

Patient Group Experience

21-02-2005



Ground Rules for a Teen Focus Group

Speaking Rules

- **Respect and Active Listening** – Everyone should listen without interrupting and respect each other's opinions, even if they disagree.
- **Fair Speaking Time** – Everyone gets a chance to talk. If you've spoken a lot, let others have a turn.
- **Speak Freely, No Judgment** – This is a safe space. You can share your thoughts without fear of being judged.
- **Keep It Short and Clear** – Try to be brief so everyone has time to express themselves.
- **It's a Discussion, Not a Debate** – We're here to share experiences, not to convince others.



Ground Rules for a Teen Focus Group

Confidentiality Rules

- **What's Said Here, Stays Here** – What we talk about in this group should not be shared outside.
- **Anonymity is Key** – If any thoughts from this session are shared later (in a report, for example), they will remain anonymous.
- **Recording for Content Analysis Only** – The session will be recorded, but only for content analysis. The recordings will be deleted once the project is over.
- **Session Summaries for Accuracy** – At the end of each session, we will provide you with a summary of the key points discussed to ensure we understood you correctly.
- **Respect Personal Information** – Don't share personal details about others outside this group.



Today's two main topics to go over together are:

- **Checking out some results from the survey we sent out** (5 min)
- **Hearing your thoughts and experiences** – This is your space to talk about what matters to you (45 min)

First, thank you for participating in the short survey

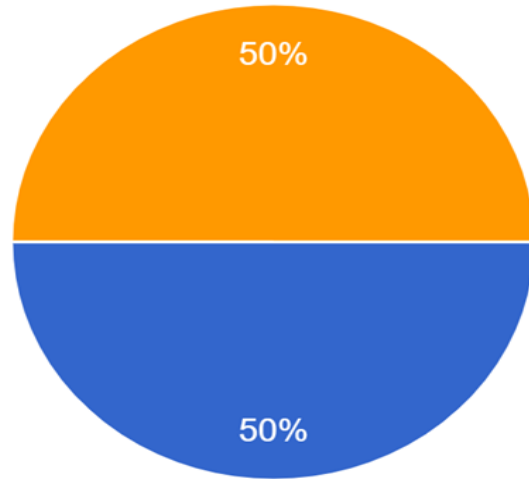


The link to the questionnaire remains open; those who haven't had time to respond can still do so



Are there any aspects of the project you would like to explore further or topics you would like to discuss in future meetings ?

2 réponses

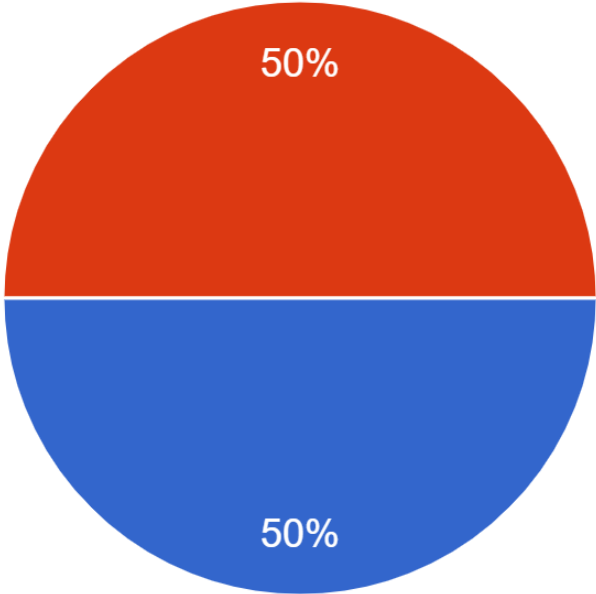


- Yes, several
- Yes, one or two
- No, everything seems fine to me

Topic = Mentally effect about disease

Did you experience any difficulties in expressing yourself ?

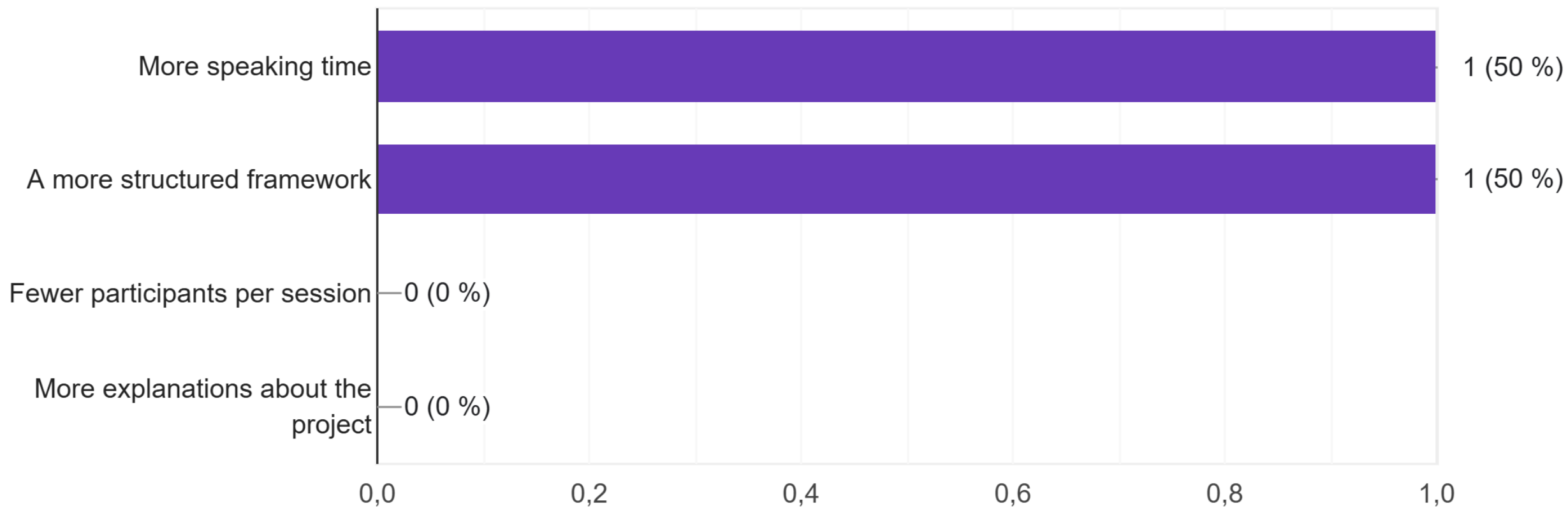
2 réponses



- No, no difficulty at all
- Yes, a little (shyness, lack of time, etc.)
- Yes, a lot of difficulty

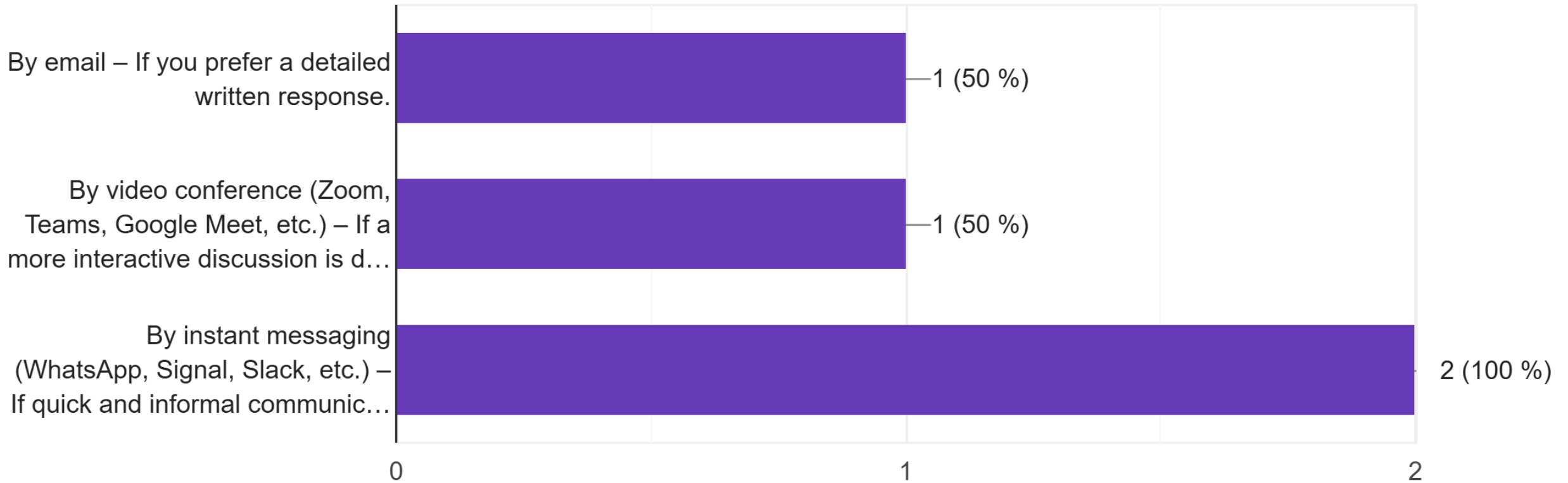
What improvements would you suggest for future sessions ?

2 réponses



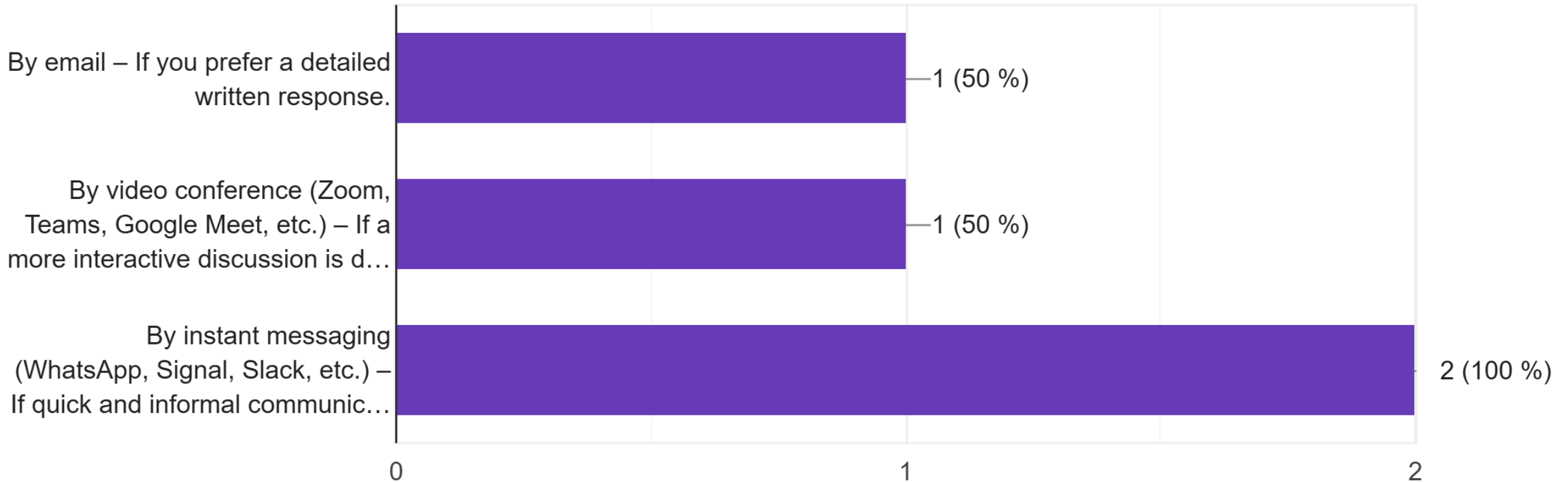
"Which mode of communication do you think is the most effective?"

2 réponses



"Which mode of communication do you think is the most effective?"

2 réponses



Regarding the communication method, we could propose creating a group to share the questionnaires, feedback from the online sessions, and any useful information related to the project. Would this be more convenient for you than email?

Today's session will be dedicated to your feedback and experience

We have prepared a short interview guide that you should have received last week

What motivated you to participate in this project: What made you want to get involved?

Your experience as a person living with a rare disease:

- How have you experienced your medical care?
- Were there any particularly significant moments, whether positive or challenging?
- If you could send a message to healthcare professionals or other young people in the same situation, what would you say?

The goal is to highlight your experiences and feelings to help improve the understanding of patients' needs and enhance their care in the future



Who would like to share their experience first?

