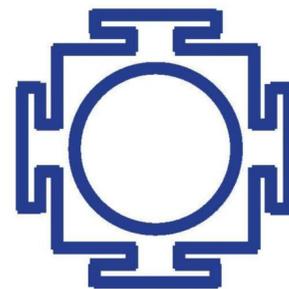


# 24th FERCAP International CONFERENCE

Maximizing Benefits through Responsible Conduct of Research

## Women driven community engagement in genomics research

Arya Gautam  
Sabitri Sciences,  
Bhaktapur,  
Nepal





**Name: Arya Gautam**

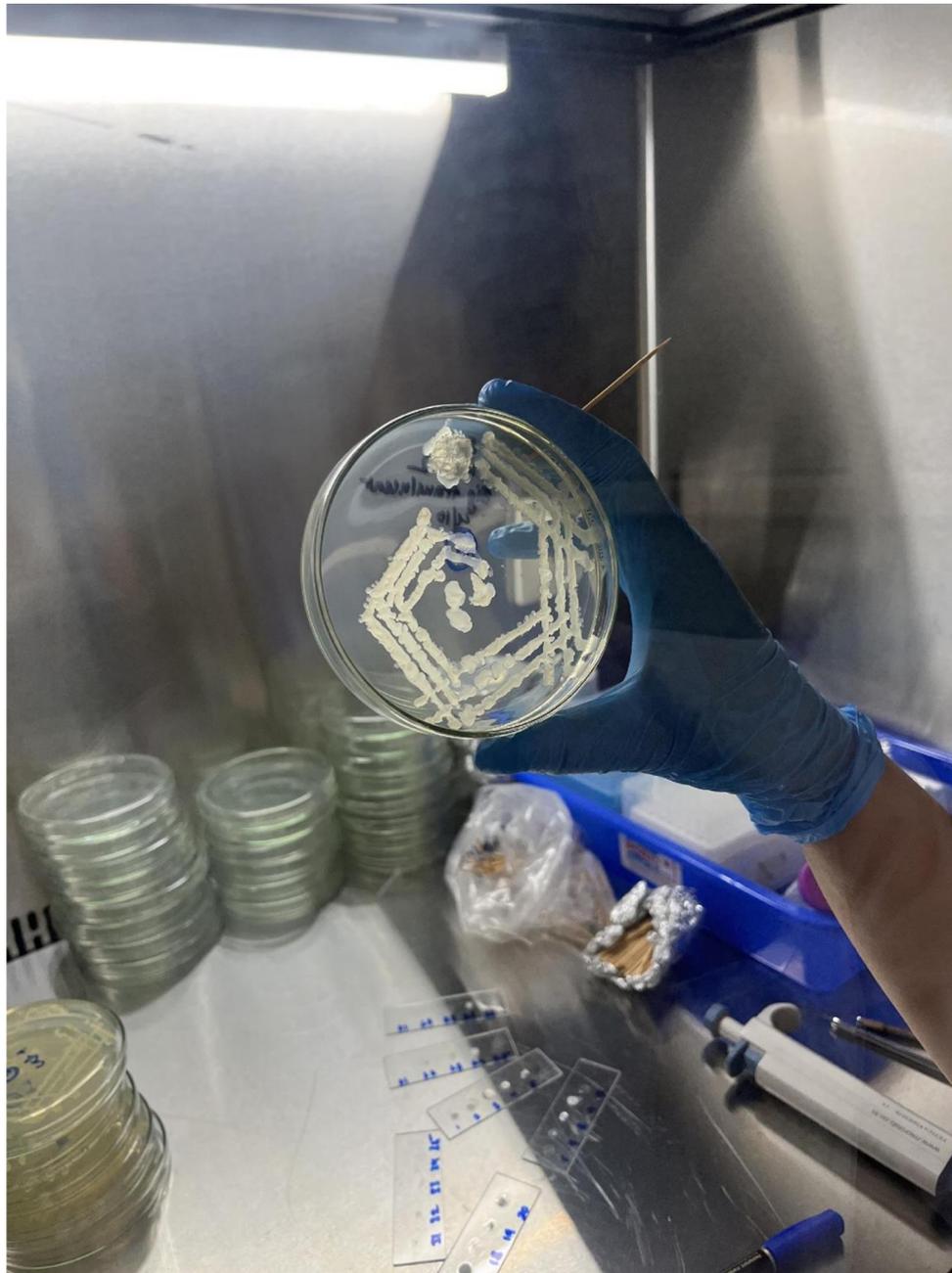
**Current position: Research Assistant, Sabitri Sciences**

**Highest Educational Attainment: Bachelors of Science, New York University Abu Dhabi**

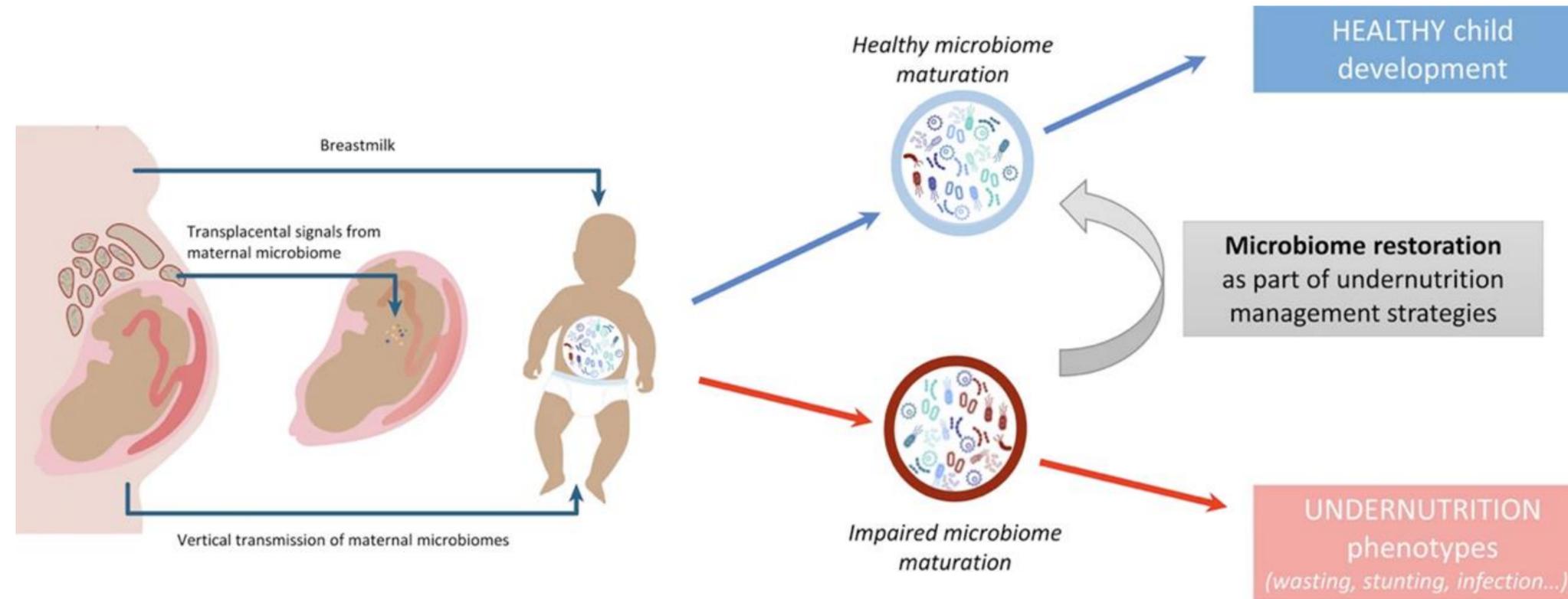
Arya Gautam is a research assistant at Sabitri Sciences, Kathmandu, Nepal. She graduated from New York University Abu Dhabi, UAE in 2023 in Bachelors of Science (BSc) majoring in Biology. Her research interest lies in investigating microbial communities in diverse ecosystems using both experimental and computational techniques. She is also passionate about science advocacy and outreach, and is engaged in initiatives to reinforce STEM education in various rural communities in Nepal. She hopes to contribute to strengthening community driven science in Nepal that integrates indigenous and local context and practices into scientific research.

## Who we are

We are a newly established biomedical research institution in Nepal, conducting **fundamental** and **translational research** in the field of **microbiology**, **population genetics**, and **public health**.



In the **Nepal Maternal and Infant Gut Microbiome Study**, we aim to understand infant gut microbiome development across lifestyles, from pregnancy to 3 years of life



Foragers



Farmers



Transitioning



Urbans

## There is a long history of genomics research in Nepal

### Ancient genomes from the Himalayas illuminate the genetic history of Tibetans and their Tibeto-Burman speaking neighbors

[Chi-Chun Liu](#), [David Witonsky](#), [Anna Gosling](#), [Ju Hyeon Lee](#), [Harald Ringbauer](#), [Richard Hagan](#), [Nisha Patel](#), [Raphaela Stahl](#), [John Novembre](#), [Mark Aldenderfer](#) ✉, [Christina Warinner](#) ✉, [Anna Di Rienzo](#) ✉ & [Choongwon Jeong](#) ✉

*Nature Communications* **13**, Article number: 1203 (2022) | [Cite this article](#)

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### Demographic History and Genetic Adaptation in the Himalayan Region Inferred from Genome-Wide SNP Genotypes of 49 Populations

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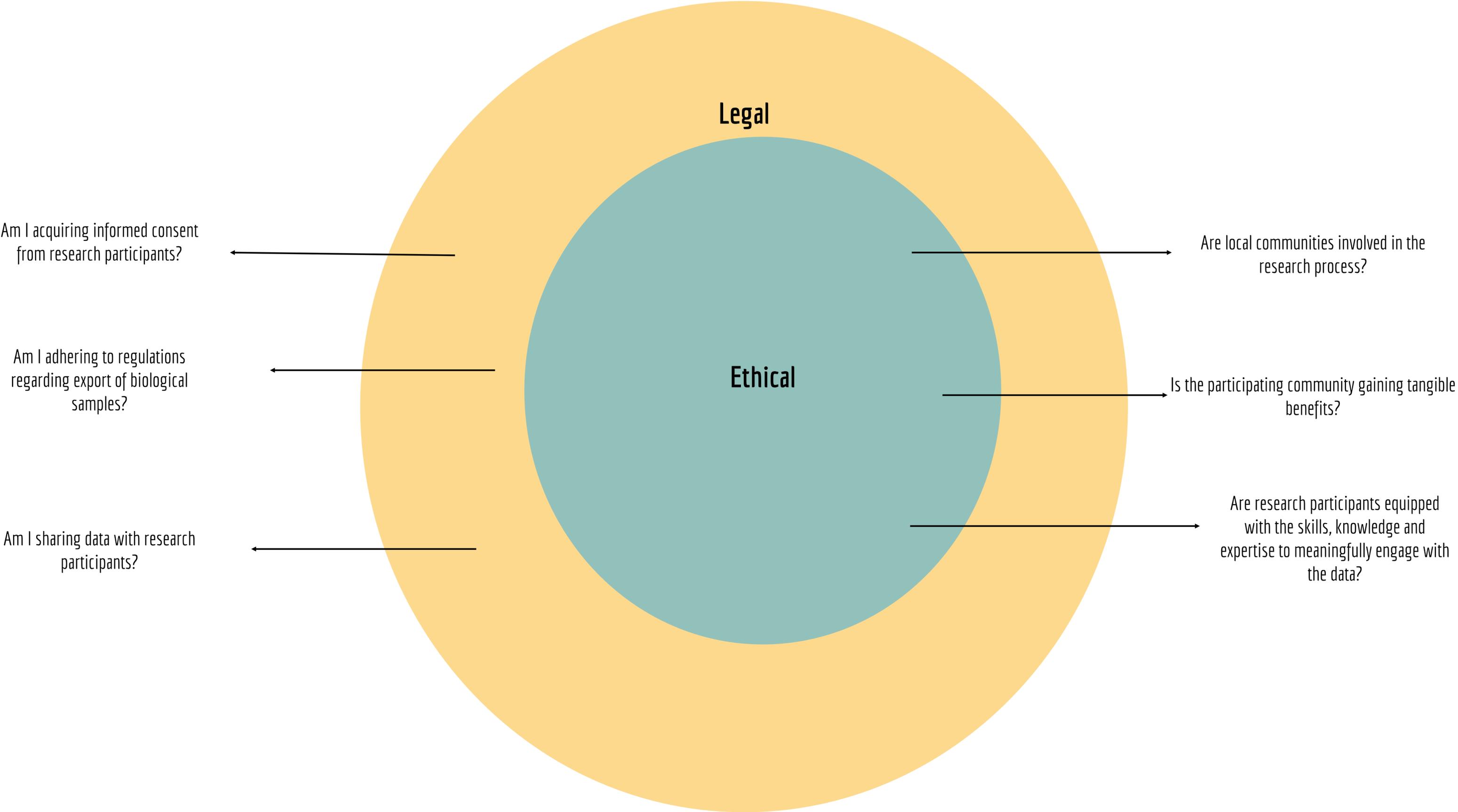
Publication History: Received January 24, 2007; Accepted February 23, 2007

DOI: [10.1086/516757](#) [Also available on ScienceDirect](#) ↗

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# What is responsible conduct of research?



**Legal**

**Ethical**

Am I acquiring informed consent from research participants?

Are local communities involved in the research process?

Am I adhering to regulations regarding export of biological samples?

Is the participating community gaining tangible benefits?

Am I sharing data with research participants?

Are research participants equipped with the skills, knowledge and expertise to meaningfully engage with the data?

# Meeting legal criteria for research



Government of Nepal  
**Nepal Health Research Council (NHRC)**  
Estd. 1991

Ref. No.: 901

6 October 2020

Dr. Aashish Jha  
Dr. Justin Sonnenburg  
Principal Investigator, Stanford University

Ref: Approval of research proposal

Dear Dr. Jha and Dr. Sonnenburg,

This is to certify that the following protocol and related documents have been granted approval by the Ethical Review Board, NHRC for implementation.

If the researcher requires transfer of the bio-samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country, only extracted and amplified samples can be taken to laboratories outside of Nepal for specific study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure and the process should be documented and informed to the NHRC timely.

स्ट्यानफोर्ड विश्वविद्यालय  
अनुसन्धान अनुपालन कार्यालय

अनुसन्धानमा भाग लिने सहमति पत्र

तपाईं एक वैज्ञानिक अनुसन्धानमा भाग लिन गईरहनुभएको छ। यस अध्ययनको शिः

क्याराक्टेराइजेशन अफ इफेक्ट अफ लाइफस्टाईल ईन गट माइक्रोबायोम अफ ः  
(Characterization of effect of lifestyles in gut microbiomes of infa

तपाईंको सहमति अगाडि अनुसन्धानकर्ताले तपाईंलाई निम्न जानकारी दिने पछि: क. प्रकृया, र अवधि; ख) प्रयोगात्मक प्रकृया; ग) अनुसन्धानबाट हुनसक्ने जोखिम, अस् तपाईंको गोपिन्यता कायम गर्ने प्रकृयाहरू। अनुसन्धानकर्ताले तपाईंलाई निम्न जान क) अनुसन्धानबाट हुने जोखिमको संभावना; ख) उपलब्ध क्षतीपुर्ती अथवा अनुसन्धा उपचारका प्रकृयाहरू; ग) तपाईंको सहभागीता बन्द हुन सक्ने परिस्थितीहरू ; घ) त लागत; ङ) अनुसन्धानमा संलग्न हुने व्यक्तिको सन्ख्या; च) तपाईंले सहभागीता बन्द कुराहरू; तथा छ) तपाईंलाई अनुसन्धानको निस्कर्ष बताउन लाग्ने समय जसले तपा: निर्णयलाई असर गर्न सक्छ।

यदी तपाईं यस अनुसन्धानमा भाग लिन सहमत हुनुहुन्छ भने अनुसन्धानकर्ताहरूले त एक हस्ताक्षर प्रितिलिपीको साथै अनुसन्धानको लिखित सारांशको एक प्रितिलिपी ि यस अनुसन्धान वा यसका प्रिक्रयाहरू, जोखिम र लाभ, वा उपचारको वैकल्पिक मा वा गुनासो भए तपाईंले यस अध्ययनका निर्देशक डा. जस्टिन सोननबर्ग सँग सोध्नस अथवा पछी फोन (६५०-७२१-१५१०) अथवा ईमेल ([jsonnenburg@stanford.edu](mailto:jsonnenburg@stanford.edu) सकिनेछ। तपाईंले डा आशिष झा सँग पनि ईमेल ([arjha@stanford.edu](mailto:arjha@stanford.edu)) वा टेल Nepali telephone number here] संपर्क गर्न सक्नुहुनेछ।

## NHRC approval



Completion Date 19-Jan-2024  
Expiration Date 19-Jan-2027  
Record ID 54941382

This is to certify that:

**Bimarsh Rana**

Has completed the following CITI Program course:

**Biomedical Research - Basic/Refresher**  
(Curriculum Group)  
**Biomedical Researchers**  
(Course Learner Group)  
**1 - Basic Course**  
(Stage)

Under requirements set by:

**New York University Abu Dhabi**

Not valid for renewal of certification through CME.



Collaborative Institutional Training Initiative

101 NE 3rd Avenue, Suite 320  
Fort Lauderdale, FL 33301 US  
[www.citiprogram.org](http://www.citiprogram.org)

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Collaborative IRB Training Initiative (CITI) trainings

## Acquiring informed consent



Sharing results with participants



Established scientists

Early career researchers (BSc, MSc, PhD students)

Adults in the community (mothers, healthcare workers)

High school students

We designed a monthly curriculum for high school students to reinforce STEM education, and trained our program officers (POs) to lead these workshops



Google Meet



Bhakundebesi, Kavre, Bagmati Pradesh

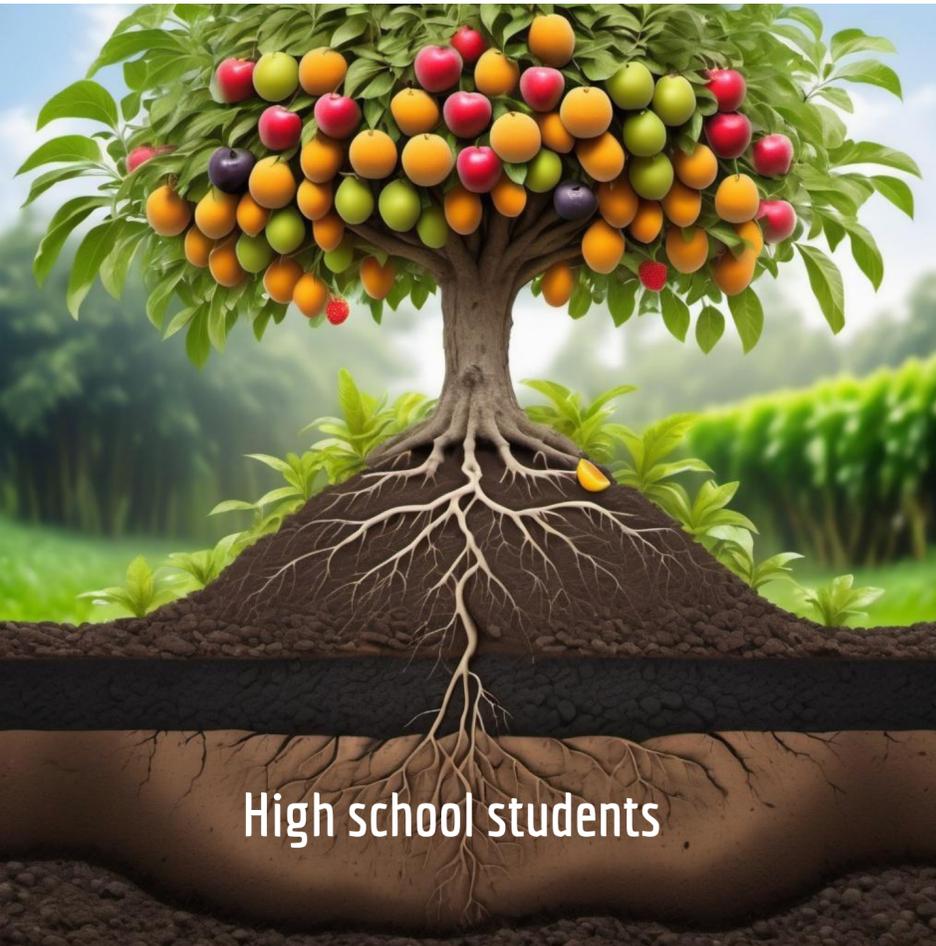


Madhuban, Parsa, Madhesh Pradesh



Bagbana, Parsa, Madhesh Pradesh

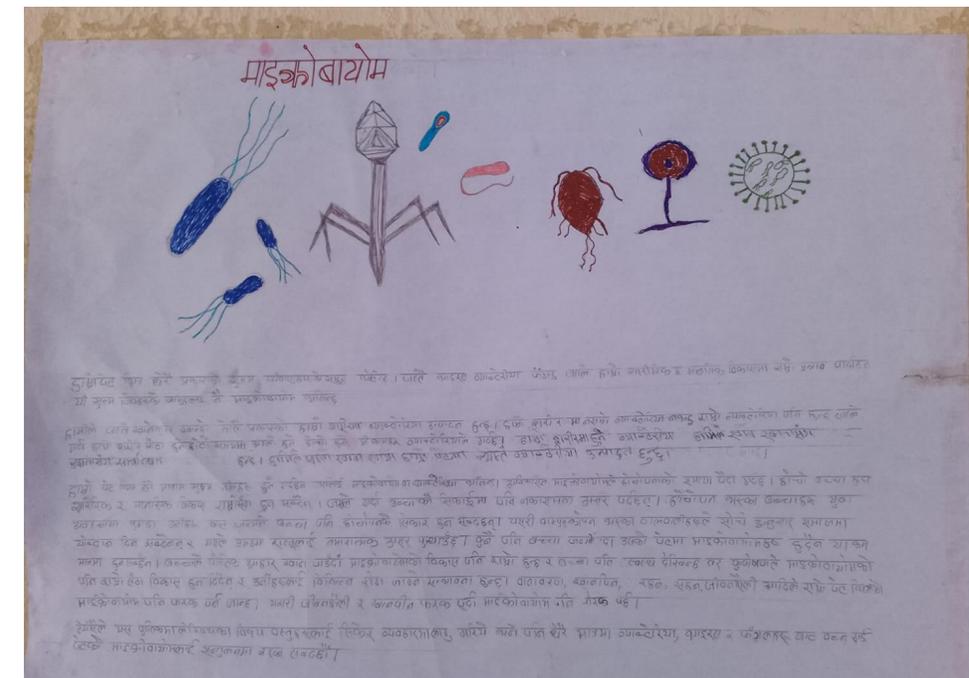
# We teach high school students about the microbiome



High school students

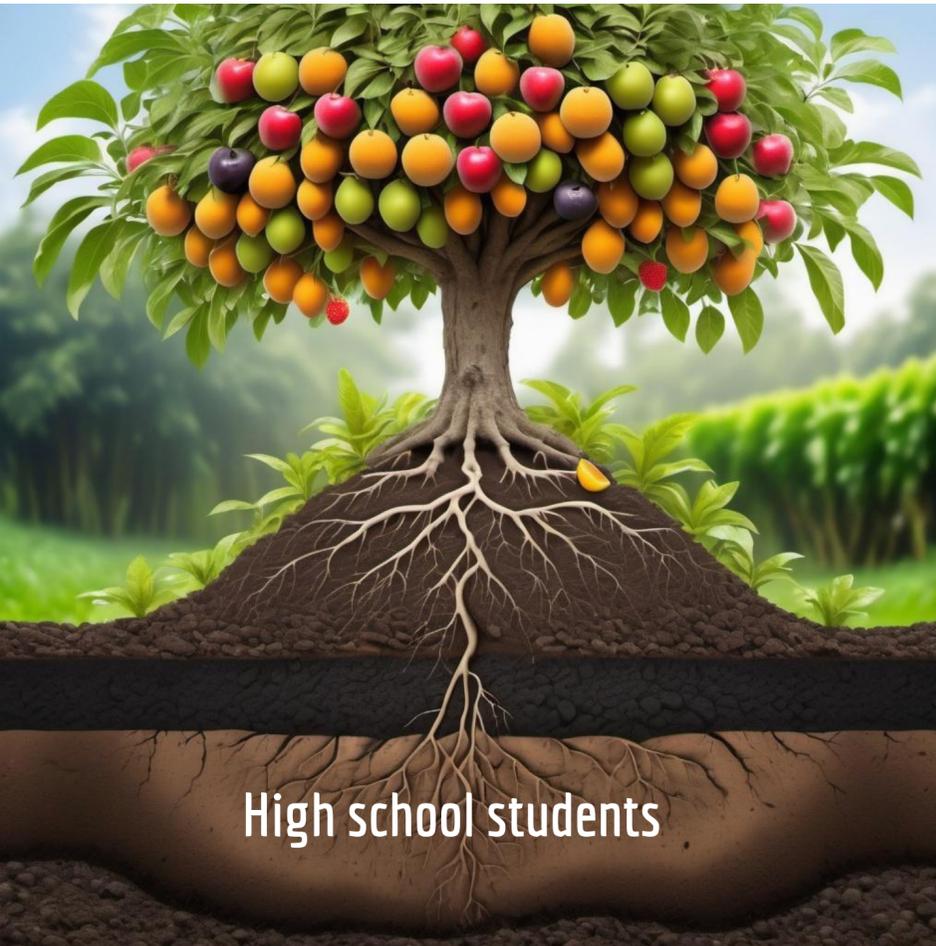


Bhakundebesi, Kavre, Bagmati Pradesh



Korak, Chitwan, Bagmati Pradesh

# Our students are emerging as confident and passionate leaders in their communities



High school students



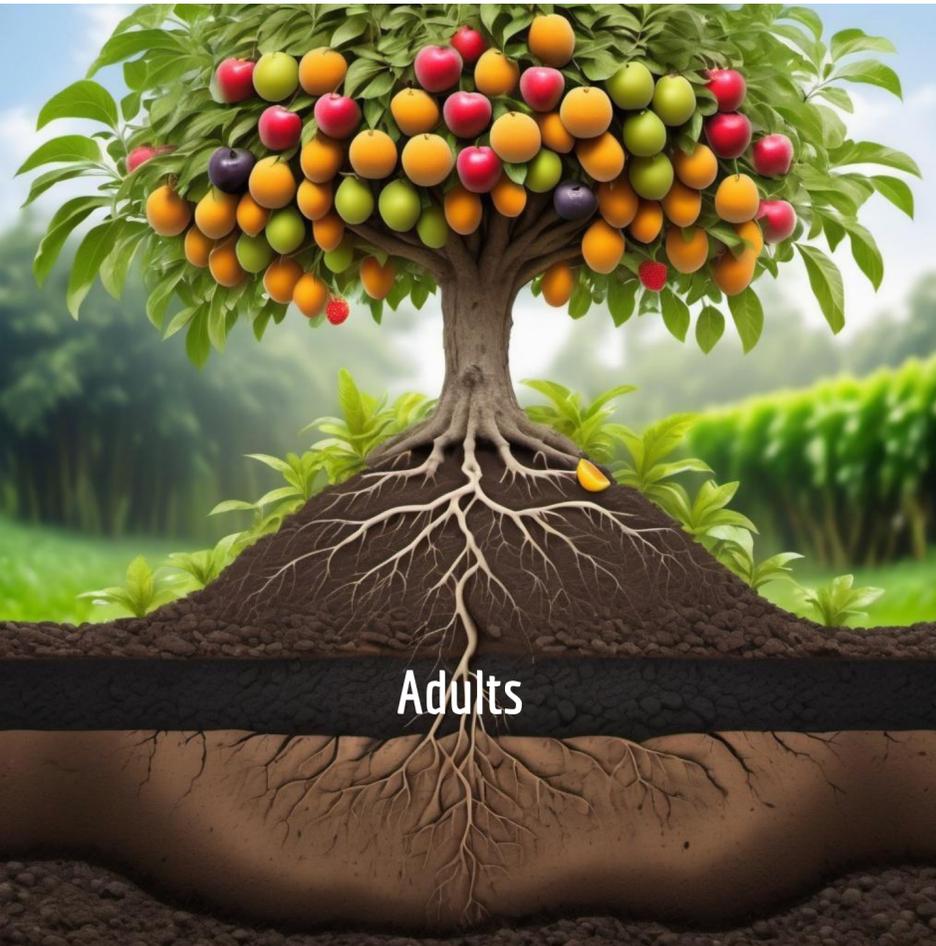
Madhuban, Parsa, Madhesh Pradesh



Bhakundebesi, Kavre, Bagmati Pradesh

Students performing a play for the community on do's and don'ts during pregnancy.

# Our POs work closely with female community healthcare volunteers (FCHVs) to identify important healthcare needs in the community



Bhakundebesi, Kavre, Bagmati Pradesh



Madhuban, Parsa, Bagmati Pradesh

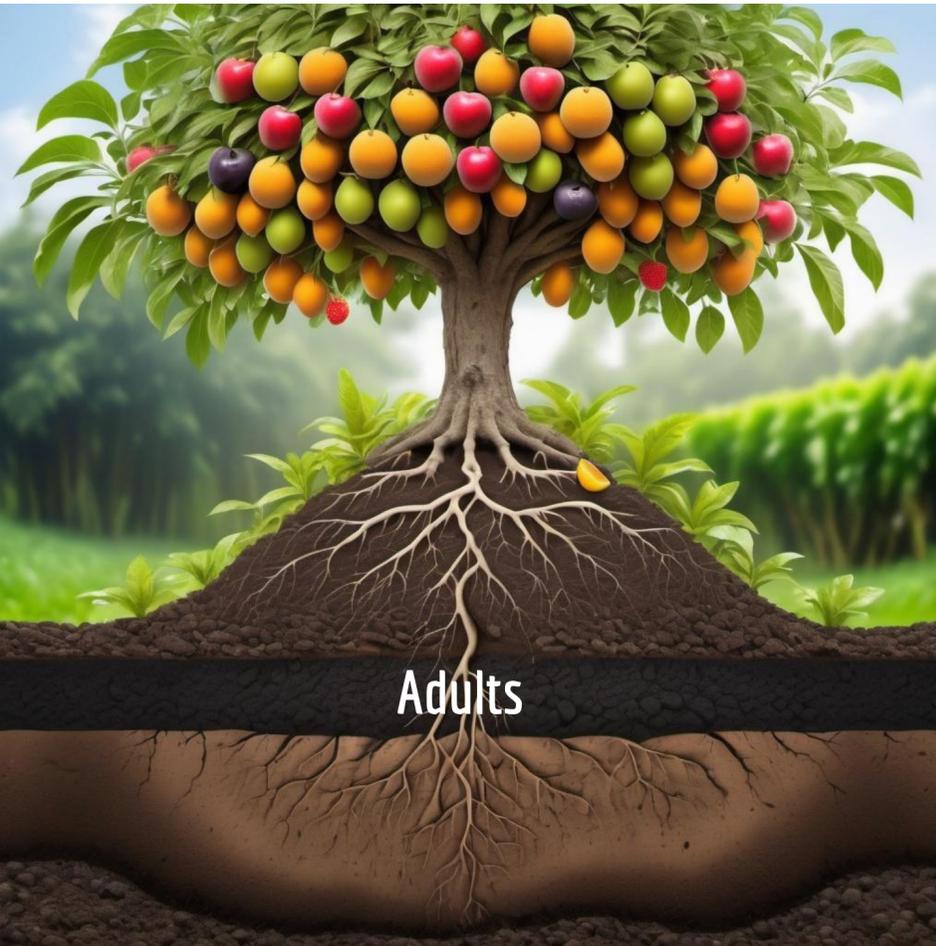


Panchkhal, Kavre, Bagmati Pradesh



Korak, Chitwan, Bagmati Pradesh

# Our POs attend monthly mothers' meetings to deliver informative sessions on maternal, reproductive and neonatal health



Bagbana, Parsa, Madhesh Pradesh



Panchkhal, Kavre, Bagmati Pradesh



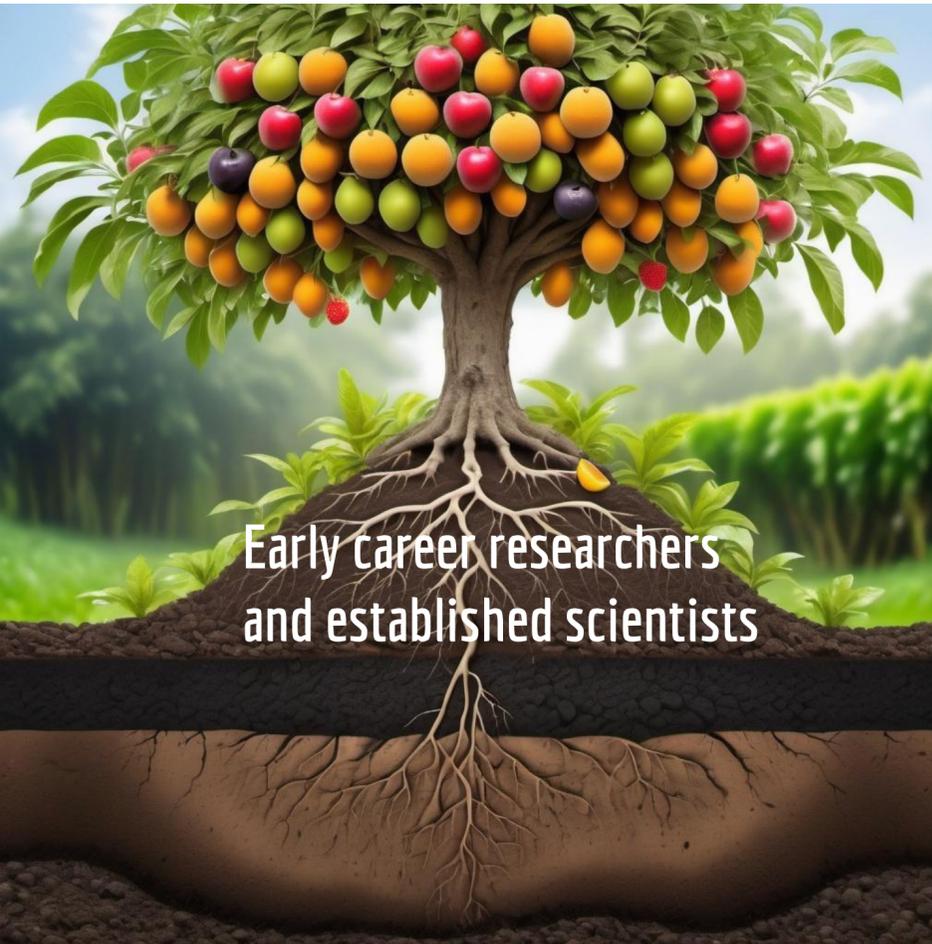
Korak, Chitwan, Bagmati Pradesh

We provided a 8-week long weekly workshop series to train BSc and Msc graduates in Nepal on statistics and bioinformatics, tailored for microbiome data analysis in R



Kathmandu, Bagmati Pradesh

We are providing opportunities for cutting-edge scientific research to early career researchers and established scientists in Nepal



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### Ecological factors that drive microbial communities in culturally diverse fermented foods

Arya Gautam, Rahgavi Poopalarajah, Anique R. Ahmed, Bimarsh N. Rana, Tsedenia W. Denekew, Nakyeong Ahn, Lina Utenova, Yadu S. Kunwar, Nitin N. Bhandari, Aashish R. Jha

doi: <https://doi.org/10.1101/2024.08.20.608727>

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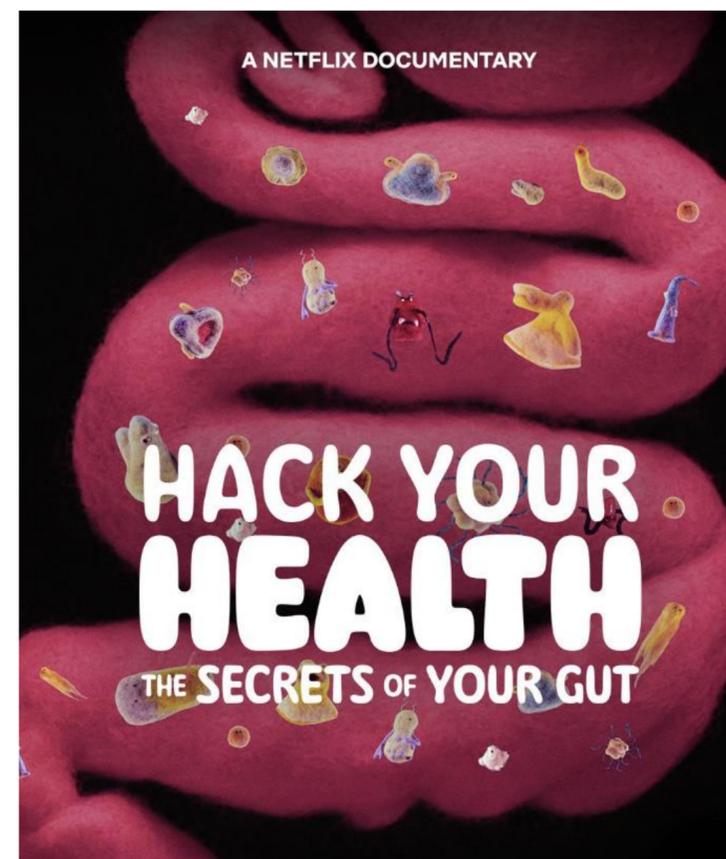
Abstract

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## Our vision:

Provide opportunities to local scientists to participate in and/or lead research

Reinforce STEM education to inspire future scientists from indigenous communities

Communicate our findings with sampling communities

Tangible benefits to research participants

## Acknowledgement

### **Sabitri Sciences**

Srijana Shakya, PhD

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Aashish Gyawali

Kusha Gurung

Hiukala Kunwar

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Erica Sonnenburg

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Sailendharan Sudakaran

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Anique Ahmad

Rahgavi Poopalarajah

Yoshina Gautam

### **Bill and Melinda Gates Foundation**

### **Center for Genomics and Systems Biology, NYUAD**

Nizar Drou

Muhammad Arshad

### **Integrated Rural Health Development Center**

Yadu Sudan Kunwar

Bimarsh Rana

Nitin N. Bhandari

Shanti Chepang

Bhagwati Praja

Kalpana Pandey

Kanchan Khatiwada

Rita Koju

Rajni Rai

Kawita Sah

Albina Poudel