

COMMUNITY ENGAGEMENT & INVOLVEMENT IN RESEARCH

Symposium on Responsible Conduct of Research in Nepal: Identifying and Addressing Gaps

Hotel Himalaya

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What is Community Engagement & Involvement (CEI) in Research?

- **Community Engagement & Involvement in Research** is a process that incorporates input from people who the research outcomes will impact and involves such people or groups as equal partners throughout the research process.
- **CEI** incorporates **involving people affected by a health condition and/or their carers in the various stages of a research proposal**. This may include planning, designing, implementing, managing, evaluating and/or disseminating their research.

NIHR vision for community engagement and involvement

- **NIHR's Community Engagement and Involvement (CEI) vision is that all global health research is undertaken in collaboration with the communities who are most likely to be affected by the research outcomes.**
- We want to enable those who are marginalised to have a meaningful voice both in the research funding process, as well as in the design, delivery and dissemination of research.
- We believe that this will improve the relevance, quality and impact of the research produced. And that a commitment to meaningful CEI from the start will lead to greater understanding and uptake of research findings in policy and practice, ultimately improving the health and wellbeing of communities.

- **Community-** The broad term 'communities' is used here to include **patients, carers, policy makers, health care workers, community organisations, faith groups, service commissioners and others who might be considered key stakeholders**
- **3 Key terms:**



Participation - people take part in a research study or clinical trial



Engagement - information about research is communicated and shared



Involvement - members of the public are actively involved in research projects and research organisations

Why CEI is important to NIHR

- NIHR has given significant emphasis to CEI as part of the UK Government's commitment to the '[Leave No One Behind](#)' agenda, a central and transformative promise of the 2030 Agenda for Sustainable Development Goals (SDGs).
- This commitment requires researchers and other stakeholders to consider issues of marginalisation, discrimination and inequality, and identify measures to address these challenges when undertaking research.

NIHR expects communities to be actively engaged and involved:

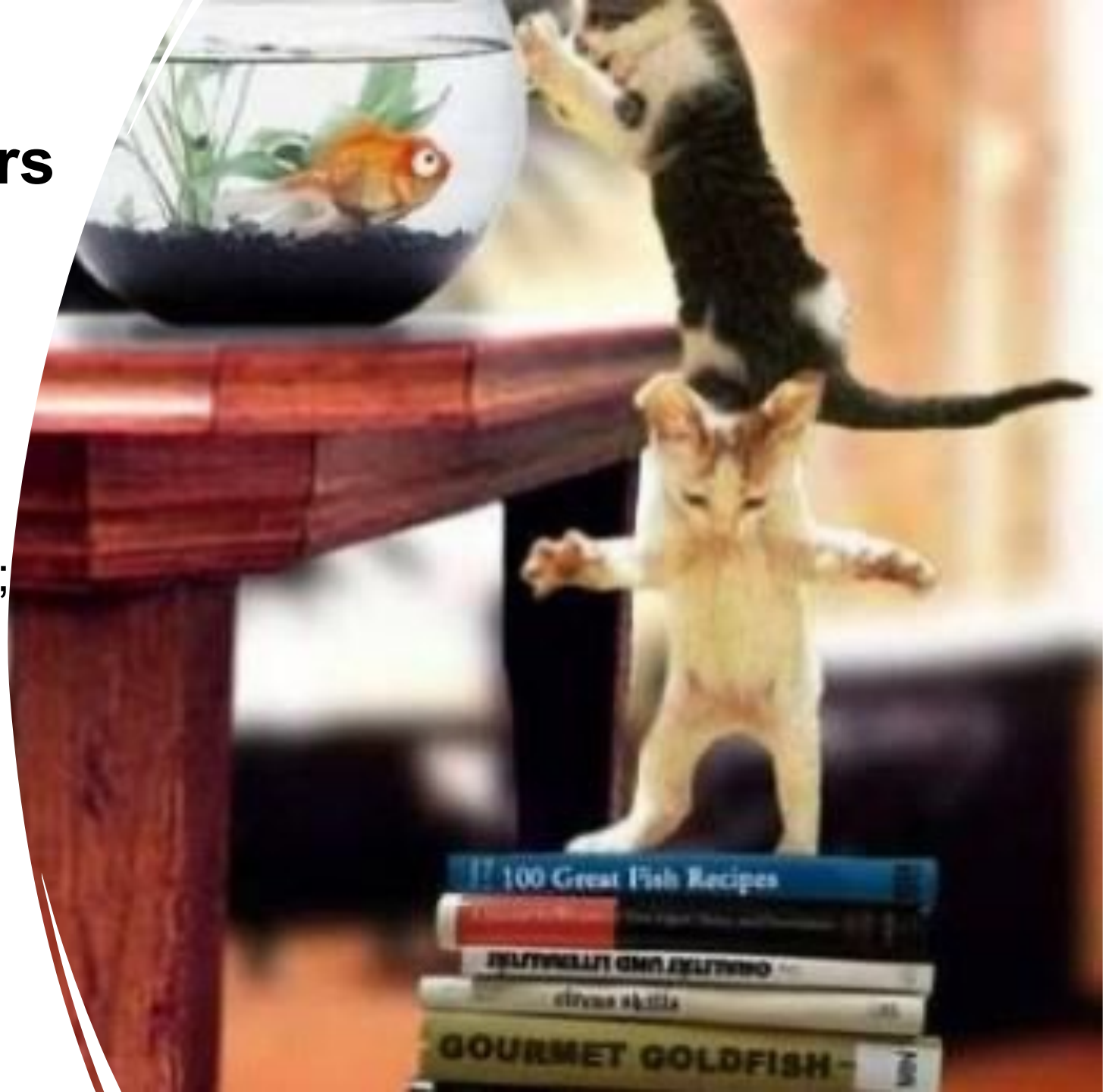
- at the start of research when priorities are being decided
- when research is being designed and funded
- through delivery of the research project, and
- in dissemination of research outputs.

- <https://www.nihr.ac.uk/explore-nihr/funding-programmes/global-health.htm>

Patients/Public as Partners

Patients and the public work alongside researchers to shape:

- **what** research is done;
- **how** research is carried out;
- **how** results are shared and applied in practice.





*“Nothing About Us
Without Us!”*

RIGHT project-TLM Nepal

Three Research Studies:

1. **TABLE** study-

- Trial of **A**utologous **B**lood products to promote ulcer healing in **LE**prosy-
- Based in Anandaban Hospital, Lalitpur -evaluates L-PRF in Leprosy foot ulcers

2. **SHERPA** Study-

- S**elf **H**elp **E**valuation for lep**R**osy and other conditions in Ne**PA**L
- Based in Butwal - evaluates the Intervention of IMPACT project of TLM Nepal

3. **INHERITANCE** study (Sustainability study)

- Susta**IN**ability of self-**HE**lp g**R**oups **I**n rau**T**ahat **A**nd makawa**N**pur distri**C**ts in Ne**E**pal
- Based in Rauthat & Makawanpur-evaluates the sustainability of CEDAR & PACED projects of TLMN

Working with **established** communities

- TLM Nepal- RIGHT project organized several CEI meetings (every 6 months) with stakeholders ie Leprosy affected people representing organizations including IDEA Nepal, READ Nepal, LAWA Nepal, New Sadle, Shanti Sewa, Khokana Aarogya Ashram along with government officials, experts from the Leprosy field, and NGOs working in the Leprosy field.

Grant Development - Visit to Nepal

Partnership working with The Leprosy Mission England and Wales helped arrange and set up meetings with key stakeholders and communities in all 3 countries. The pre-grant meeting was arranged in Nepal with people affected by Leprosy, government (LCD) representatives and clinicians from leprosy field in Dec 2018.



Virtual meeting- TLM Nepal and UK team!





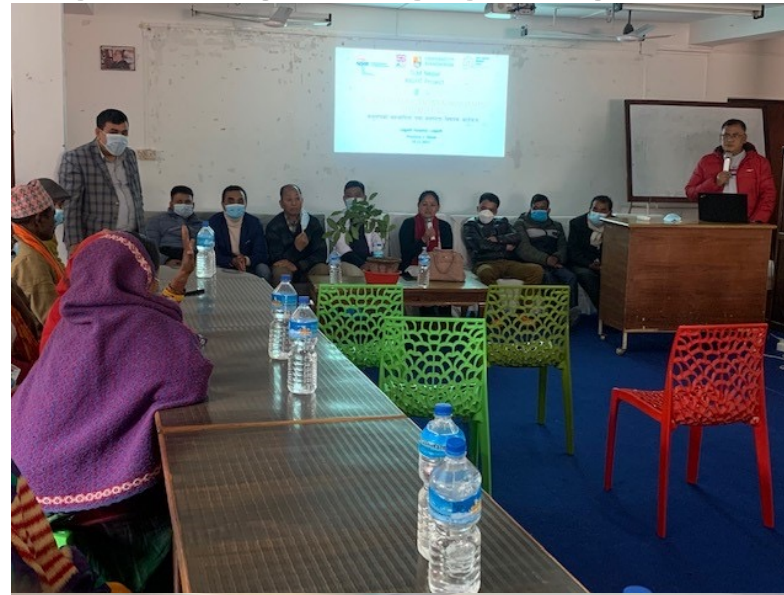
Virtual CEI meeting with Magdalena and Sopna during COVID Pandemic 30 July 2020



CEI on 06 Dec 2022 in Ktm- RIGHT project Representation from NHRC



Community Engagement & Involvement in Province 2: on 19 Dec 2021



Meeting with stakeholders in Nigeria-RIGHT Project



Way Forward:

- We recommend all research projects in Nepal incorporate CEI to improve the relevance, making them accountable and taking ownership and sharing the final results with this group.
- We believe this will impact the uptake of research findings in policy and practice improving the health and well-being of communities in Nepal.

Our Partners



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