

Communicating about research

How is a research project developed?

How safe is it?

What is the difference – research and clinical care?



Kilifi

Basic workshop

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Referencing and acknowledging the iCARE-Haaland model

- *Please feel free to use and adapt the material in this presentation, and the model it is built on, by referring to the model, and the authors:*
- This presentation is adapted from «**Communicating about research**», which is part of the learning materials in the iCARE-Haaland model.
- **To reference this content please use the following:** Haaland A, with Boga M, 2020. Communicating with awareness and emotional competence: introducing the iCARE-Haaland model for health professionals across cultures. With contributions from training teams, Vicki Marsh and Sassy Molyneux. <https://connect.tghn.org/training/icare-haaland-model/>
- The authors' names should remain on the presentation, with a by line recognizing the person who (has adapted and) is presenting the presentation

Learning needs: From baseline

What would you like to learn, to understand research better and be able to communicate with patients well about it?

- “I would like to know after the research has been done in the community what are the **benefits** the community gets? and what are the criteria taken to **choice the area** of study research.*
- I would like to learn how to communicate well with the patient such that they don't feel **misused as guinea pigs** but feel that we are very concerned for their welfare.*
- To learn about **benefits** to the provider, patient, researcher, the guardian and the family.*
- How to make the participants and relatives understand we **mean** no harm, always hence improve on **consent acceptance***

Learning needs: From baseline (2)

- *“The **ethical principles** involved in conducting research.”*
- *“How to undertake the **consenting** process especially when the caretaker has just come in and is worried about the condition of the child or patient.”*
- *“The **role of staff** in research’*
- *“How to convince those who **oppose conventional type** of treatment.”*

Objectives

To **strengthen understanding** of:

- What a research project is in a clinical care setting, how a research project is developed, and how safety and quality is checked (summary from open day)
- Main ethical principles guiding research
- Skills providers need to explain need for research to a patient

To further **strengthen awareness** of

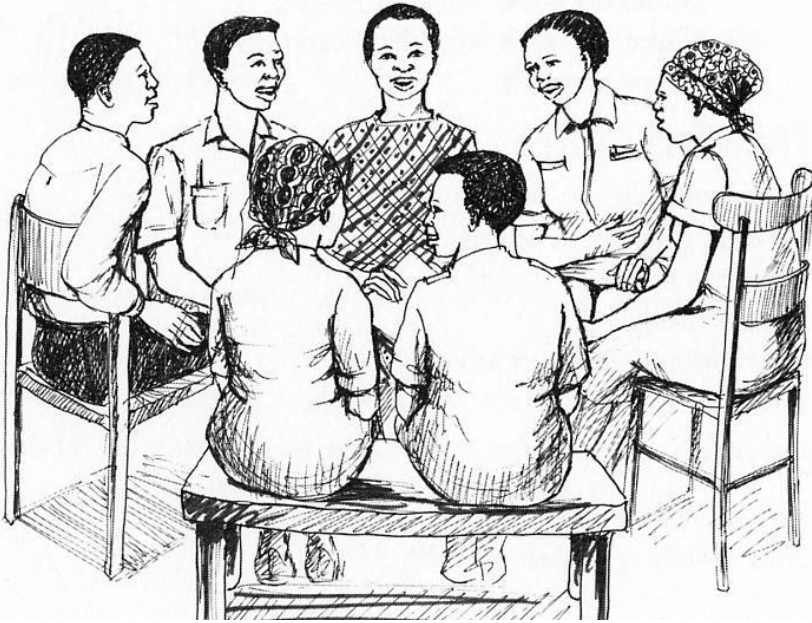
- The role of KEMRI in planning and conducting research in a national and international perspective
- Main achievements of KEMRI researchers in contributing to change in health policies

Objectives (2)

To strengthen awareness of and skills on

- Common reasons why patients/parents refuse to participate in research, and how and when to address these with the intention of creating better understanding of the needs for and benefits of research in the long run
- Common misconceptions and anxieties patients/parents have about research, and how and when to address these by acknowledging them and having a respectful dialogue, with the intention to create better understanding of the needs for and benefits of research, while maintaining the rights for patients to have a free informed choice to participate – or not.
- Common reasons why patients DO choose to participate in research, and how to use this knowledge to communicate constructively about research
- Provider attitudes and skills which help facilitate a respectful dialogue about participation in and understanding of a research project, and attitudes which hinder such a dialogue.

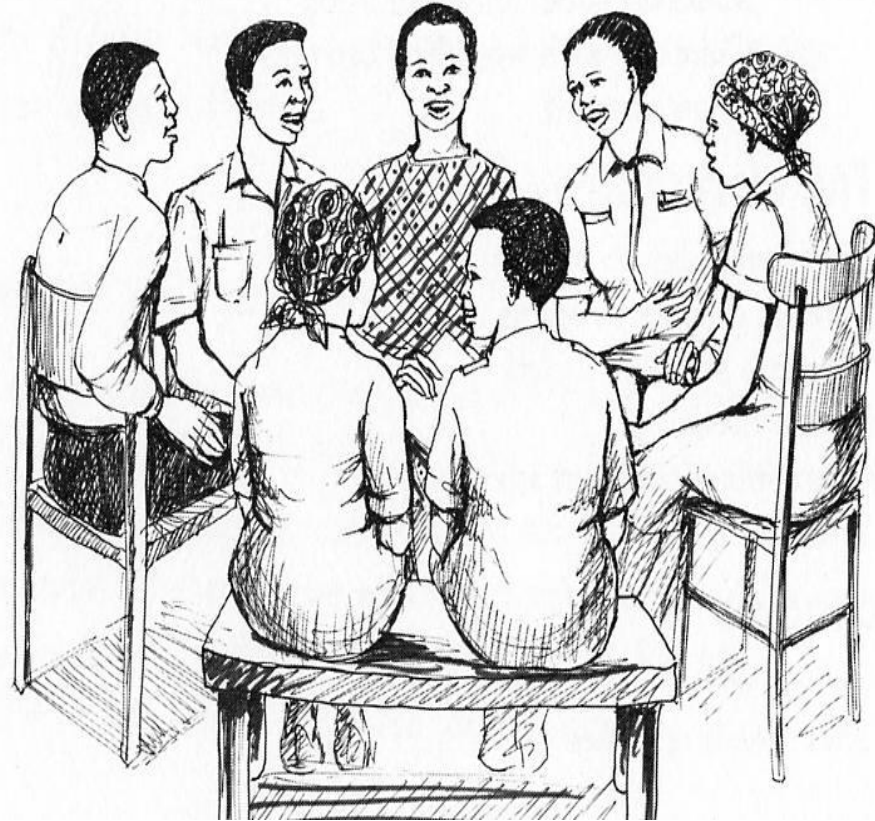
Sharing information and skills



- Some participants have been involved in research projects
- You are our resources for this module
- Spread yourselves in the groups – make sure there is at least 1 in every group

Have you ever participated in a research project?

- Share experiences of participating in a research project (*or talking with someone who did*)
- What was the research about?
- What made you (or the other person) decide to participate?
- What questions did you/the other have about it?



What is health research?

➤ **Systematic learning –**

➤ about health for the benefit of all in the future

• ***Examples: Bednet study in Kilifi***

- *Polio vaccine study: All children protested, disease almost extinct*

➤ **Research ALWAYS has a question:**

➤ *e.g “can a new drug treat people with malaria in Kenya better than an old drug?”*

• ***Examples: Lumefantrine/Artemeter (Coartem) compared with suphadioxine/pyrimethamine (Fansidar)***

- Why do so many people with epilepsy not take treatment when there is treatment available?

➤ **Working towards health benefits for all = social value**

Why do we need research?

Future benefits for all:

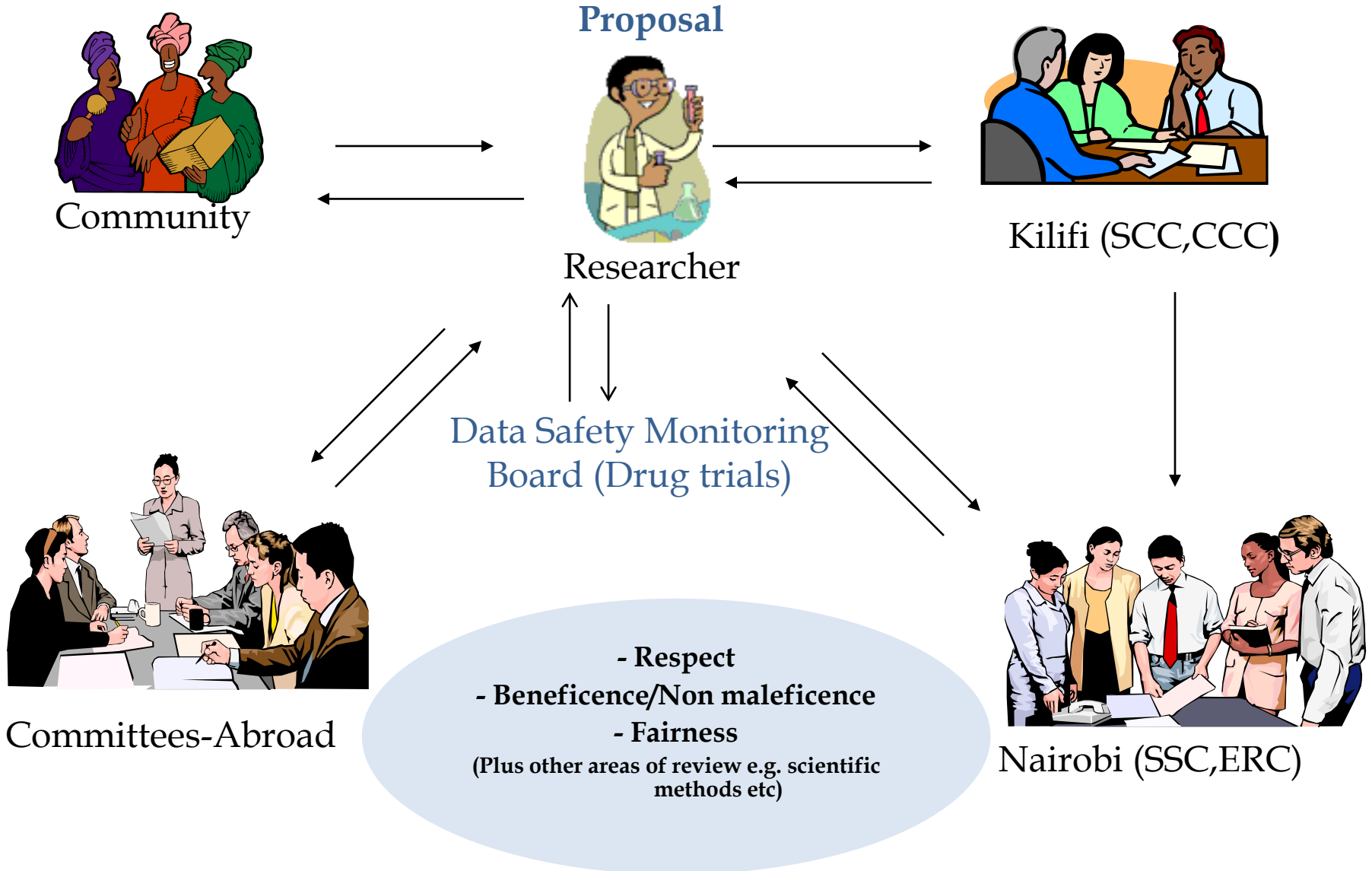
- Help in obtaining new effective ways of treatment/interventions/vaccine/drugs
- Help in improving health to the community/future patients
- Establish causes of diseases
- Help in finding evidence based explanations to situations, hence reduce rumours and stigma

Benefits to participants involved in research at the time:

- Patient gets free treatment/investigation, and close observations
- *Anything you would like to add?*

Review of open day

Research Review Process



Summary from open day: Example of research project

Research on quinine vs artemeter

- **Question:** Best drug to treat severe malaria in children?
- **Quinine:** Problems: Long stay in hospital, high cost, complex adm
- **Research Process:**
 - Proposal developed; methods agreed; safety assured
 - Project reviewed by science and ethics committees, all countries
 - **Implementation:** Research teams trained to request consent and administer project. Drugs tested with 1000 children in each of 4 countries
 - Results analyzed (after 3 years' research), compared across countries
- **Clear results: Artemeter is better than quinine**
- **Recommendation to policy makers:** Use artemeter to treat children with severe malaria in children, rather than quinine
- **Policy makers may change** national drug policy



Research **ethics**

- **What are ethics?**
- *Do's and don'ts of how we interact with other people (written, spoken etc)*

- **What are research ethics?**
- *Do's and don't' of how we interact with other people in research*
- Written e.g. National guidelines, GCP

Universal principles of research ethics

Respecting persons:

- **FREE CHOICE**, based on **UNDERSTANDING** (autonomy)
- Making sure any costs are balanced by benefits to the individual: **SAFETY, BENEFITS**
- **Fairness** in who takes risks and who gains from results of research: **NO EXPLOITATION**



What is the difference between research and clinical care?



Matibabu




Utafiti

DIFFERENCE BETWEEN CLINICAL CARE AND RESEARCH

Clinical care/treatment

1. It specifies appropriate treatment
2. Goal is to provide benefit to the individual
3. Care is individualized to each patient
4. No consent needed
5. It's a right

Clinical research

1. New products on trial /for that illness
 2. Aims at looking for better ways to prevent diseases / treat in the future
 3. Benefit is to entire population
 4. Written consent is a must
 5. Voluntary
- 

Exercise:

What information does the mother want, and need?

- *Put yourselves in «the shoes of the mother»*

Discuss:

- What information would «you» like to be given – to consider if you give consent to participate?
- What would be «your» main concerns?
- Which skills would it be important for the provider to practice with «you»?



Summary:

What information is the patient/parent given when requested to give consent?

Parents asked to give consent to participate are informed:

- Participation is voluntary – the child will be treated well regardless of whether they agree to participate or not
- **If they participate – the child will:**
 - Be observed closely as per the study guidelines
 - Blood samples taken to monitor the treatment
 - In case of side effects – necessary treatment offered
 - Come back for follow-up after 28 days
 - Transport costs – reimbursed
 - Free treatment in case of any problem with the child during the follow up period

Communicating about research:

Skills and attitudes needed to facilitate constructive dialogue



- Creating safe environment to talk
- Respect person, culture, concerns
- Empathy; Appreciation
- Asking open questions
- Listening actively
- Engage in dialogue
- Encourage discussion among patients/parents
- Professional, friendly, competent care
- Ability to step back from automatic reactions (e.g if parent refuses)

Communicating about research: Attitudes and behavior which **hinder** constructive dialogue

- **Judging** patient/parent for their culture, opinions etc



- Focus on your **own needs to recruit**, rather than **patient's right to volunteer**:
- **Convince, rather than explain**
- **No respect** or concern for patient's emotions

Demonstration:

Mama Mary refuses to participate

- Mama Mary brings her baby with severe malaria to hospital
- Asked to participate in research on artemeter vs quinine
- She is scared, just wants her baby to be treated
- She says **no** to participate:
«Mwenye Kaho Husband would not agree»



Role play:

Communicating with the mother when the child is stable

- In groups of 3 – play roles of nurse, mother and observer
- **Tasks:**
 - Addressing mother's concerns
 - Dialogue on research – to enable her to possibly participate next time



Need a drawing of nurse talking with mother at bedside, child lying in bed

Exercise to dialogue on:

Some possible reasons mother refuses to participate

Lack of understanding about KEMRI, and research

- *«KEMRI is just interested in research»*
- *«KEMRI is a foreign organization»*
- *«KEMRI uses patients as guineapigs»*
- *«Research only benefits the researchers»*
- *«Researchers do what they feel like and when they feel like»*

Fear – lack of understanding of safety

- *«Researchers take too much blood»*

Buzz in pairs (one is provider, the other «patient/parent»):

- Pick one concern, dialogue to inform and discuss
- Repeat, change roles, dialogue about another concern

Staff skills on communication



- Policies and guidelines are only as good as the people who implement them!
- Skills for addressing ethical and communication issues ‘on the ground’ are critical
- Training on research, ethics and communication for staff responsible for ICF
- Training and support supervision
- **This training!**

Remaining questions – and issues for follow-up course?

Buzz in groups

- Bring out questions, discuss
- **What is needed** – to learn to deal better with research issues?
- List issues for follow-up course on flipchart

