

Engaging community members in co-designing interventions to address non-communicable disease risk: Lessons from forming co-production groups in Kathmandu, Nepal

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Background

- Urban populations face complex challenges in addressing NCDs, influenced by socio-economic, environmental, and behavioral factors
- Engaging community members as equal partners enables equitable and sustainable solutions
- Participatory engagement for cities communities against NCD risk (PECAN) uses a participatory learning and action approach
 - Community level co-production groups (CPGs) formed ensuring inclusive and diverse membership
 - CPGs act as a co-researchers or citizen scientists to understand community context, issues and contribute to design interventions



Objective

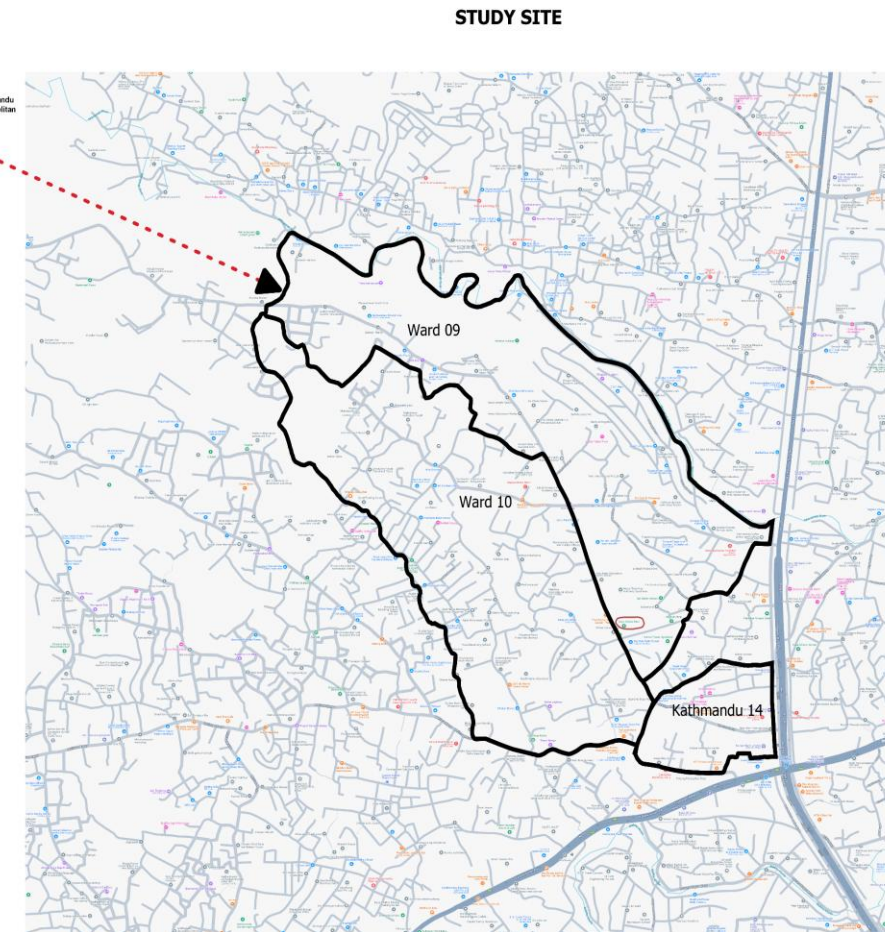
- Analyze the CPG formation process, highlighting key challenges, and practical lessons for meaningful community engagement as co-researchers



Methodology

Study site

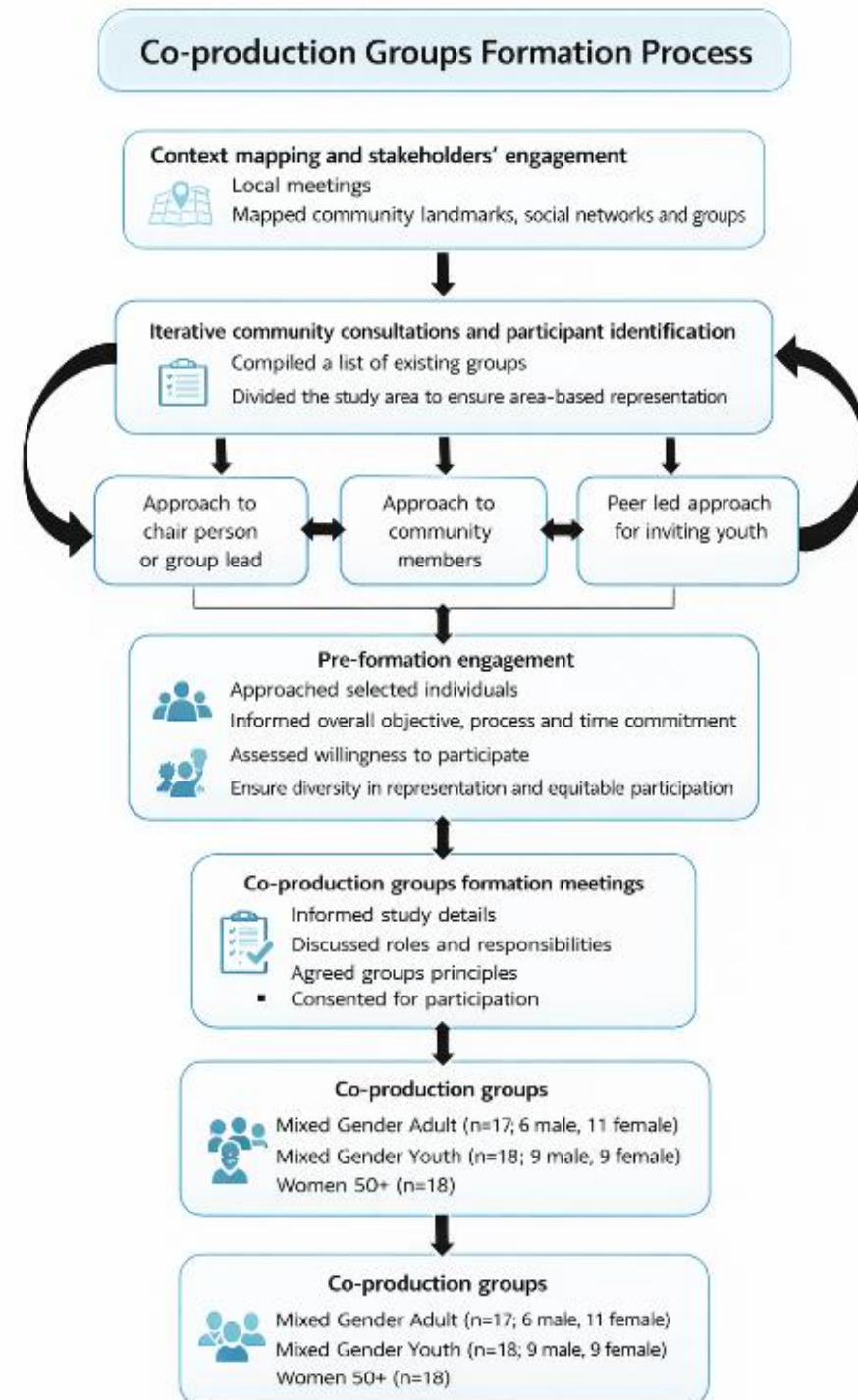
- Nagarjun Municipality: Ward 9 and 10
- Kathmandu Metropolitan City: Ward 14



Methodology

Formation process

- Proposed three co-production groups of mixed adult, women 50+, women and youth between 18-24 years
- Ensure diversity of membership in terms of age, sex, education level, occupation, ethnicity, disability status, location and residence type



Methodology

Iterative consultation process

Stakeholder meeting and group discussions with local gatekeepers

Participants (n=28; 15 male, 13 female)

- ward chairpersons
- municipality representatives
- ward members
- health facility staff
- school teachers
- female community health volunteers
- local club member
- lead of community groups
- community member



Methodology

Formation process

- Compiled a list of existing community groups
- Division of study area to ensure area based representation
- Contacted lead or chair person of the group for participant identification

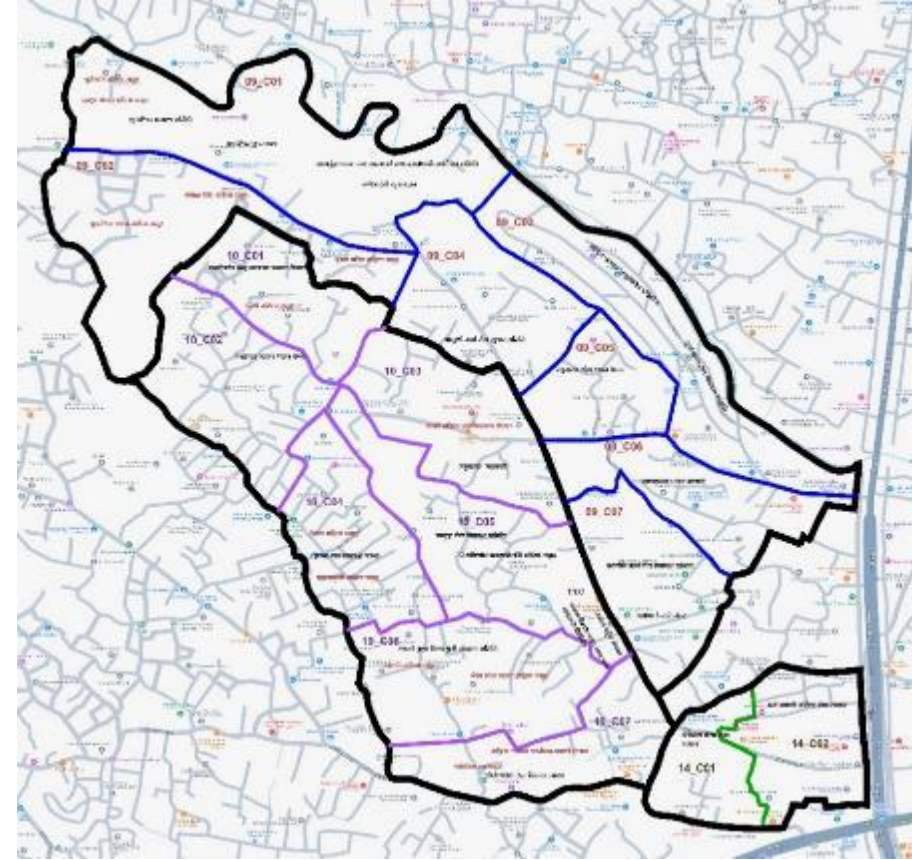
Pre-formation engagement

Approach selected participants

Inform overall objective, process and time commitment

Assess willingness to participate

Ensure diversity in representation and equitable participation



Co-production group formation meeting

- Informed study details
- Discussed roles & responsibilities
- Agreed groups principles
- Informed consent for participation

Result

Co-production groups as 'Citizen Scientists' [53 members]



Mixed Adult Group



Mixed Youth Group



50+ Women Group

Result

Socio-demographic profile

Characteristics	Mixed Youth (n=18)	Mixed Adults (n=17)	Women 50+ (n=18)
Sex	9 Female, 9 Male	11 Female, 6 Male	Female
Age range	18–22 years	34–61 years	50–73 years
Ethnicity	Brahmin & Chhetri dominant Few dalit, janajati, tharu	Brahmin & Chhetri dominant Few dalit & janajati	Brahmin & Chhetri
Religion	Hindu dominant Buddhist (1)	Hindu	Hindu
Education	Secondary	Many secondary Few primary and higher Illiterate (1)	Many secondary Few primary and higher Some illiterate
Occupation	Student Some part-time	Most women: homemakers Most men: working*	Most women: homemakers Few: social worker, teacher
Residence type	Mostly owned Some rented	Owned	Mostly owned Few rented

*private job, social workers, lecturer & retired

Result

Challenges of forming co-production groups in urban context

Mobile & busy urban population

- Frequent movement for work, healthcare, family and migration

Low participation from renters

- Short-term stay, limited community interaction, uncertainty about commitment

Lessons learned

- Recruit members through existing networks
- Engage gatekeepers to map groups and identify participants
- Ensure flexible participation based on participants' availability
- Clearly communicate the expected level of effort

- Emphasize commitment & self-motivation
- Allow replacement of members over time

Result

Challenges of forming CPGs

Youth involvement and fluctuating membership

- Participants joining groups mid way

Lessons learned

- Promote consultative approach to support evolving group participation
- Remain open to participant input and suggestions
- Ensure participation is non-obligatory and allow entry at different stage
- Adopt a peer-led approach to invite youth

Result

Challenges of forming CPGs

Gender roles and imbalance

- Men's participation limited by work commitments; women's participation limited by household responsibilities
- Initial discomfort in mixed-gender groups

Difficulty in including minority ethnic participant

- Mostly upper-caste groups participated due to proximity and representation in existing networks
- Minority groups harder to reach

Lessons learned

- Discomfort in youth groups decreases over time with repeated engagement
- Gender segregated group discussion in later stage

- Iterative consultations to include diverse participants
- Rotate meeting venues across wards to ensure accessibility and social acceptability

Result

Challenges of forming CPGs

Difficulty including people with disability

- Limited identification: few gatekeepers knew people with disabilities
- Caregiver refusals prevented participation, especially for those with multiple disabilities or communication challenges
- One person wanted to participate with a friend, but her friend did not consent

Ethical concerns

- Under-18 participants raised ethical consent challenges
 - ✓ Some people with disabilities were under 18 years of age
 - ✓ Some youth under 18 were keen to participate

Compensation

- Participants were provided compensation for time, travel and communication to support inclusion of marginalized people

Conclusion

- Formation of co-production groups with diverse urban participants is feasible, though achieving truly inclusive and equitable participation remains challenging.



Key takeaways

- ❑ Flexibility is critical – adaptable scheduling and open entry-exit models maintain participation in busy urban settings.
- ❑ Inclusive participation requires deliberate planning, intersectional consideration, iterative consultations, and compensation to engage marginalized groups.
- ❑ Ownership and engagement grow when local resources are shared and community members are involved as co-researchers to better understand the context and co-design tailored interventions.

THANK YOU



Diabetic Association of Bangladesh



UK Research and Innovation



Biography

Ms. Sulata Karki is a Senior Research Officer at HERD International with extensive experience in evidence-based health research. She has a strong background in mixed-methods implementation research, including participatory approaches, and has contributed to numerous field studies and evidence generation. Her work focuses on non-communicable diseases, maternal and child health, and digital health interventions, including surveys and intervention evaluations across Nepal.

