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*Ready for the Future*



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## **Participatory action research: the use of photovoice in a fragile, conflict affected and marginalised community setting**



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# Background; community engagement

- ensure individual and communities curate, own and are engaged in their stories are truly engaged in the collection of data, setting of priorities, review of services
- objectives often set by researchers / projects / donors
- power differentials and dynamics
- systems of communication & data engagement
- cultural issues
- crucial part of social justice



<https://www.thewhpc.org/about-us-3/direct-stakeholders-project>

# Uganda; Integration in a protracted crisis

*‘These refugees, we are the same people. We have the same future we have the same destiny. **When your house is on fire where do you run, you run to your neighbours.** Whenever they are here they are like us and if they run for help they must get it’. Local government official*

*Leng M, Downing J, Purewal G, et al. Evaluation of the integration of palliative care in a fragile setting amongst host and refugee communities: Using consecutive rapid participatory appraisals. Palliative Medicine. 2024;38(8):818-829. doi:10.1177/02692163241269129*

<https://eapcnet.wordpress.com/2024/10/08/when-your-house-is-on-fire-where-do-you-run-you-run-to-your-neighbours/>

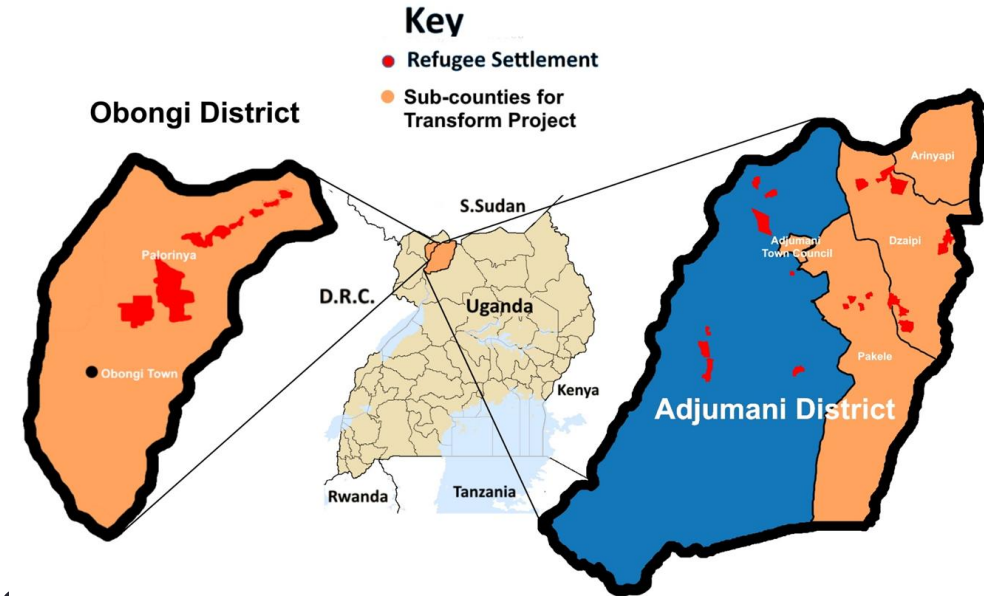




# Uganda; Integration in a protracted crisis

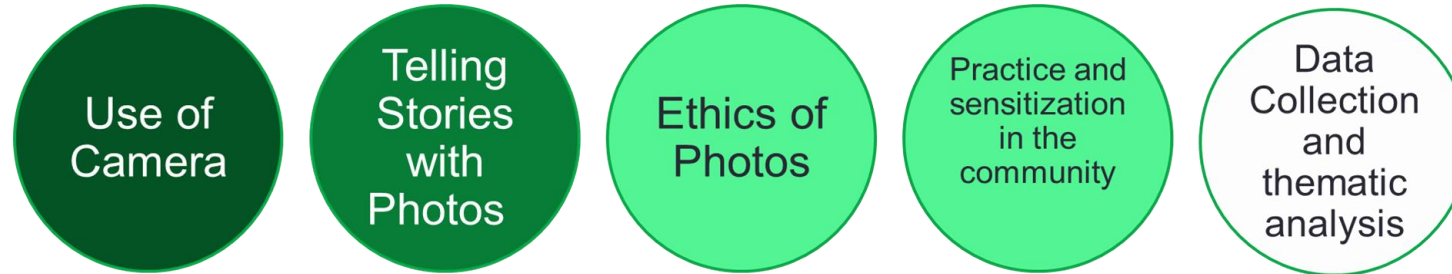
## Integrate project; Adjumani District 2018-2019

- *Mixed methods study in refugee population*
  - *Step One: Rapid Participatory Appraisal (69 interviews)*
  - *Step Two: Training and mentorship (300 HCW, VHT and FC)*
  - *Step Three: Needs assessment*
- **Transform project 2020-2022**
  - *Steps above in Obongi and Adjumani host and refugee populations*
  - *Addition of **mentorship** training*
  - ***Novel evaluation methods including Photovoice***



# Community generated data; photovoice

- Process



- Analysis

- qualitative critical dialogue using the SHOWED criteria focusing on 2 selected pictures
- *What do you See here? What is really Happening here? How does this relate to Our lives? Why does this situation, concern, or strength exist? What can we do about it?*

- Results

- 32 interviews recorded and analysed by 2 experienced researchers; then discussed with the VHT mentors and health leaders.

# Results; thematic analysis

*4 key themes and associated subthemes;*

- **living positively**, community contribution, self-management, living not dying, hope, health literacy



***‘She is having strength and is taking her drugs well, and in her family are other people who support her, they motivate her and help her take care of the goats, she knows that people are always on her side’***

# Results; thematic analysis

- **challenges faced;** access to healthcare, unrelieved symptoms, caregiver burden, health literacy, social issues



***‘when you see this person there is fear..when you go to this home it is not healthy with no one to wash her clothes...people cannot even talk and her condition is very low’***



# Results; thematic analysis

- **VHT role;** identification, advocate, holistic care, supporting health access, opinion leaders



Dominic Imaku (5)

***'We are now guided to guide people; we are able to guide these clients such as positive ways to manage'  
Being trained and having the heart to help her I can show her no much worry so it comforts her.'***

# Results; thematic analysis

- **messages for health leaders;** collaborative working, health literacy, access to healthcare, social welfare, research



***‘Give the health care workers a time to visit these people in their own home...even if they are to die they have that hope that they are loved by the government.’***

# Conclusion

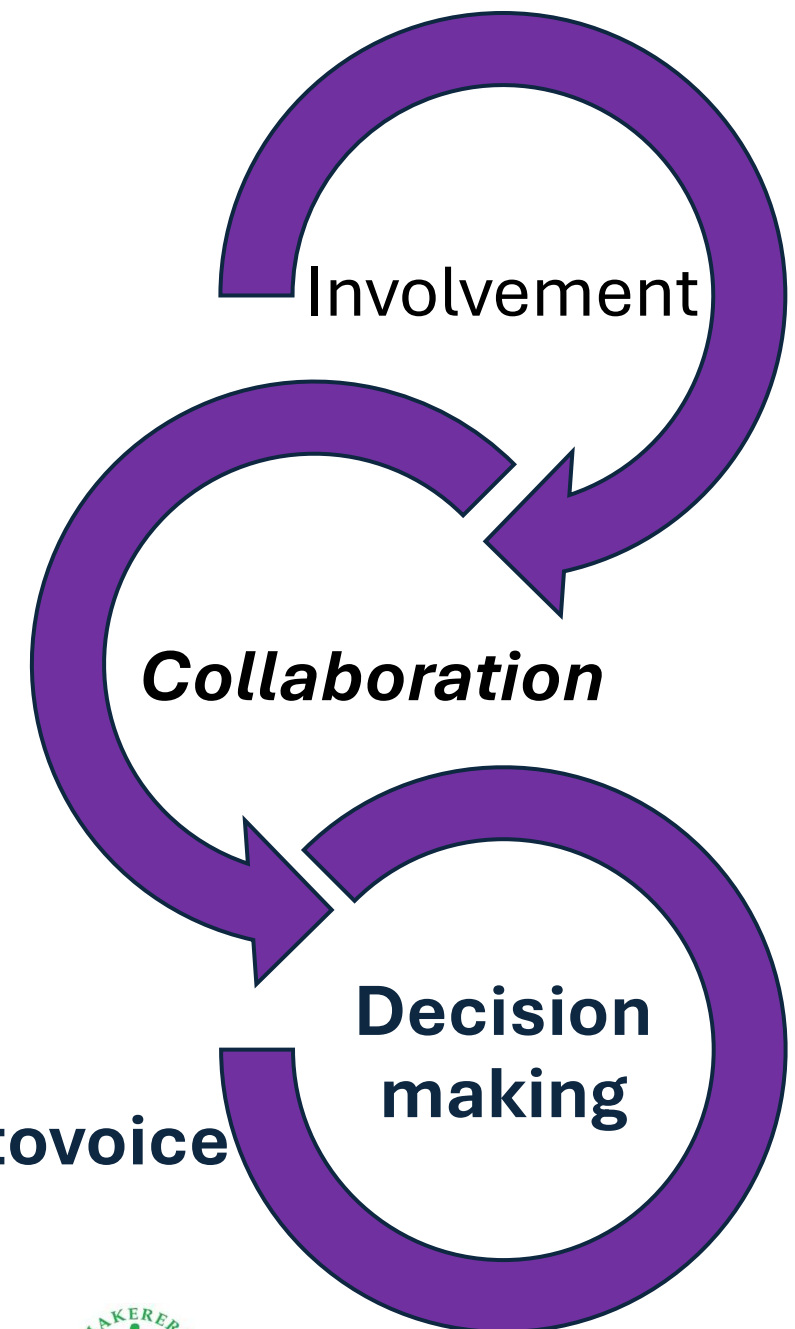
- Photovoice is a feasible and acceptable tool for participatory action research in remote settings enabling in-depth understanding of life experiences.
- Pre-existing relationships and training were important for mutual trust as was leveraging local partnerships.
- Further work is needed to extend the use of this tool.





# Community participation

- Initial situational analysis
- *Training*
- *Identification of palliative care need*
- *Palliative care interventions*
- *Repeat and extend situational analysis*
- **Review and redesign**
- **Mentorship**
- **Community participation research; Photovoice**





# Thank You

