-identified
- How to share? Drop box, Email
- Third parties
- Data Transfer Agreement (DTA)

MANAGING INFORMATION



LAYERS OF STAKEHOLDERS



Good Participatory Practice (GPP) Guidelines, 2nd Edition,

MANAGING INFORMATION WITH STAKEHOLDERS

- What information for which stakeholders
- Provide ongoing information
- Sponsor/ funder specific requirements for what information they want (regular reporting)

CAG/ CAB

COMMUNITY ADVISORY GROUPS (OR BOARDS)-CABs

Protecting participants rights

CABs have a responsibility to report back to the communities they represent

•Assist in the development of educational programs

•Valuable in the development and implementation of the research protocol development

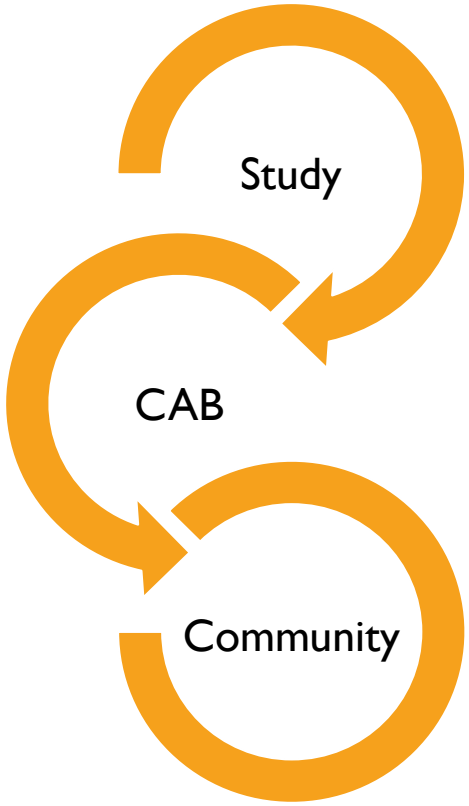
•Informed consent review

•Ethics dialogue

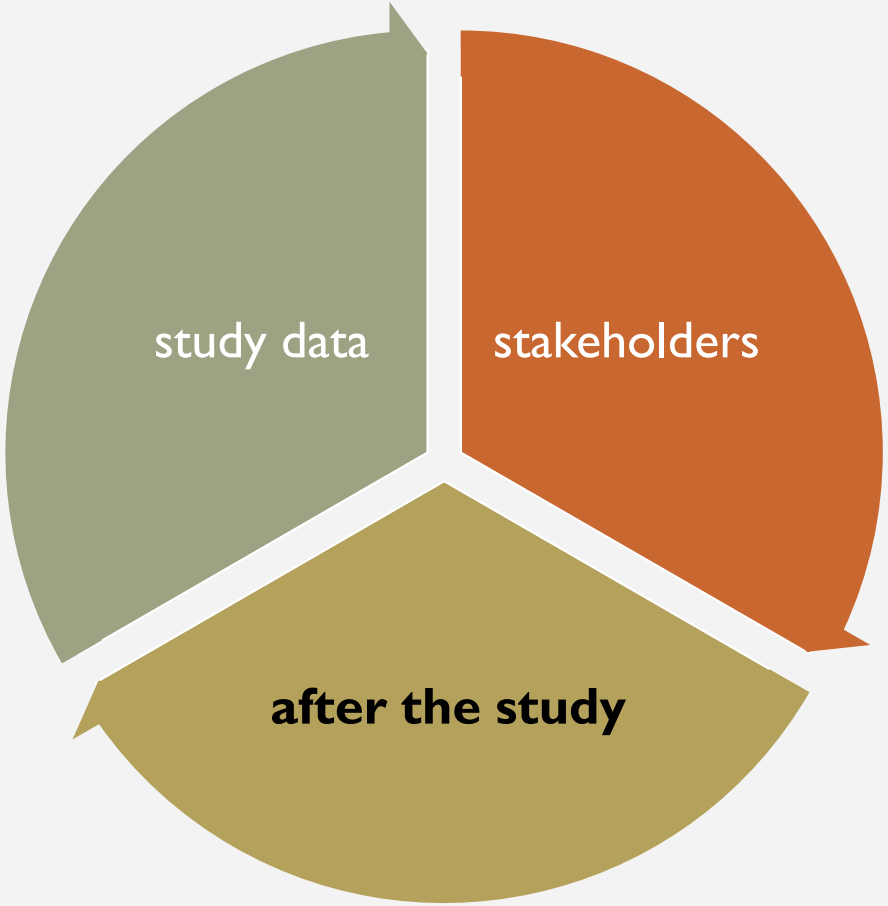
•Advice on recruitment strategies • CABs should NOT:

•Be members of the research team

Actively recruit study participants



MANAGING INFORMATION



MANAGING INFORMATION AFTER THE STUDY

Dissemination to participants and the community

Retention and Archiving Policy

Guidelines for ……

- Publication
- Authorship
- Agree on policy early on

KEY TO EFFECTIVE DISSEMINATION

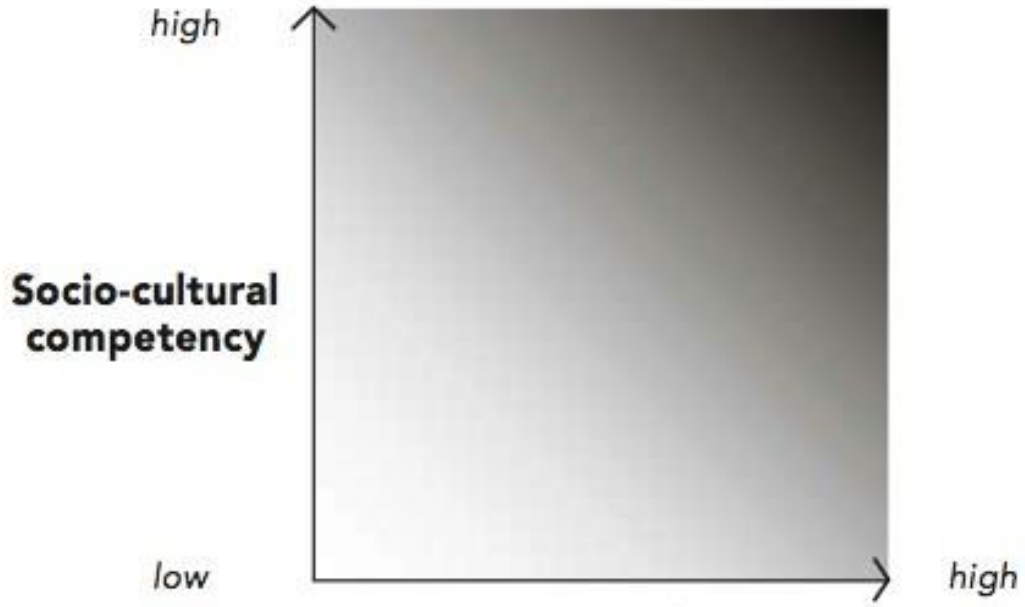



Figure 4. Trial Competency Range