

# Developing participatory inclusive methods for qualitative research with adolescents with disabilities in Nepal: as part of PARDAN

(Participatory Action Research with Adolescents with Disabilities in Nepal)

## Introduction

Adolescents with disabilities are often not included in research because of concerns about difficulties in access, communication, protection and ethics<sup>1</sup>. However, it is important to hear directly from them about their lives and their participation can help researchers to design inclusive methods and overcome some of these concerns.

We developed and used participatory inclusive tools and methods in research with adolescents with disabilities about the COVID-19 pandemic to inform an inclusive response and improve understanding of how to conduct research with adolescents with disabilities. We discuss what worked best and the lessons learnt.



## Participants

Twelve adolescents with moderate to severe disabilities (five girls, seven boys) between the ages of 11 and 17 years old. Seven had physical impairments (three had multiple impairments), two had visual

impairments, three had speaking impairments, two had hearing impairments. Our participants lived in the hills of rural Nepal (Udaypur and Myagdi Districts).

## Preparation

- We located adolescents through local organisations of persons with disabilities.
- We developed 'easy read' consent forms and took consent from caregivers and participants.
- We used pictures to screen for COVID-19 symptoms.
- We asked the caregiver and the participant about what would make them comfortable and what specific needs they had.
- We asked the participant if they wanted a sibling or friend to support them during the interview.

## Collecting data

We used a flexible topic guide to discuss their experience of the COVID-19 pandemic. We used a mix of open and closed questions, vignettes (fictional stories) and narrative (participant stories).

Interactive tools helped the discussion: pictures, a family of dolls in local dress, illustrated story sequences, an emotions chart (where children could put a thumb print to indicate an emotion), a large soft dice with buttons (to make answering questions into

a game), numbered pencils (to structure stories), coloured pencils and paper.

Using observation and discussion we developed an understanding of:

1. Which tools worked best with participants with different impairment types
2. Which tools were preferred by participants
3. How to improve the tools and methods

Table 1 illustrates which tools worked best for participants with different impairments.

Tool	Purpose	Worked well	Worked less well
Numbered sticks	To help structure telling their own story	Visually impaired	Intellectually impaired
	To help organise ideas.	Hearing impaired	
Family of dolls	To help think and talk different people. Playful, colourful, and tactile.	Nearly everyone	Older children less interested
Dice with questions	To make answering questions into a game.	Everyone	
	Something active, colourful and tactile.		
	Possibility for participants to read questions themselves.		
Sequence of picture cards and story	To provide a visual version of the story.	Physically impaired	Intellectually impaired
	To help focus, comprehension, and discussion.	Hearing impaired	Visually impaired
Picture cards of organisations and situations	To help participant understand questions and think of possible answers.	Physically impaired	Visually impaired
		Hearing impaired	
		Intellectually impaired	
Pictures of faces with emotions	To help with thinking about and expressing feelings.	Physically impaired	Visually impaired
		Hearing impaired	
		Intellectually impaired	
Emotion chart (using thumb print)	To help with thinking about and expressing feelings. Something active.	Physically impaired	Intellectually impaired
		Hearing impaired	Visually impaired

## Key lessons learned

### Flexibility

Approaching a participant with several tools meant that the researcher could choose which ones were suitable and could change their approach as necessary. For example, younger adolescents found the dolls more interesting than older adolescents. Preferences depended on the age of the participant, their skills, interests, and support needs. Researchers took the interview at the pace of the participant enabling them to draw or play while taking a break from the questions.



## Enabling choice and participation

Participants chose which tools they used and within the tools there was choice – for example the stories were about girls and boys with different impairments and of different ages. Participants chose which story they

wanted to discuss. Emotions charts enabled participants to physically mark their feelings on paper. Making the research fun was important, especially as being interviewed was usually a new experience.

## Robust and local tools

We used tools which did not require electricity or an internet connection, and we used a Nepali artist to produce simple, locally appropriate images. Adolescents with intellectual impairments can be

distracted if pictures have too much detail. It was important to develop tools that were designed to be touched, played with, transported, and used.



## Focus tools and movement

Adolescents can feel uncomfortable communicating with adults and may need to move around. To make participants comfortable we talked about things that were important to them, we tried to emulate an elder sibling (instead of a researcher, a teacher, or other authority figure) and used tools to keep their interest.

Participants enjoyed having something to focus on, to hold or to touch. Answering questions was sometimes easier when they did not have to look directly at the researcher. The dice was used to make data collection into a game, but it was also used as a focus object to feel and throw.

## Ethics

Safeguarding protocols, consent procedures, and accountability mechanisms were implemented. We provided remuneration for participants. Participants indicated when they were bored or tired and could take

a break or stop completely. Concerns about ethics can be overcome with careful planning to ensure safe inclusion of adolescents with disabilities in research.

## Time

The relatively small number of participants meant that we could take time to visit remote locations, and visit households several times to explain the research,

to get to know the family, to understand and adapt to the needs and interests of the participants and to incorporate breaks.

## Training and support

Researchers had limited experience with adolescents with severe disabilities and they received 4 days training. We sought to develop researchers' confidence to be flexible and participant led as much as possible. Using role play and pilot testing with adolescents with disabilities was useful during training. Providing written and verbal feedback while researchers were working remotely was also important.



## Conclusion

We collected interesting data from adolescents with disabilities about their experiences of COVID-19, using tools that enabled their participation. Our example can

encourage others to undertake inclusive research with adolescents with disabilities to inform responses to humanitarian emergencies and the COVID-19 pandemic.

## Reference

- [1] Thompson S, Cannon M, Wickenden M, et al. Exploring Critical Issues in the Ethical Involvement of Children with Disabilities in Evidence Generation and Use, 2020.

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