

 Simultaneous translation from English into Spanish, Portuguese and French.

# Workshop: *Empowering Communities - Innovative Approaches to AI Health Research and Engagement*

Day 1: Tue May 21, 2024 13:00-15:00 London

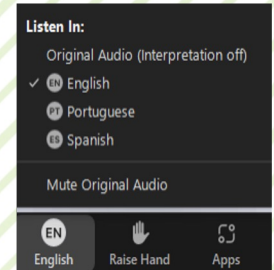
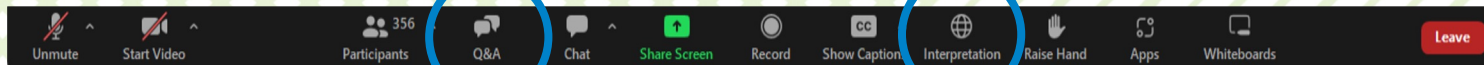
Day 2: Tue May 28, 2024 13:00-15:00 London



Register.

# Housekeeping

- This workshop is being recorded and will be shared on AI4GH knowledge hub.
- It will be held in English and simultaneous translation will be provided into Spanish, Portuguese and French.
- In the toolbar, click on *Interpretation function* and select your desired language input.
- Please use the *Chat function* for introductions and to report any technical issues.
- Please use the *Q&A function* to post your questions and comments.
- Please take a moment to answer the pre-workshop poll that is onscreen.





# **Day 1: Understanding Community Engagement: The Foundations**

# Panel and agenda

## Welcome from chair

**Dr. Bryain Maradiaga-Mendoza** - Coordinator, AI for Global Health Project, LAC Region, The Global Health Network, University of Oxford, Honduras

## Overview of Community Engagement in Global Health Research

**Dr. Alun Davies** - Lead, MESH Community Engagement Network, The Global Health Network, University of Oxford, UK

## Ethics of health research with artificial intelligence

**Dr. Manuel Colomé-Hidalgo** - Principal at Instituto de Investigación en Salud Universidad Autónoma de Santo Domingo, Dominican Republic

## Stakeholder analysis and mapping

**Luis Felipe Arias** - ETIKOS-The Global Health Network, University of Oxford, Dominican Republic

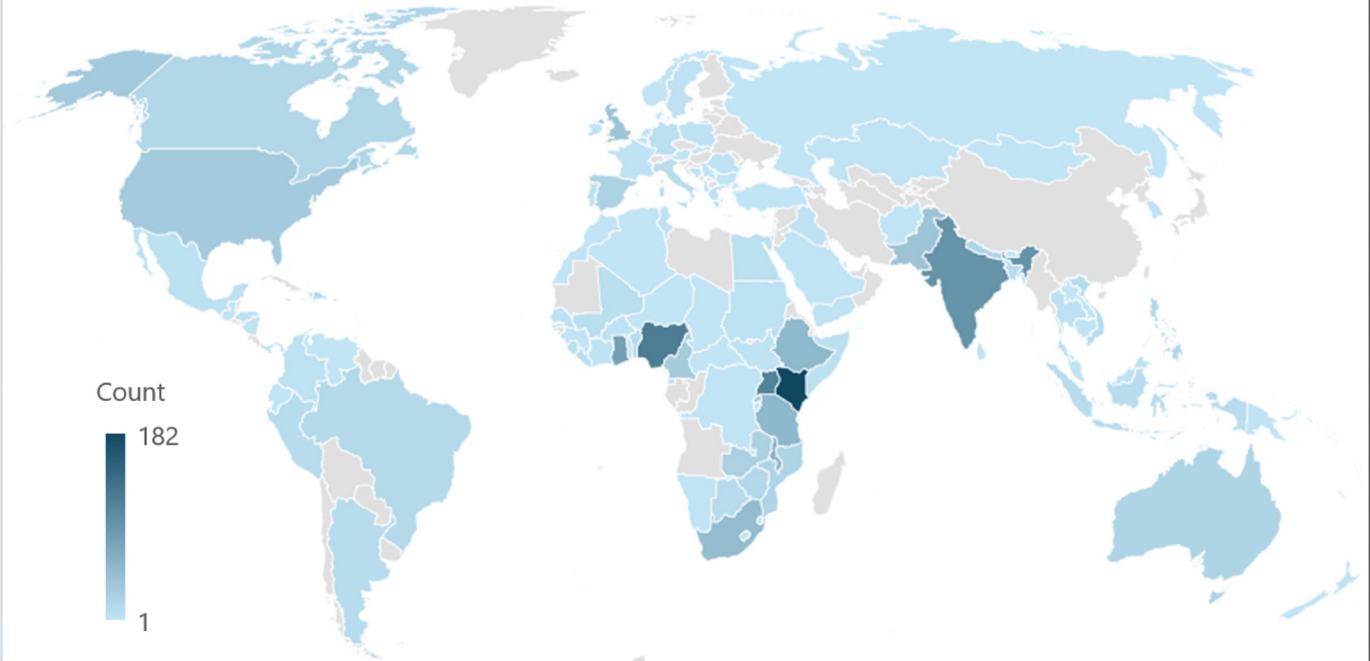
# Learning objectives

1. Participants will understand community engagement's fundamental principles and importance in health research.
2. Participants will identify practical considerations and challenges in integrating AI into community engagement efforts.
3. Participants will be able to effectively identify and prioritize critical stakeholders in health research projects, utilizing stakeholder mapping techniques to develop comprehensive strategies for engagement and collaboration.
4. Participants will learn practical strategies for engaging communities in health research and decision-making processes.

# Registered interest for today's workshop

	Country	Count
1	Kenya	182
2	Nigeria	120
3	Uganda	114
4	India	94
5	Ghana	79
6	Malawi	57
7	Tanzania	53
8	Ethiopia	52
9	South Africa	47
10	Rwanda	38
11	Pakistan	38
12	United Kingdom	38
13	United States	31
14	Cameroon	30
15	Zambia	24
16	Spain	22
17	Nepal	20
18	Mozambique	20
19	Australia	20
20	Canada	17
	<b>Total</b>	
	118	1476

## Empowering Communities - Innovative Approaches to AI Health Research and Engagement



# Overview of Community Engagement in Global Health Research

**Dr. Alun Davies**

Lead, MESH Community Engagement Network, The Global Health Network, University of Oxford, UK



## Empowering Communities - Innovative Approaches to AI Health Research and Engagement

Public, community and stakeholder engagement and involvement in global health research

Alun Davies  
21<sup>st</sup> May 2024





*“Community engagement is not just a part of global health research; it's its heart and soul. It ensures that our efforts are not only scientifically sound but also socially relevant and culturally sensitive.”*

Dr. Tedros Adhanom Ghebreyesus,  
Director-General of WHO, 2023

# Engagement increasingly demanded by research funders

*“**NIHR** champions community engagement and involvement (CEI) as a core principle of its global health research portfolio, alongside equitable partnerships and local research capacity strengthening. All applicants for NIHR global health research funding are required to plan for and undertake active and participatory CEI.” [nihr.ac.uk](http://nihr.ac.uk)*

## Wellcome Fellowship Application Form

How have patients, patient advocacy groups or communities been involved in developing the clinical aspects of this proposal?  
(300 words max.)

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community engagement network

**NIHR** | National Institute for Health and Care Research


Module 1: Understanding Community Engagement and Involvement (CEI) in Health Research



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Module 5: Approaches and Methods for CEI



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Module 4: Principles and Models for CEI



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Module 2: Justifying CEI, Considering Stakeholders and Engaging Policymakers



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Module 6: CEI Partnerships, Relationships and Project Planning



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Module 3: Ethical CEI



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Module 7: Evaluation of CEI



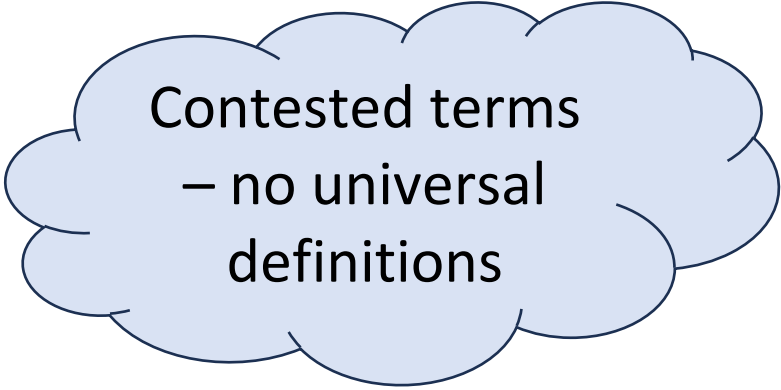
## Authors

- Gill Black
- Rodrick Sambakunzi
- Robin Vincent
- Alun Davies
- Noni Mumba
- Helen Latchem



community dialogue  
community driven research  
Stakeholder engagement  
community engagement and involvement  
community engagement  
public engagement  
public engagement  
Stakeholder involvement  
GPP-IPP  
Patient Involvement  
community sensitization  
social participation  
Good Participatory Practice  
community involvement  
Engaged research  
PPE  
citizen engagement  
public participation  
PPI  
outreach

What is  
community/public/stakeholder  
engagement and involvement?



Contested terms  
– no universal  
definitions

# Who is the community?

- People living in a specific geographical area?
- ... and from a specific religion?
- ... and from a specific ethnicity
- People with a common interest,
- People sharing health conditions
- People belong to several communities



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PHOTO: AIDS 2016 TREATMENT ACCESS MARCH BY PAUL  
KIDD

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# Who are 'the public'?

- The Global population?
- City, country or continent?
- National health programme users?
- TV and radio audiences?
- People on the streets
- Voters? Or taxpayers?



People in Grafton Street, Dublin by Mcdreamy

# Who might stakeholders be?

## **Stakeholders**

- Local community representative
- Non-Governmental Org leader
- Research Institute Director
- Women's group lead
- Hospital manager
- Health policy maker
- Local chief or mayor
- Minister of Health

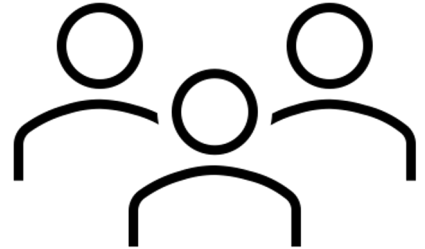
## **Community Groups**

- Women's groups
- School teachers
- Young people Living with HIV
- Community Based Orgs
- Nurses
- Youth groups
- Research participants
- Religious groups



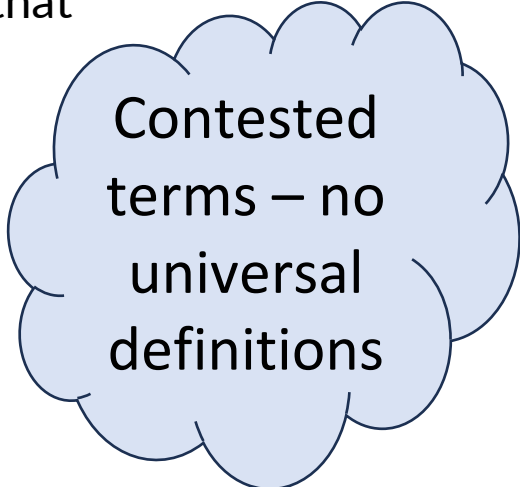
# Working definitions – from a research point of view

- ‘**Stakeholders**’ are people who have an interest in, or influence over, what research is done and how it is done.
- The ‘**community**’ comprises the people who are affected by the research, whether they take part in the research or not. They may also be stakeholders.
- ‘**The public**’ are a broader group of people, which the community and stakeholders are part of, who may have a general interest in research and its role in society.



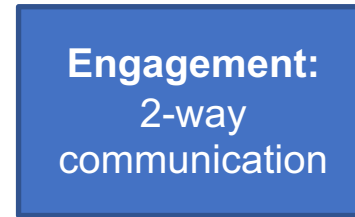
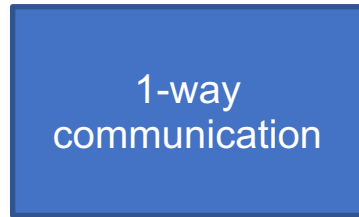
# What is '*engagement*' and '*involvement*'

- NIHR
  - *Involvement* – “An active partnership between patients, carers and members of the public with researchers that influences and shapes research”
  - *Engagement* – “information and knowledge about research is provided and disseminated”
- Other definitions
  - *Engagement* – “inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership” (Ahmed et al 2010)



Contested  
terms – no  
universal  
definitions

# The spectrum of participation?



INCREASING IMPACT ON THE DECISION

**INFORM**

**CONSULT**

**INVOLVE**

**COLLABORATE**

**EMPOWER**

© IAP2 International Federation 2018. All rights reserved. 20181112\_v1

Source: IAP2

# What is community/public/stakeholder Engagement and involvement?

- **A range of activities**

- Community meetings
- Radio interviews
- Community advisory boards
- Meeting health teams
- Social media

- **A range of goals**

- Raising public awareness
- Assessing acceptability
- Community input into research design, implementation etc.
- Fostering trust and collaborative partnerships
- Creating a demand for policy change

- **A range of terms**



# Why engage? Possible goals of engagement

Understand community norms and views

Identify local health priorities

Promoting understanding of research

Facilitate community input into research design

Identify and address ethical issues

Assess/ensure acceptability and feasibility of research

Gain permission and community consent

Improve communications and consent materials

Improve recruitment and retention rates

Build relationships, trust and partnership; expressing respect

Share the research findings

Improve healthcare

Support young people locally to take up research careers

Goals sourced from:

- Good Participatory Practice – AVAC
- Molyneux S, Bull S. *et al.* 2013
- UK standards for Public Involvement

# Good Participatory Guidelines (**GPP**)- engagement throughout the research lifetime



# Selecting from a range of engagement methods

- Community Advisory Boards
- Patient Advisory Group
- Laboratory open days
- Townhall/village meetings
- Radio or TV interview
- Social media posts
- Meeting hospital management group
- Nurses workshop
- Surveys and focus group discussions

## Type of research

- Community-based research
- Hospital-based clinical trial
- Hospital based staff intervention study

## Type of goal

- Input into study design/implementation

# Community-based study

- Community Advisory Boards
- Laboratory open days
- Townhall/village meetings
- Radio or TV interview
  
- Surveys and focus group discussions

## Type of research

- Community-based research



# Hospital-based clinical trial

- Patient Advisory Group
- Radio or TV interview
- Meeting hospital management group
- Nurses workshop

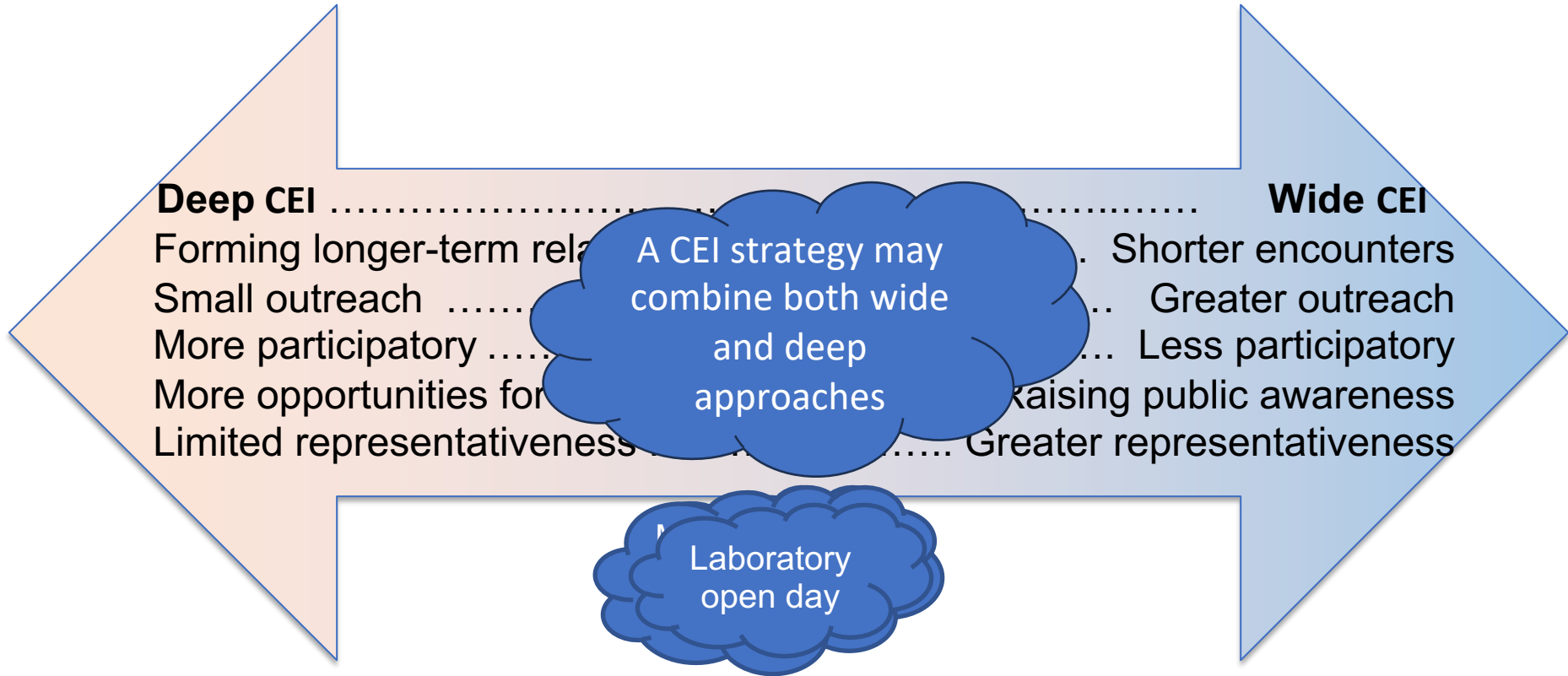
- Hospital-based clinical trial

# Input into study design

- Community Advisory Boards
- Patient Advisory Group
  
- Meeting hospital management group

- Input into study design/  
implementation

# Deep or Wide CEI?



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## Authors

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# Q&A

# **Overview of Community Engagement in Global Health Research**

**Dr. Alun Davies**

Lead, MESH Community Engagement Network, The Global Health Network, University of Oxford, UK

# **Ethics of health research with artificial intelligence**

**Dr. Manuel Colomé-Hidalgo**

Principal of Health Research Institute Universidad Autónoma de Santo Domingo

# Ethics of health research with artificial intelligence

**Dr. Manuel Colomé-Hidalgo**

Principal of Health Research Institute Universidad Autónoma de Santo Domingo





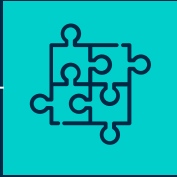


# Ethics of health research with artificial intelligence

**Manuel Colomé, MD, PhD**

Director – Health Research Institute  
Universidad Autónoma de Santo Domingo

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INTELLIGENCE

AI for health



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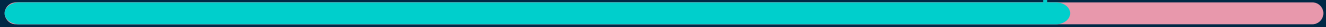
ETHICS AND  
REGULATION

Bioethics

# HEALTH

Research

01



# 01 HEALTH RESEARCH

- Research is indispensable to solving public health challenges, whether it is addressing the diseases of poverty, responding to the rise in chronic diseases, or ensuring mothers have access to safe childbirth practices.

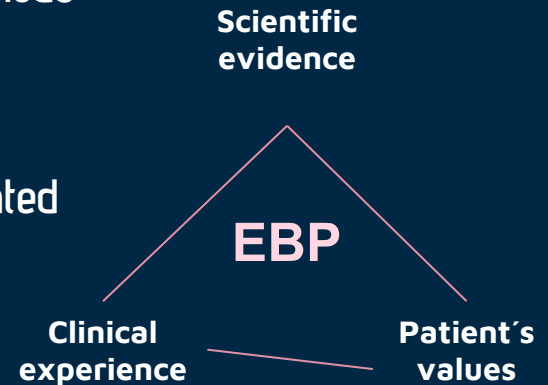



# 01 AREAS OF HEALTH RESEARCH

- Measure the magnitude and distribution of the health problem.
- Understand the various causes or determinants of the problem, whether due to biological, behavioral, social or environmental factors.
- Develop solutions or interventions that help prevent or mitigate the problem.
- Implementation or delivery of solutions through policies and programs.
- Evaluate the impact of these solutions on the level and distribution of the problem.


# 01 HEALTH RESEARCH

- Health research is the lynchpin of health systems that are effective and efficient.
- To improve public health and understand the economics and mechanics of health systems, a wide range of research methods are required.
- There is a need for new knowledge to be applied and translated into better health.





■ Today, society expects decisions to be based on the best available knowledge, but research initiatives are still not adequately organized or managed



# ARTIFICIAL

intelligence

02





# ARTIFICIAL INTELLIGENCE.

# 546 million

Of people use ChatGPT  
in the world



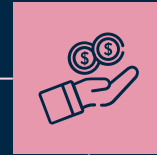
# 02 ARTIFICIAL INTELLIGENCE

- AI is the ability of algorithms encoded in technological means to learn from data in order to perform automated tasks without a person explicitly programming each step of the process.
- The WHO recognizes that AI holds great promise for the practice of public health and medicine.
- The ethical issues that AI entails for health systems and services must be addressed.

# 02 APPLICATIONS OF AI TO HEALTH

## MEDICINE

Diagnosis and treatment

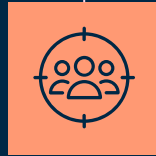


## ADMINISTRATION

Assistance in logistics tasks

## PUBLIC HEALTH

Promotion, prevention, surveillance



## RESEARCH

Drugs development

# 02 UNDERSTANDING THE PROBLEM

## IMPLICATIONS

Rushing adoption of unproven systems could lead to errors by healthcare staff, cause harm to patients, erode trust in AI, and thereby undermine (or delay) the potential long-term benefits and uses of such technologies. Worldwide.

## CONCERNS

Biased data, wrong answers, data without consent, post-truth and not being able to distinguish what is real from what is unreal and security.



# ETHICS

And regulation

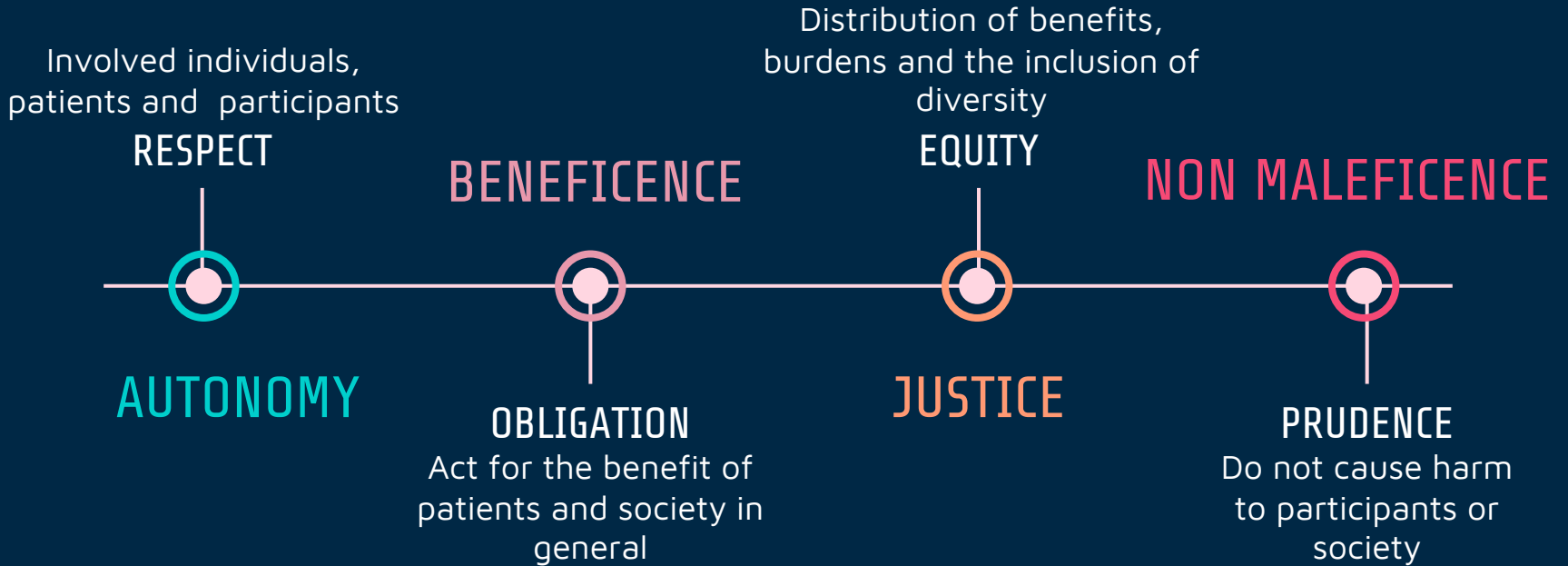
03



# 03 ETHICS AND REGULATION

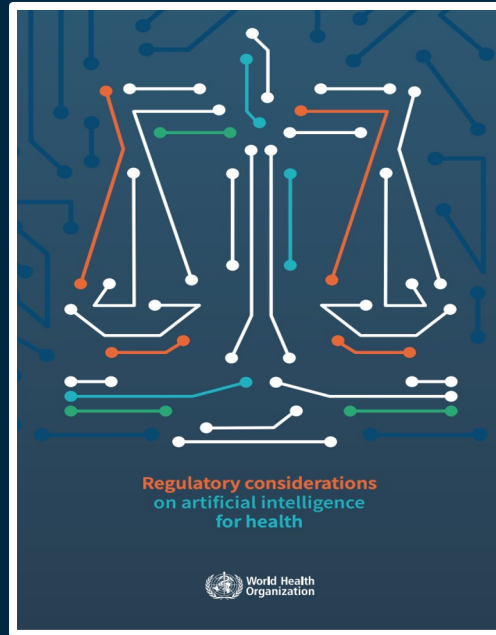
- Ethics is the ability of algorithms encoded in technological means to learn from data in order to perform automated tasks without a person explicitly programming each step of the process.
- The World Health Organization (WHO) that AI holds great promise for the practice of public health and medicine.
- The ethical problems that AI entails for health systems and services must be addressed.

# 03 ETHICAL PRINCIPLES





# 03 ETHICS, GOVERNANCE AND REGULATION OF AI



«AI holds great promise for health, but also presents significant challenges, including unethical data collection, cybersecurity threats, and the rise of bias and misinformation»

—TEDROS ADHANOM

# 03 ETHICAL PRINCIPLES: AI for Health – WHO



“Protect human autonomy”

—AUTONOMY



“Promote the welfare and safety of people and the public interest”

—WELL-BEING



“Ensure transparency, clarity and intelligibility”

—TRANSPARENCY



“Promote responsibility and accountability”

—RESPONSIBILITY



“Ensure inclusivity and equity”

—EQUITY



“Promote responsive and sustainable AI”

—SUSTAINABILITY

# 03

## ETHICAL CHALLENGES IN HEALTH RESEARCH WITH AI

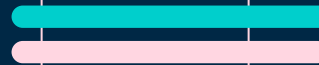
### PRIVACY AND CONFIDENTIALITY

Use of sensitive patient data in algorithms



### FAIRNESS AND ALGORITHMIC BIAS

Algorithms trained with biases and discriminatory decisions



### INTERPRETABILITY AND EXPLAINABILITY

Lack of transparency in algorithms makes it difficult to understand decision



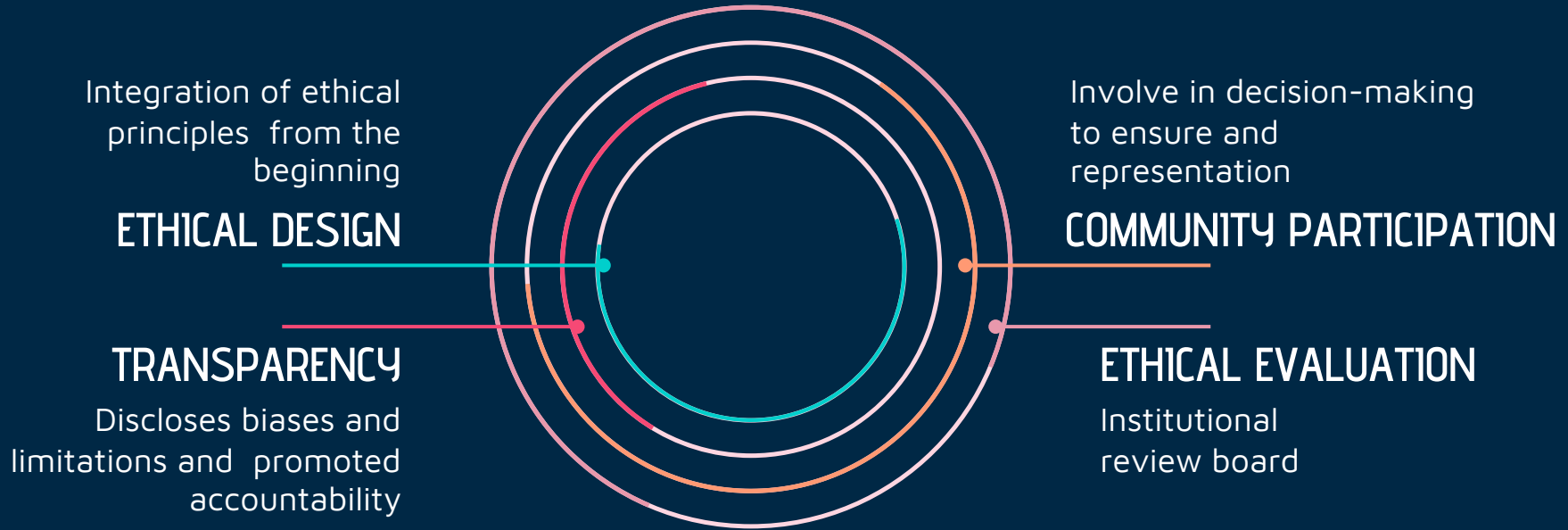
### RESPONSIBILITY AND SUPERVISION

Clear assignment of development responsibilities



# 03

## STRATEGIES TO ADDRESS CHALLENGES



# CONCLUSIONS

## ■ ETHICAL PRINCIPLES

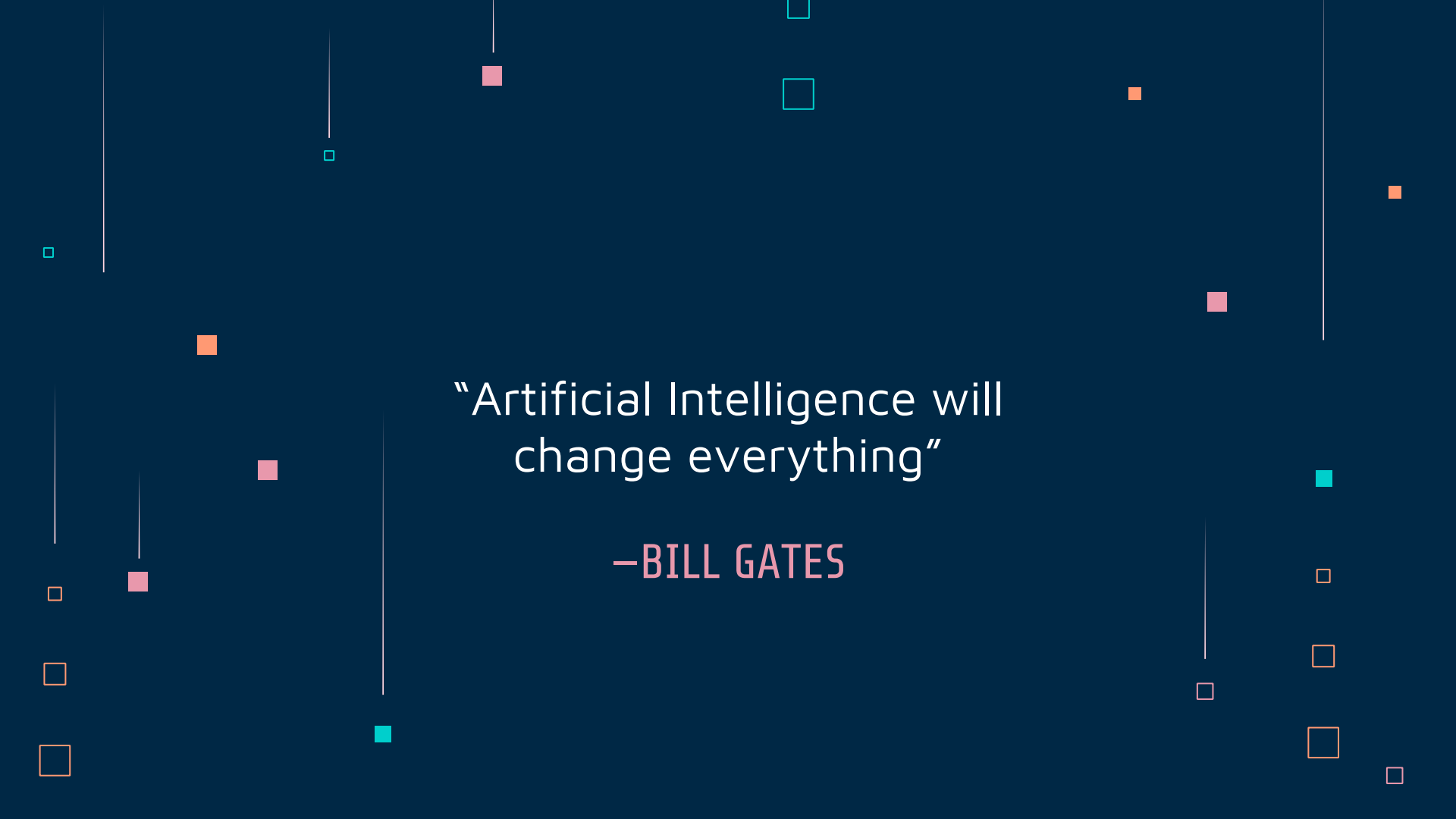
Include fundamental ethical principles and specific challenges in AI research.

## ■ ADDRESS CHALLENGES

Importance of addressing these ethical challenges to ensure integrity, equity and safety in health research.

## ■ CALL TO ACTION

□ Adopt robust ethical principles approaches in the development and implementation of AI in healthcare.

The background is a dark blue gradient. It features several vertical white lines of varying lengths. Scattered throughout are small squares in various colors: light blue, pink, orange, and teal. Some squares are solid, while others are hollow outlines. The overall aesthetic is modern and minimalist.

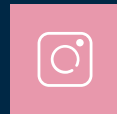
“Artificial Intelligence will  
change everything”

—BILL GATES

¿Any questions?

mcolome17@uasd.edu.do  
Twitter (X): manuel\_colome

# THANKS!



CREDITS: This presentation template was created by Slidesgo,  
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# Q&A



**Watch the full workshop  
on the AI4GH and mesh  
knowledge hubs.**



# Stakeholder analysis and mapping

**Luis F. Arias**

Investigator in training and research unit at ETIKOS, with interest in implementing research and ethics. LAC coordinator for MESH, The Global Health Network, University of Oxford, Dominican Republic



community engagement network

Presents

# Stakeholder Mapping

**Luis Felipe Arias Soto**

21th of May, 2024



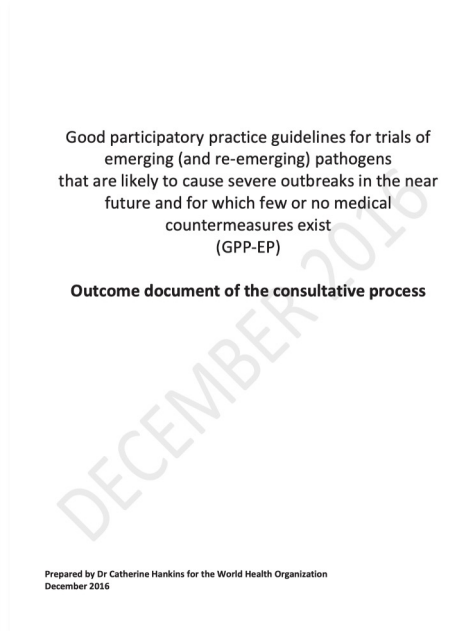
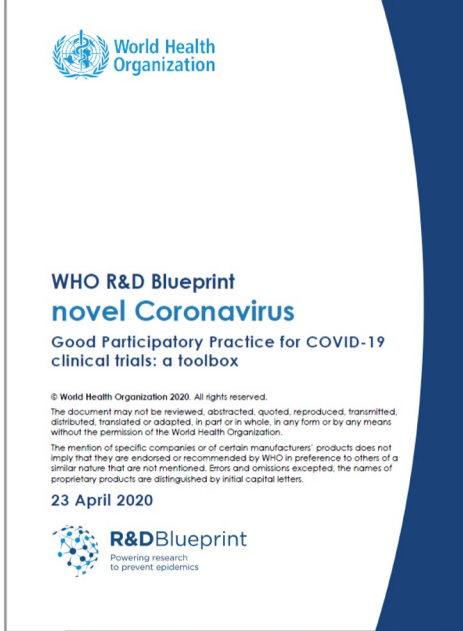
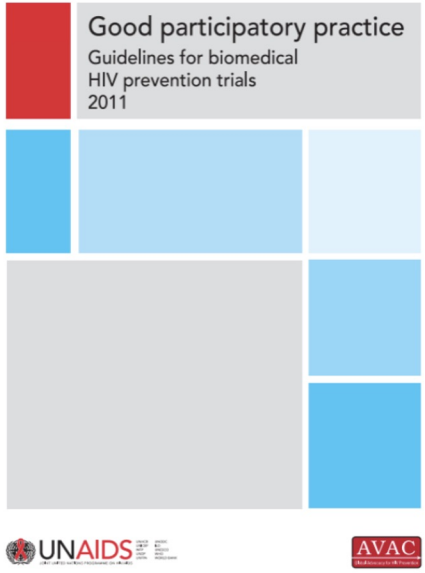
What is Stakeholder mapping?

*“Mapping stakeholders and bringing on board the most relevant actors at the start of the research study is the first step in the engagement process. This will ensure that your research questions are developed based on local priorities, context, and the needs of the study beneficiaries.”*

*-RESPIRE, Stakeholder Engagement in Global Health Research, 2023.*

*Considering:*

- **Stakeholders** - people who influence what, how and whether research is done.
- **Stakeholder mapping** – Identifying possible stakeholders, their priority to engage and the best way to do so.
- The **community** or **community group** - the people who are affected by the research, whether they take part in it or not.



Good Participatory Guidelines for Clinical Trials

- Guidelines for community engagement to support clinical trials in HIV, TB, Emerging Pathogens and COVID-19

## The range of stakeholders in GPP



- Global stakeholders
- National stakeholders
- Broader stakeholders
- Community stakeholders
- Trial Participant

# Multi-country COVID-19 vaccine trial in Africa and Latinoamerica

## Global Stakeholders

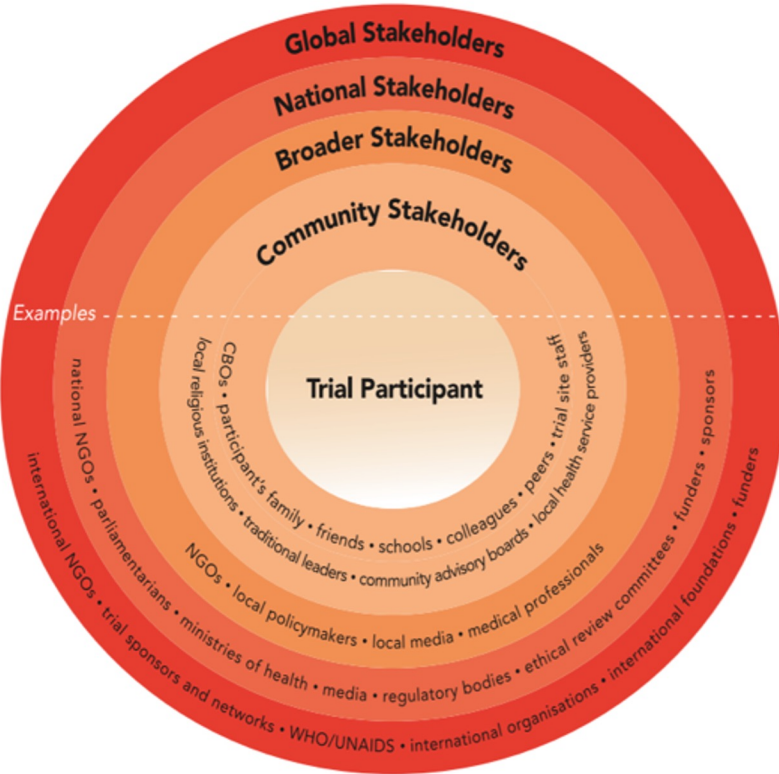


Who were the stakeholders?	Why were they engaged?
Research leaders	Adapting research plans to local context
International press	Advocacy – public support

### Engagement methods

- Face-to-face meetings and online meetings
- Sharing policy briefs, animated videos etc.

# National Stakeholders



Who were the stakeholders?	Why were they engaged?
Ministry of Health	Gaining public and institutional support Agreement on trial costs and benefits Assessing trial acceptability

## Engagement methods

- Face-to-face meetings and online meetings
- Sharing policy briefs, animated videos, powerpoints etc.



# Broader Stakeholders



Who were the stakeholders?	Why were they engaged?
<p>National Medical Association</p> <p>National Nursing Assoc.</p> <p>National media, radio</p> <p>Non-Governmental Organisations</p>	<p>Advocacy – public and institutional support</p>

Engagement methods – mostly informing

- Sharing policy briefs, animated videos etc.
- Emails, letters etc
- Some presentations

# Community Stakeholders



Who were the stakeholders?	Why were they engaged?
County Health Minister County and sub-County Health Management Teams Hospital Staff Community leaders, women's groups, religious leaders, schools Community Advisory Board	Assessing feasibility and acceptability Institutional support Input into implementation Raising awareness and addressing rumours Recruitment

## Engagement methods

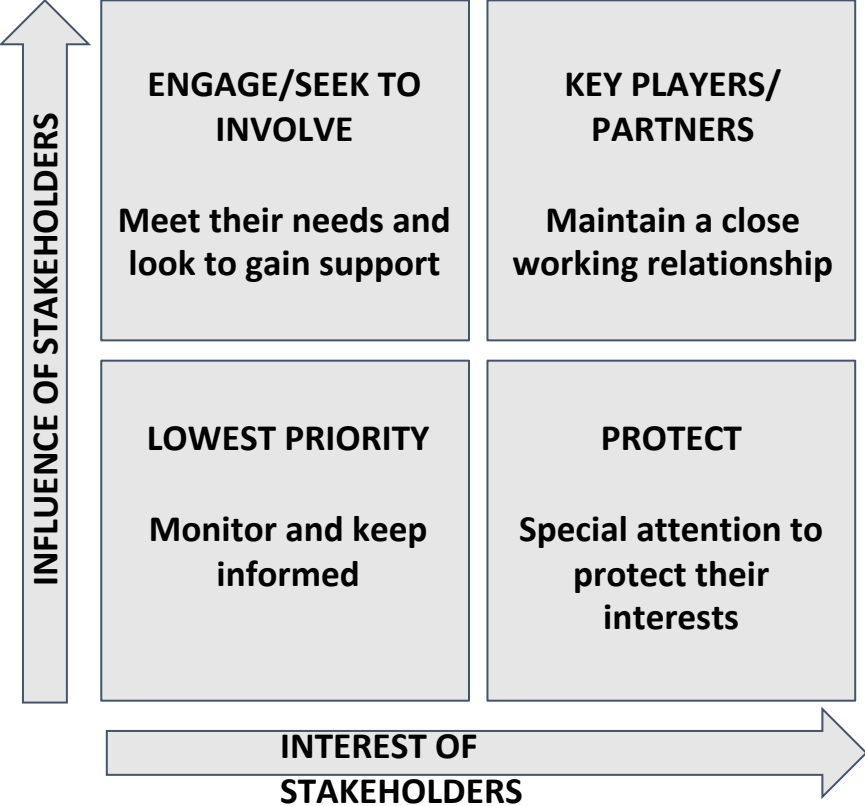
- Face-to-face meetings
- Town hall/Community Center meetings and lab tours
- Regular Community Advisory Board meetings
- Recruitment Posters

## Mapping: How stakeholders were identified

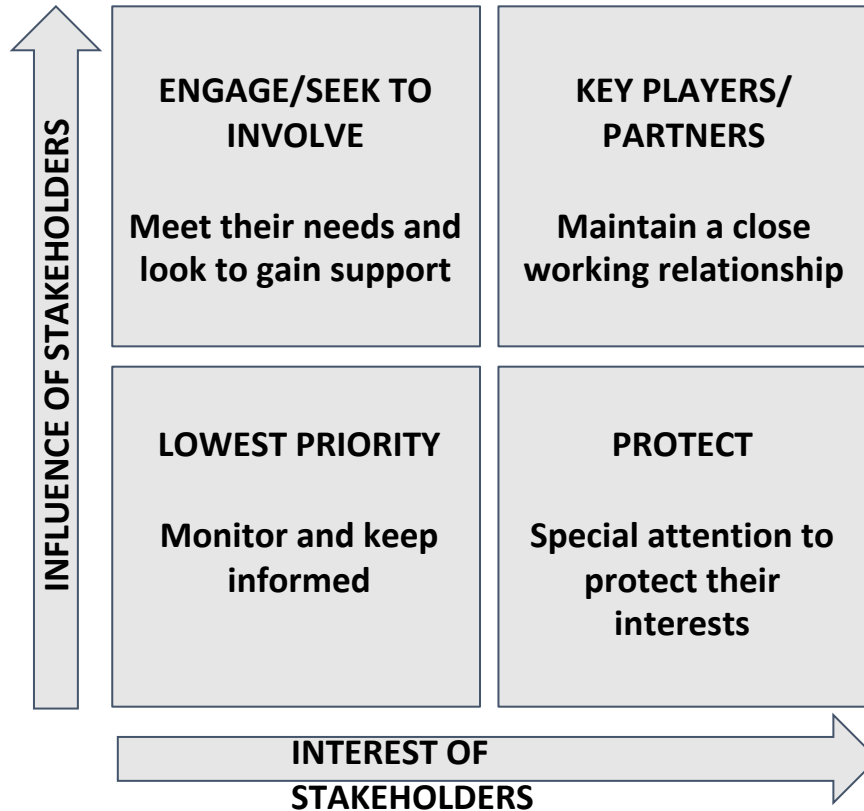
- A research coordination team was set up, comprising: The Principal investigator, engagement lead, communications lead, social scientist
- Brainstorming –
  - Identify the range of stakeholders at National, Community and Broader levels
  - Each stakeholder's 'interest' and 'influence' in the proposed research



# The stakeholder matrix



# Place individual stakeholders on the stakeholder matrix



Consider a school-based trial exploring the impact of de-worming and vitamin tablets on health and educational outcomes

People in neighbouring district

District education officer

Parent teacher groups

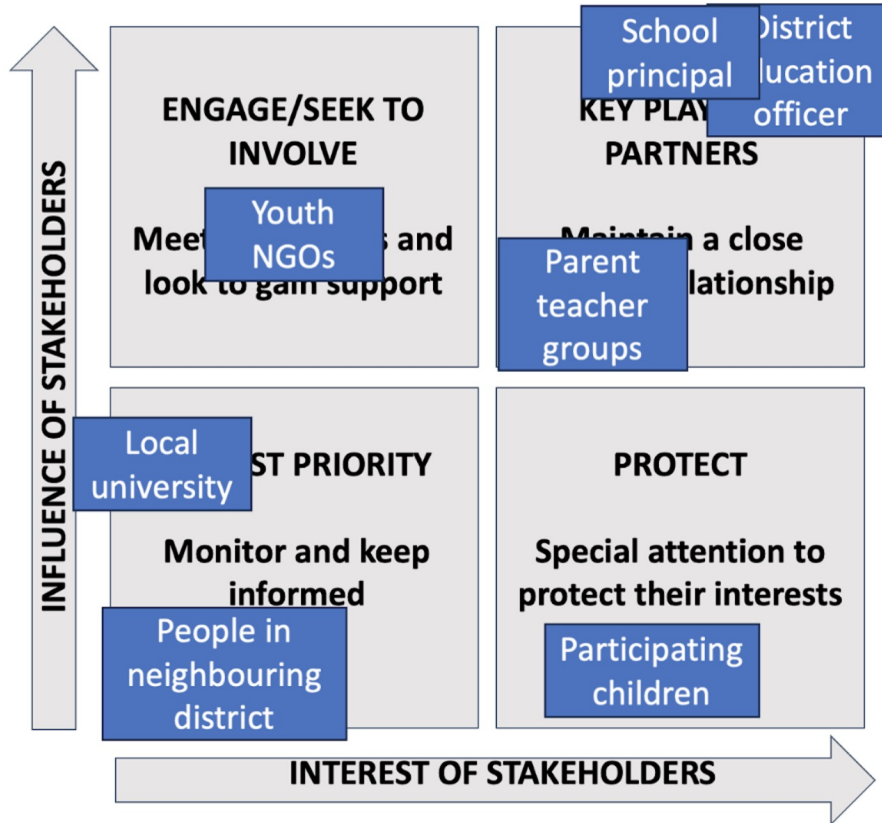
School principal

Local university

Participating children

Youth NGOs

# Place individual stakeholders on the stakeholder matrix



## Mapping

- Who to engage and
- How much to engage them

Activity:

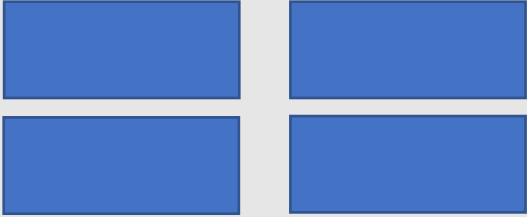
Your turn to map stakeholders

**A research group based in East Africa wants to conduct a research which to compare tumor diagnostics based on scans interpreted by doctors, against scans interpreted by AI. The research will be conducted in a large referral hospital.**

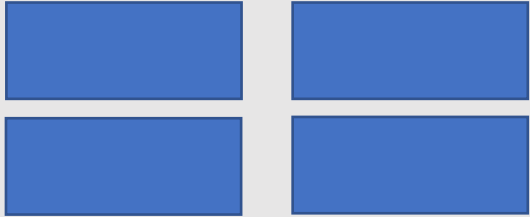
- In the Chat – please suggest who might be important stakeholders to engage with for this research
- Assign their relative interest and influence

**INFLUENCE OF STAKEHOLDERS**

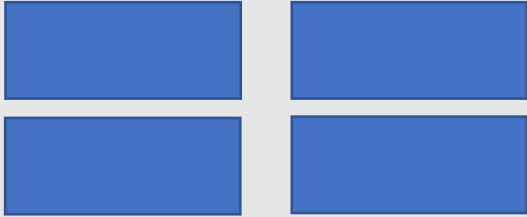
**ENGAGE/SEEK TO INVOLVE**  
Meet their needs and look to gain support



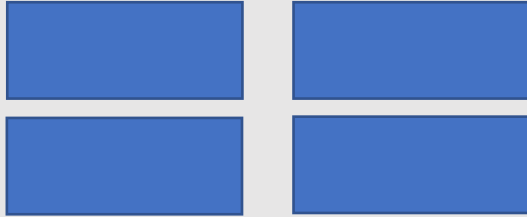
**KEY PLAYERS/ PARTNERS**  
Maintain a close working relationship



**LOWEST PRIORITY**  
Monitor and keep informed



**PROTECT**  
Special attention to protect their interests



**INTEREST OF STAKEHOLDERS**



# Resources: Guide for Stakeholder Engagement

## Stakeholder Engagement in Global Health Research

A RESOURCE GUIDE



<https://mesh.tghn.org/articles/resource-guide-stakeholder-engagement-global-health-research/>



# Q&A

# Certification

If you wish to receive a certificate of attendance for this workshop:

- Requirement 1: **Completion of the TGHN Workshop Feedback Survey.**
- Requirement 2: **80% attendance of the workshop.**
- Please include the “**Empowering communities- Innovative approaches to AI health research and engagement**” and the code **210524** when requested.
- Your certificate will automatically be emailed to you within one month.



<https://app.onlinesurveys.jisc.ac.uk/s/oxford/tghn-workshop-feedback-survey-v3-0-with-code-duplicate>