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
- Stakeholders
- After the Study
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

- study data
- stakeholders
- after the study
LAYERS OF STAKEHOLDERS

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

- study data
- stakeholders
- after the study
MANAGING INFORMATION AFTER THE STUDY

Dissemination to participants and the community
Retention and Archiving Policy
Guidelines for ......

- Publication
- Authorship
- Agree on policy early on
Figure 4. Trial Competency Range

Socio-cultural competency

Research competency

high

low