Working with emotional competence in a research environment:

Understanding and communicating about **the difference between research and treatment**

Follow-up 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 **«*Working with emotional competence in a research environment: Understanding and communicating about the difference between research and treatment»,*** 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

Objectives

To strengthen awareness and understanding of

- The difference between research and treatment
- Why it is important to understand this difference, and what can be the consequences for the patient if the two are mixed up

To strengthen skills of

- Communicating about the difference between clinical care and research to a patient/parent, by explaining and discussing it, and by addressing the questions and concerns of the patient/parent

Sharing information and skills
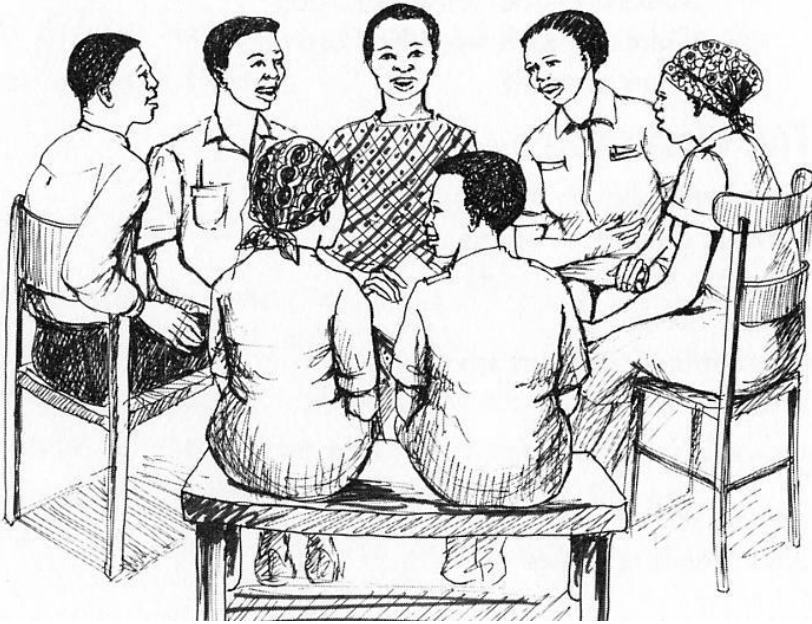
- Some participants have been involved in research projects

- You are our resources for this module

- Spread yourselves in the groups – make sure there is at least 1 in every group

Why do we need research?
Participants' suggestions

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

Buzz:

➤ *Anything you would like to add?*

What do you do differently in relation to research now?

- **Share experiences on changes** you have made in relation to dealing with *patients involved in research*

- Also discuss **changes in how you talk with colleagues** about research, and **how you feel** about research now

- Identify further **learning needs**

Research projects conducted in Kilifi

- SAS/CLG: Do you have a slide with examples?

- (we had in an earlier presentation, 1st year?)

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

What is the difference between research and clinical care?

Matibabu

Faida kwa mgonjwa mmoja

Utafiti

Faida kwa jamii wote

In our study: What is the difference between research and clinical care?

- Parents are asked to consent to participate
- Participation is voluntary – child will be treated well regardless of wether they agree or not
- **If participate – the child will:**
  - Be observed closely (more closely than others)
  - Blood samples to monitor the treatment
  - Incase of side effects – necessary Rx offered
  - Come back for follow-up after 28 days
  - Transport costs – reimbursed
  - Access to free treatment incase of any problem with the child during the follow up period
- **BUZZ: What is research, what is treatment?**

Mama's fears: Will Mary get good care?

- Mama Mary brings her baby to hospital, with severe malaria

- Asked to participate in research: Artemeter vs quinine

- She is scared, just wants her baby to be treated

- She fears that if she says no, her baby will not get good treatment

- *She reluctantly agrees to participate in the research, because she believes this is the same as treatment*

Discussion in groups:
What is the difference between research and clinical care?

- **Does this happen?**

- Why does Mama Mary confuse research and clinical care/treatment?

- *Does it matter?*

Why are research and treatment confused?

- Language e.g. technical, hard to understand

- Lack of experience of research, treatment very familiar

- Also, these situations often overlap – especially in clinical research

- *Insert - Example of using technical language – mother does not understand*

Why does it matter if research activities are confused with treatment?

- Patients refuse treatment – confuse with research
- Agree to participate in research because think it is treatment
- Participation is not voluntary, thus not ethical
- Can influence patient's attitudes to research
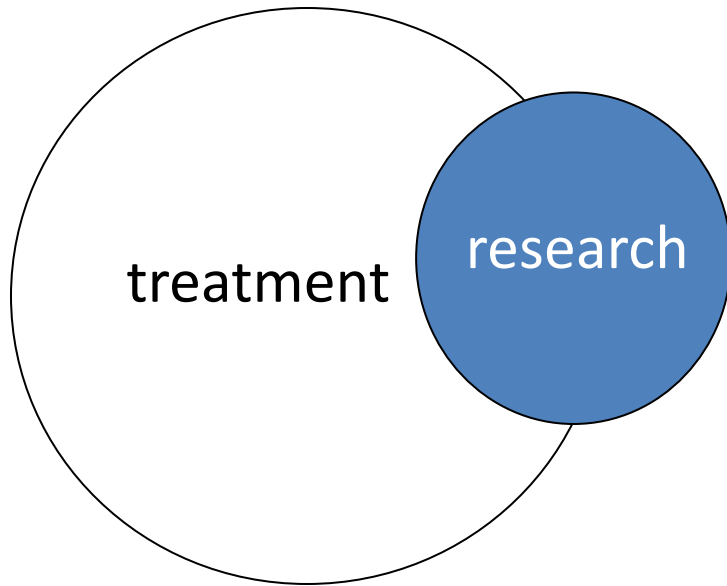- Can influence others negatively

How would you explain difference to Mama Mary?

In groups:

- **Discuss and demonstrate:** how to explain and dialogue about *the difference between research and clinical care* to Mama Mary

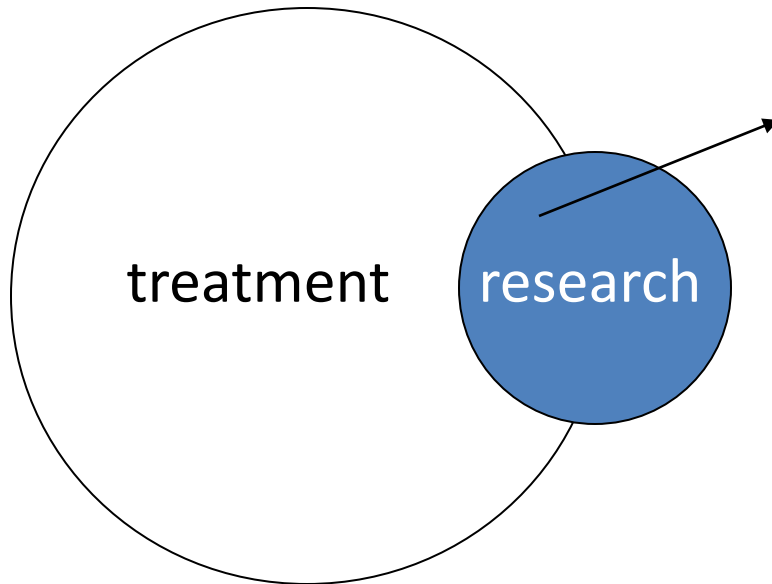- Volunteer to show how you would do it, in front of big group

The overlap between treatment and research

treatment

research

- **Any examples of confusion or overlap??**

The overlap between treatment and research (2)

Overlap:
1. Drug trials (the study is ABOUT treatment)
2. Research with treatment (you get treatment because you are part of research)
3. Ward 1/KEMRI ward (provide routine care too, so people not pressured to join)

treatment

research

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

Communicating about research:
Attitudes and behavior which hinder constructive dialogue

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

- Focus on *own needs to recruit*, rather than *patient's right to volunteer:*

- *Convince, rather than explain*

- *No respect* or concern for patient's emotions

A challenge to health providers…

- Ensuring patients have free informed choice about participating in research

- Explaining vs convincing? Long term effect of persuading someone to participate if not really comfortable?

- Recognizing critical importance of research in improving health of individuals/populations in future

COMMUNICATION SKILLS!!

Staff skills on communication:
Essential for communicating well about research

- 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!

Collaboration KEMRI – KDH: Why collaborate, and how?

Discuss in groups:

- What are advantages of KEMRI-KDH staff cooperating to facilitate smooth running of research projects?

- What do we do now?

- What can we do, to improve collaboration?

- What are sources of information and people to contact for questions and problems related to research?

Questions?

Thank you!