

# Sualeha in ResearchEthicsLand: Down the Rabbit Hole

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# Setting the Stage

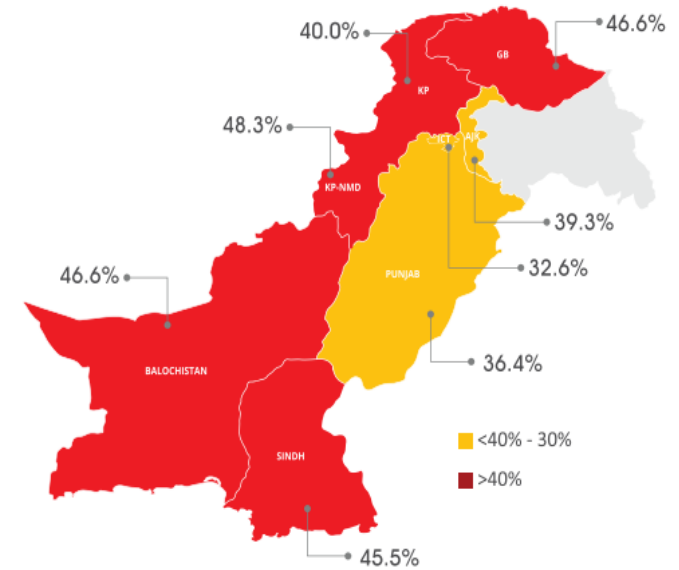




## 10.7m Stunted Children: Pakistan Unable To Make Progress For Achieving SDGs, As Malnutrition Remains A Challenge

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Prevalence of Stunting by Province/Region



The prevalence of stunting improved from 1965 (48%) to 1994 (36.3%) but deteriorated from 2001 (41.6%) to 2011 (43.7%). In 2018, at 40.2%, it remains at a global critical level. The average annual reduction rate is estimated at 0.5%, too slow to significantly reduce the stunting rate in Pakistan.

Integrated Food Security Phase Classification, 2022

56 (12%) of 276 studies approved between 2018 to August 2023 were on malnutrition (maternal and child)

- In **50** out of the 56 studies approved for research, the PIs were from one private medical university
- Over-researched communities: **49**

<https://nbc-pakistan.org.pk/assets/nbc-r-approved-project-status-of-last-five-year-2018-to-2023.pdf>

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# 50 clinical trials on malnutrition registered on clinicaltrials.gov in Pakistan as of September 2023

**Focus Your Search**  
(all filters optional) << Hide

**Condition/disease** ⓘ  
Malnutrition

**Other terms** ⓘ  
[Empty field]

**Intervention/treatment** ⓘ  
[Empty field]

**Location**  
Search by address, city, state, or country and select from the dropdown list  
Karachi, Pakistan

**Study Status** ⓘ  
**Looking for participants**  
 Not yet recruiting (1)  
 Recruiting (4)

Clear Filters (2) Apply Filters

**Search Results**  
Viewing 1-10 out of 25 studies  
[+ Synonyms of conditions or disease \(3\)](#)

None Selected [Download] [Bookmark] [RSS]

● ACTIVE, NOT RECRUITING  
**NCT04012177**  
Nutritional Support and Prophylaxis Doses of Azithromycin for Pregnant Women - Mumta Pregnant Women Trial  
Conditions: **Undernutrition**  
Locations: Karachi, Sindh, Pakistan

● COMPLETED  
**NCT03564652**  
Nutritional Support for Lactating Women and Azithromycin to Infants - Mumta Lactating Women Trial  
Conditions:

25 in Karachi, Sindh

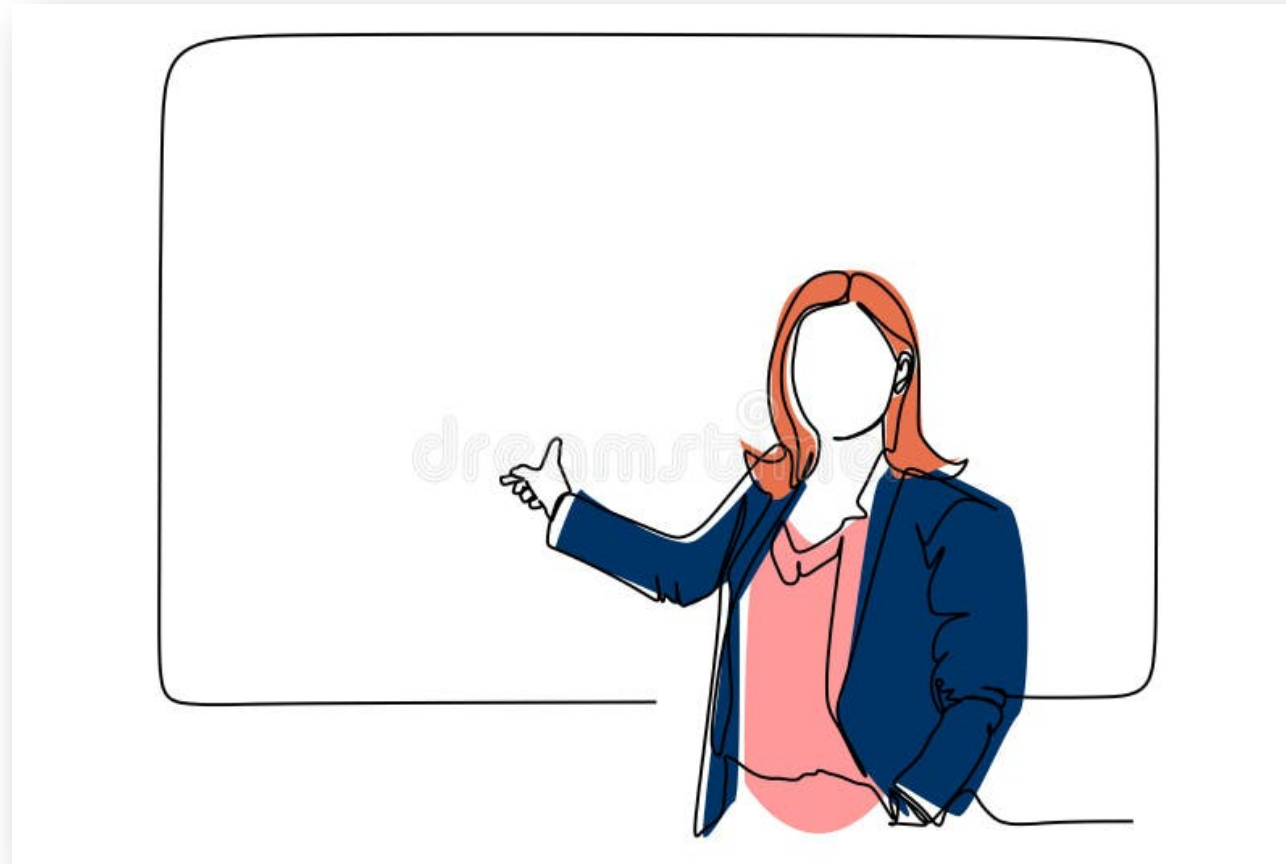
9 in peri-urban communities

A video clip from a movie made in 2001.....



<https://www.youtube.com/watch?v=ovZFEuaQkcc&t=20s>

# Tumbling down to early 2023



"Stakeholder Engagement" AND "Malnutrition" AND "Sindh" AND "Pakistan"

Search

Advanced Create alert Create RSS

"Community" OR "Public" AND "malnutrition" AND "Sindh" AND "Pakistan"

Search

Sort Advanced Create alert Create RSS

User Guide

No results were found.

Save

Email

Send to

Sort by:

Best match

Display options



Filters applied: in the last 10 years. [Clear all](#)

22 results



Page

1

of 3



Filters applied: in the last 10 years. [Clear all](#)

Community Engagement processes: Mere  
Tokenistic gestures

Are these communities being used merely as a  
means to an end?



# Ethical Issues: Domestic Injustice

Justice issues: Structural inequities, post colonial legacy

How Domestic Researchers Benefit:

- More money
- Promotions
- More publications
- Recognition & Prestige

How do Communities Benefit?

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## Ethical Issues: Lack of Inter-sectoral collaboration

Priority setting: Who sets the priority? Which sector?

Where is the government? Translating research into policy

Funders and researchers do not look at problem 'holistically'

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# Ethical Issues: Problems of Governance



National Bioethics Committee for Research  
Health Research Institute  
National Institutes of Health (NIH)



Drug Regulatory Authority of Pakistan  
Ministry of National Health Services, Regulations & Coordination

## Problems of Regulators

- Limited exposure to implementation research
- Changes in governmental structures, barriers in wider policy-making

Funded on Scientific Merit

Approved on Technical Merit

Outcome:  
Persisting Health Inequities  
Inefficiencies



# Recommendations for Health-Priority Setting

- Too much emphasis on *disease-specific* research
  - Address health systems and implementation research
- 
- Funding to be directed NOT only on scientific merit
  - Consider health equities in the long-run

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What research evidence can support the decolonisation of global health?  
Making space for deeper scholarship in global health journals

[Sudha Ramani, PhD](#)   • [Eleanor Beth Whyle, PhD](#) • [Nancy Kagwanja, MSc](#)

[Open Access](#) • Published: September, 2023 • DOI: [https://doi.org/10.1016/S2214-109X\(23\)00299-1](https://doi.org/10.1016/S2214-109X(23)00299-1)

## Recommendations

- Negotiate benefit sharing with and for over-researched communities, an important obligation
  - Governance structures to ask for detailed plans for engagement and collaboration with relevant stakeholders including communities and government
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## Emerging Challenges

- Impact of nutrition research on climate and biodiversity, e.g. wheat composition
- Climate change will continue to threaten food insecurity, e.g. recent floods in Sindh, Pakistan

**Health research priority setting ought to include climate change**

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*“Would you tell me, please, which way I ought to go from here?”*  
*“That depends a good deal on where you want to get to,” said the Cat.*  
*“I don’t much care where—” said Alice.*  
*“Then it doesn’t matter which way you go,” said the Cat.*  
*“—so long as I get somewhere,” Alice added as an explanation.*

