# DATA OWNERSHIP AND KNOWLEDGE IN TRADITIONAL AND ALTERNATIVE MEDICINE RESEARCH: CASE OF BATWA INDIGENOUS PEOPLE AND LOCAL COMMUNITIES IN KISORO DISTRICT, UGANDA

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## Introduction

 Traditional and Alternative Medicine (TAM) relies on Indigenous Knowledge Systems (IKS)

 These community held practices contributes to biodiversity conservation and primary health care for people and animals



## Issues at hand with TAM

- In research settings in TAM, issues of who owns data, who controls knowledge, and who benefits have recently become critical.
  - Data ownership refers to who holds the rights/control over data collected e.g., traditional knowledge records and biological samples.
  - In documentation of traditional medicine knowledge Who collects? How is it stored? Who benefits from research commercialization of products
- Often TAM information has been obtained from THPs without adequate recognition or compensation, and ownership, access, and benefit-sharing

#### Nagoya Protocol on Access to Genetic Resources

- The Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits arising from their utilization was adopted by contracting parties at the conference of parties in 2010 in Nagoya, Japan
- CSIR of South Africa helped the San community negotiate the enefit sharing agreement relating to use of
  - Hoodia gordonii (Family: Apocynaceae) -an appetite suppressant a drug for weight loss management and anti-obesity effect
  - Sceletium tortuosum plant (Family Mesembryathemaceae) developed as a drug -Zembrin for treatment of anxiety, stress, and depression
  - Aspalathus linearis (Family Fabaceae) called Rooibos plant



#### Batwa Indigenous people and Local communities (IPLCs)

- The Batwa are an indigenous people in southwestern Uganda - lived in forests Bwindi Impenetrable National Park and Mgahinga Gorilla National Park)
- In 1992, these forest were gazetted for conservation and Batwa were pushed out- now marginalized and landless
- The traditional medicine knowledge they poses is very important
- This pilot is bioprospecting Batwa Indigenous people and local communities for development of herbal products



#### Ethical Engagement of the Batwa IPLCs in Research

- Study protocol was cleared with Makerere School of Health Science REC & UNCST
  - Consent was obtained from individuals Batwa IPLCs
  - Local language (Rukiga & umufumbira) were used in communications
  - Batwa IPLCs are recognized as rights-holders of this knowledge.
  - Batwa are co-creators of the products and feedback has to be given to them regularly



COLLEGE OF HEALTH SCIENCES SCHOOL OF HEALTH SCIENCES OFFICE OF THE DEAN

29/09/2023

To: Francis Omujal

Type: Initial Review

Re: MAKSHSREC-2023-588: DOCUMENTATION OF BATWA INDIGENOUS PEOPLE AND LOCAL COMMUNITIES' KNOWLEDGE FOR BIO-PROSPECTING FOR THERAPEUTICS PRODUCTS



# Prior Informed Consent with Batwa IPLCs

- National ABS regulation has been used to guide the Batwa IPLCs on Prior Informed Consentingaccessing any information related TM and biological resources based on benefit-sharing agreements
- Traditional knowledge remains the intellectual property of the Batwa.
  - Including formula & preparation methods
- NCRI as research institution holds the custodial rights to the dataset of Batwa IPLCs — storage and regulated access





# Community protocols

. We can write to UWA asi trees./plants. - We can ask our friends on availability - We can ask from pocket fore RESOURCES ACCESS community pagagement (a) Malaria ownerd - Holding community meetings.
- Senstise the community about product - Omubilizi/Umubilizi. - Omufurura. - Form commeet/Exuction - EKIZINYa MUriro. rensponsible for making the proi - · Omutagara. - Discus the benefit and challe - . Omuhara Vumba. Grant of vathorisation b. Worms/Enjoka/Injoka - We Staft with LCI chairman - Iginchunchu - UWA · Umuho Ko 1 mara.

Community Protocols define how Batwa knowledge and resources can be accessed, used, and shared

- Hold community meeting
- Sensitize the community
- Discuss benefits

- COMMUNITY PROTOCOL ON ACCESS AND BENEFIT SHARING OF GENETIC RESOURCES OF THE BATWA IPLC IN KIGEZI SUB-REGION OF UGANDA
- Made under the National Environment Act, Cap. 181 and the National Environment (Access to Genetic Resources and Benefit Sharing) Regulations, 2005)

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# Engagement with Kisoro Local Government District leader and UOBDU





**UOBDU** 

District leaders (RDC, LCV, CAO, SDEO etc

# **Engagement with Batwa IPLCs**



# Data collection

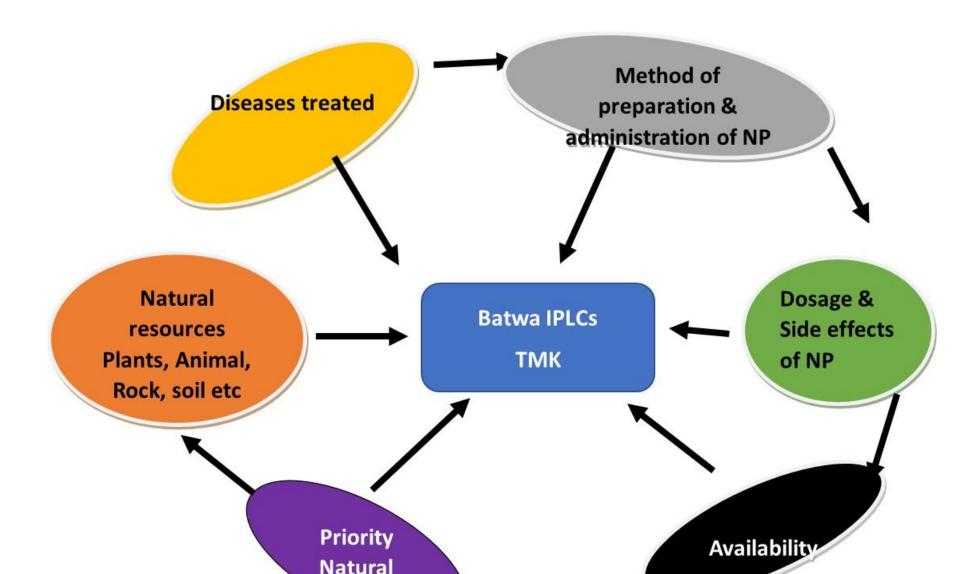






Ethnobotanical survey Focus group discussion Field Observations

# Type of data collected



#### Who owns Batwa IPLCs traditional medicine knowledge?

Batwa IPLC PIC Set conditions for Collect, analyze, (Owners of store & act as access and storage of TM Researcher-Trad, Med. custodians data and resources **NCRI Knowledge**) **Traditional** medicine Knowledge **Government-**NEMA, Kisoro **District Local** Research governmet **Funders- GEF** 

## Accessing Biological resource from Batwa IPLCs









# Community engagement on products





Biopr



# Conclusion

- While Batwa IPLC own traditional medicine knowledge while NCRI remains as custodian of data under legal and ethical agreements as per ABS regulation
- There is meaningful participation of Batwa IPLCs, and fair benefitsharing arrangement have been agreed upon for their empowerment and cultural sustainability

# Acknowledgement









# THANK YOU