

**Patient  
Insights on  
Co-Design in  
Clinical  
Trials**



Joining You  
Today



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Senior Vice President, Rare Patient Voice



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Family Caregiver and  
Participant in Clinical Trial Co-  
Design



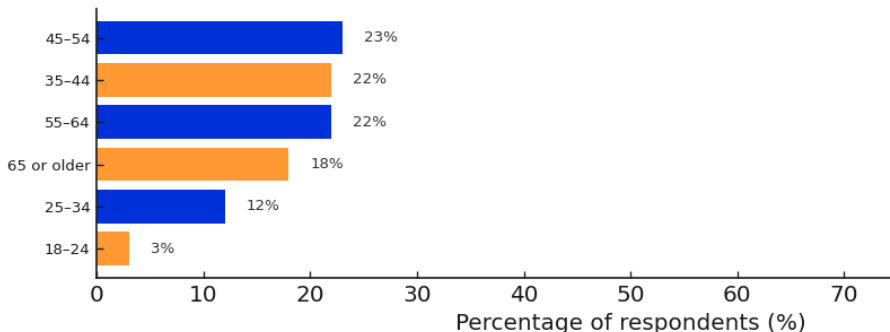
# ABOUT RARE PATIENT VOICE

Rare Patient Voice (RPV) connects patients and family caregivers with research opportunities. Founded in 2013, the RPV community now includes 180k+ patients and family caregivers across 1,500+ diseases and conditions in 9 countries.

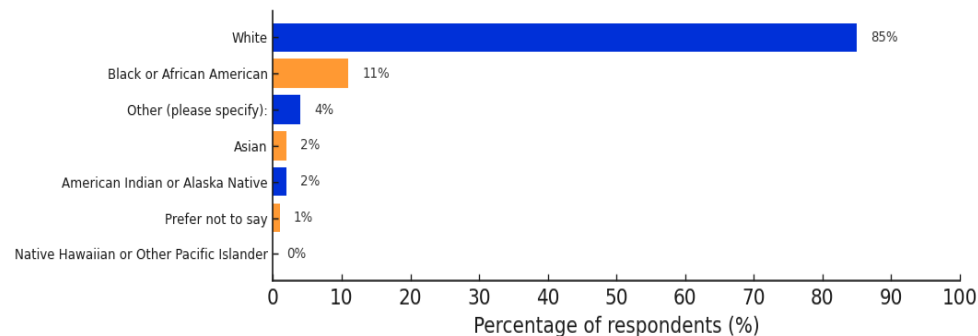


# 2025 Rare Patient Voice Co-Design Survey

Q17. What is your age?



Q19. What is your race? (Select all that apply)



- 347 - less than \$25000
- 404 - \$25000-\$49999
- 635 - \$50000-\$99999
- 460- \$100000 +

Income



- 1697 women
- 414 men
- 37 nonbinary/third gender
- 2 prefer not to answer

Gender



- 147 Hispanic
- 2000 non-Hispanic

Ethnicity



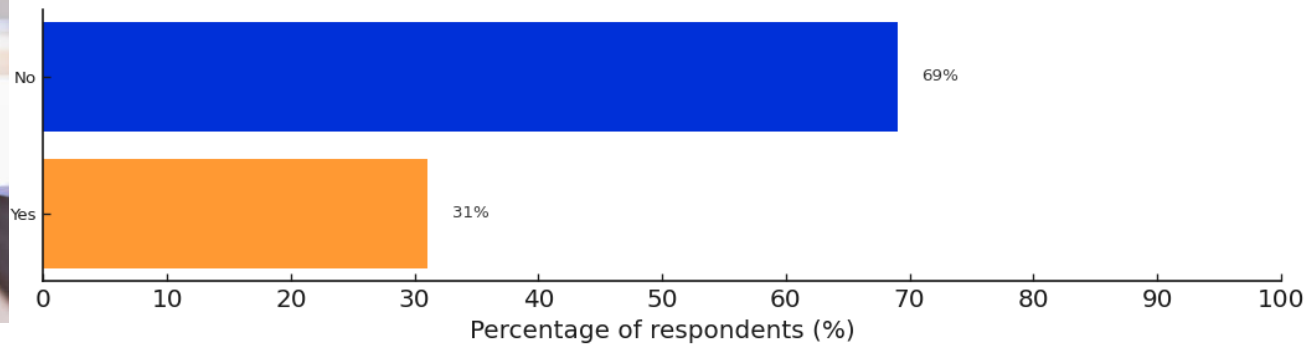
**2156 patients in the United States were asked for thoughts on participating in co-design for clinical trials**



# Awareness of Patient Involvement in Clinical Trial Co-Design

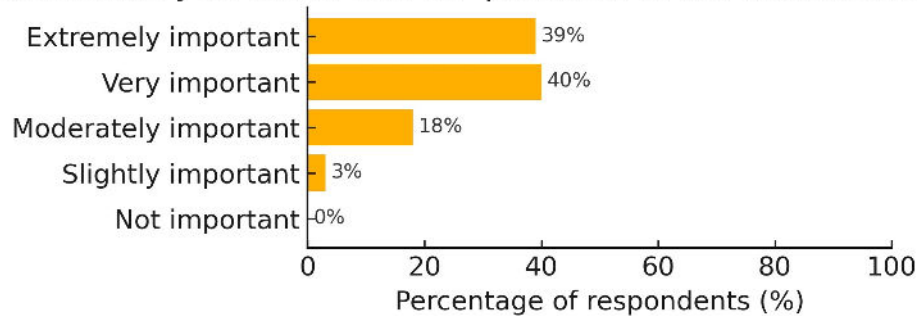


Q1. Before today, were you aware that patients can be involved in designing clinical trials?



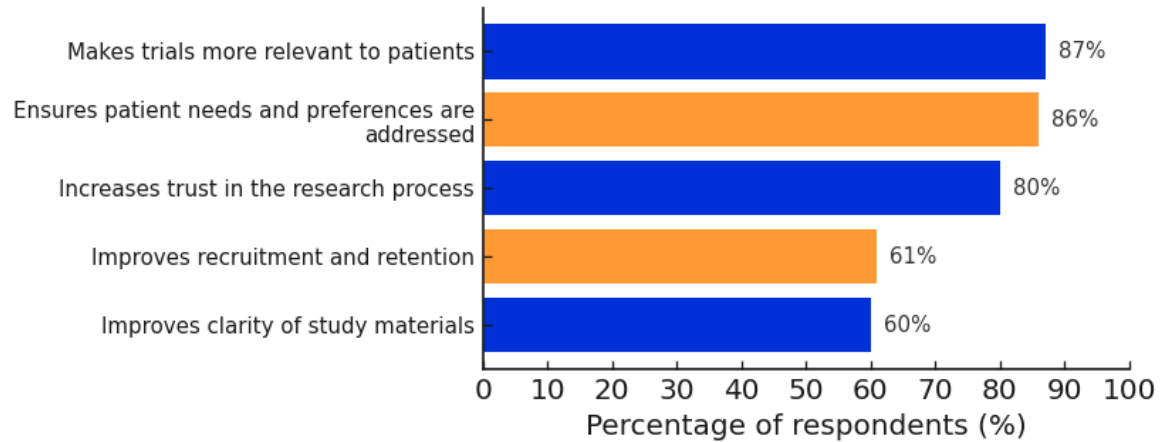
# Importance of Involvement in Co-Design

Q2. How important do you think it is for patients to be involved in the design of clinical trials?



# Benefits of Involvement in Co-Design

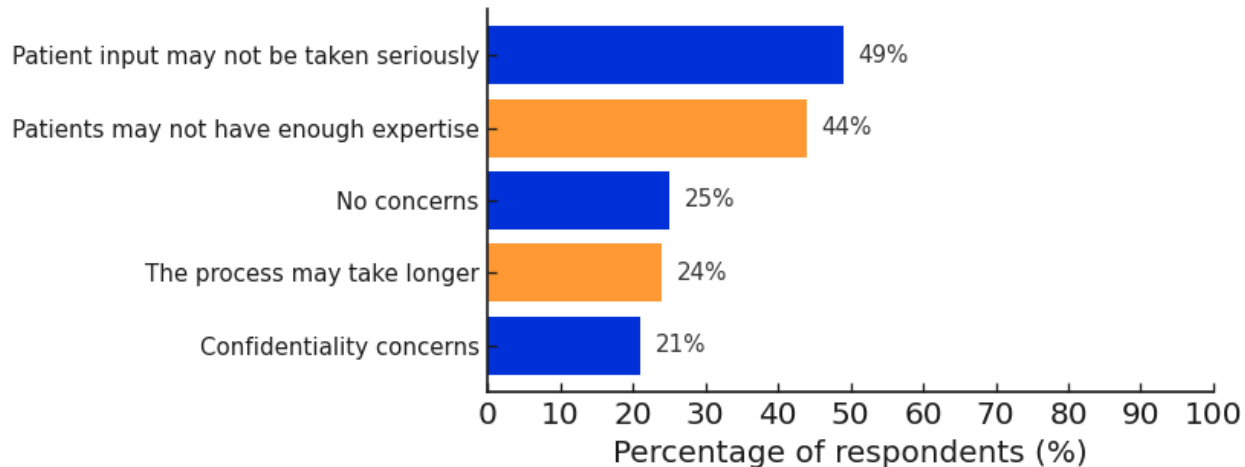
Q3. What benefits do you think patient involvement brings to clinical trial design?



# Concerns about Involvement in Co-Design



Q4. What concerns do you have about patient involvement in codesign?

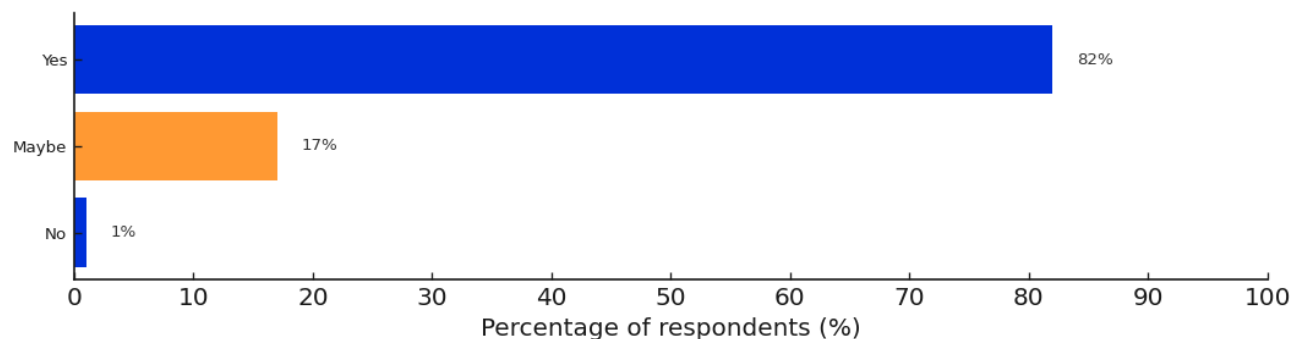




# Interest in Co- Design

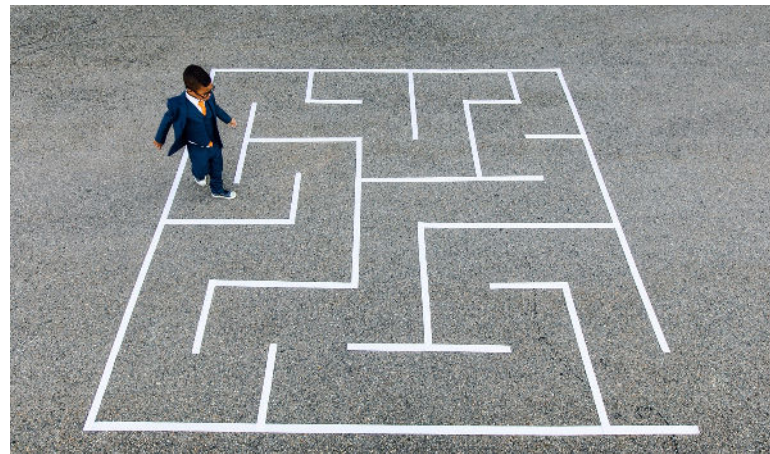
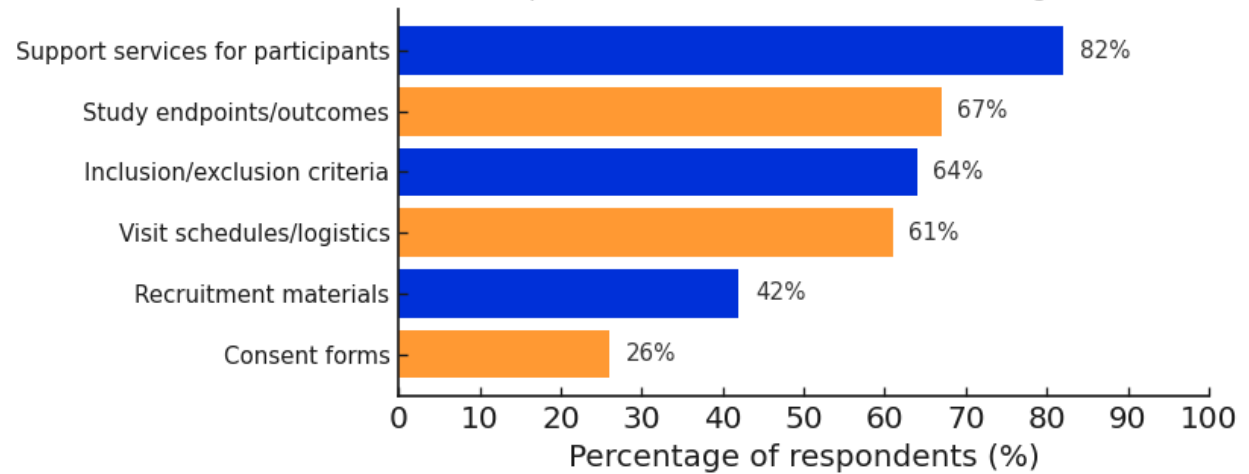
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Q5. Would you be interested in being involved in the design of a clinical trial in the future?



# Most Important Aspects of Co-design

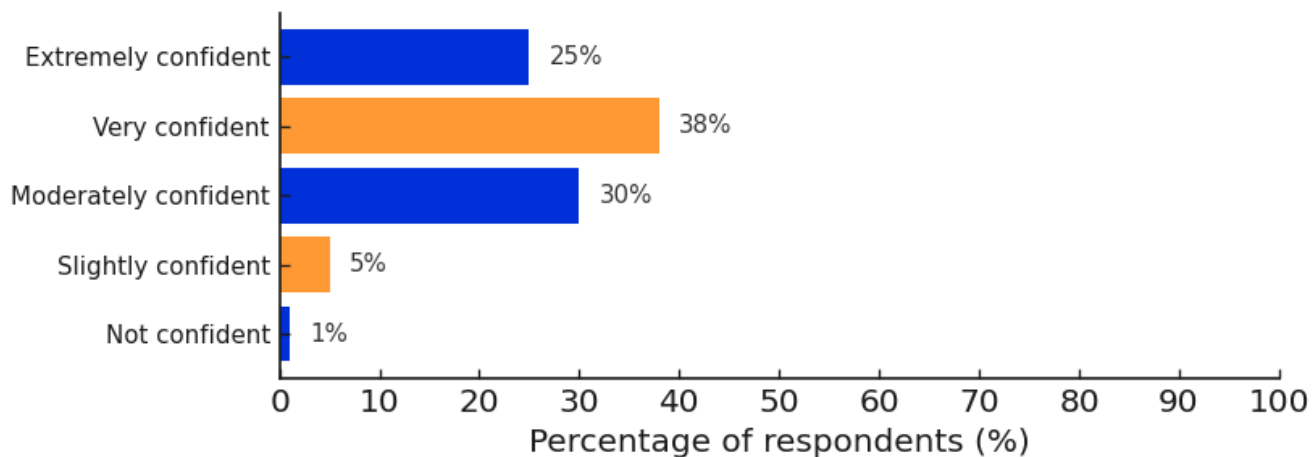
Q13. What do you think are the most important aspects for patients to influence in clinical trial design?



# Patient Involvement and Trial Outcomes

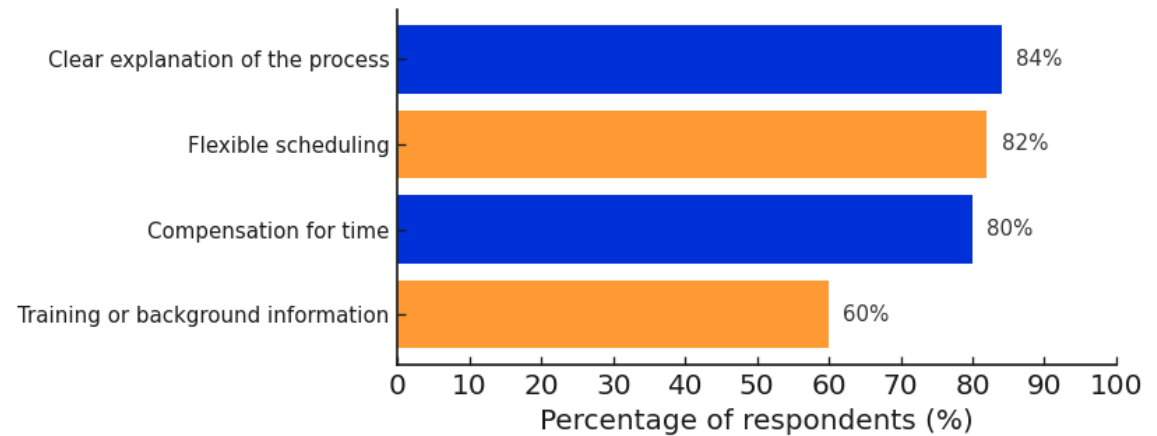


Q14. How confident are you that patient involvement leads to better clinical trial outcomes?



# What Would Encourage You to Participate in Co-Design?

Q15. What would encourage you to participate in codesign activities?

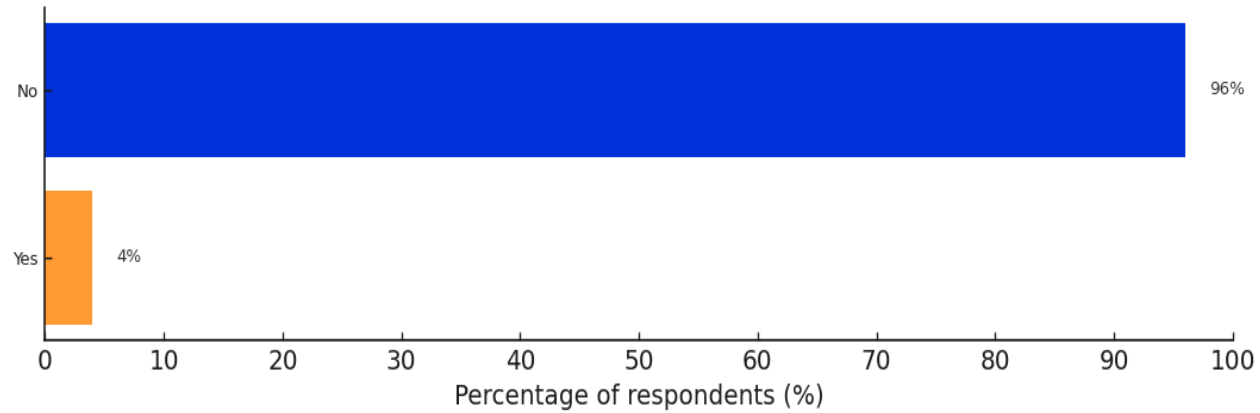


# Experience with the Co-Design Process

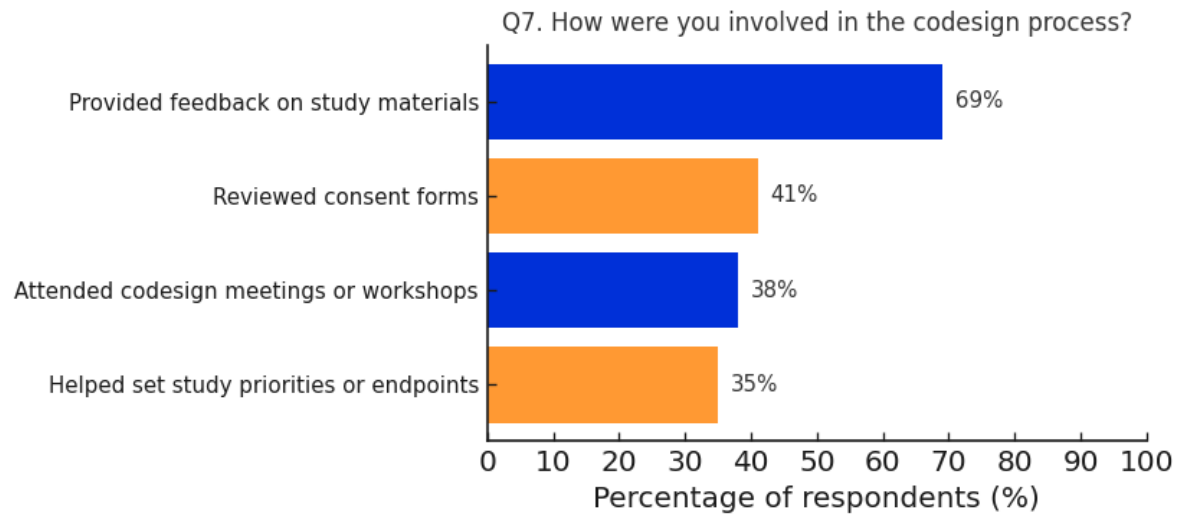


# Experience in Clinical Trial Co- Design

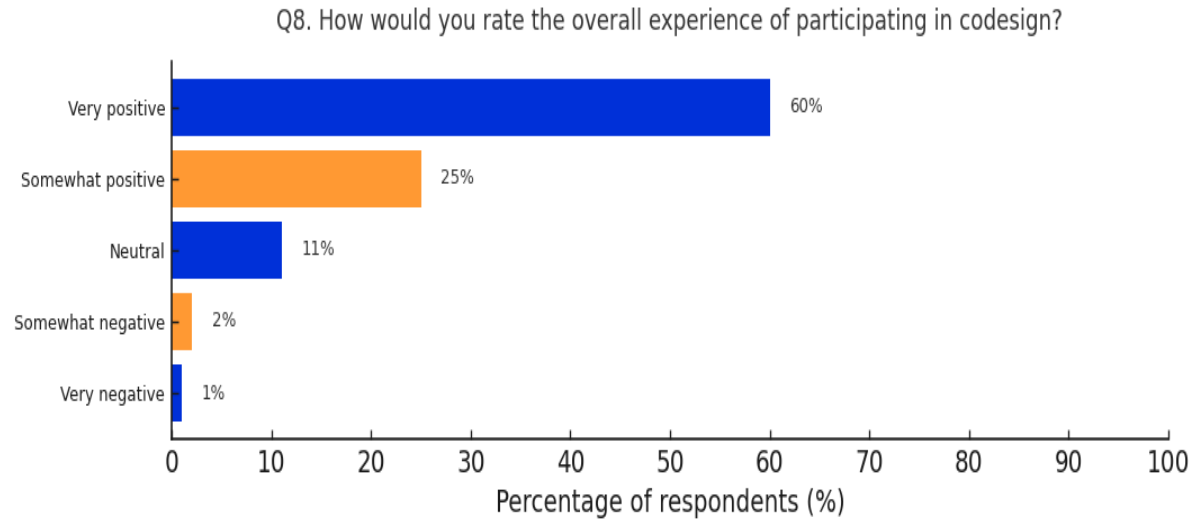
Q6. Have you ever participated in the codesign of a clinical trial?



# Co-design Activities

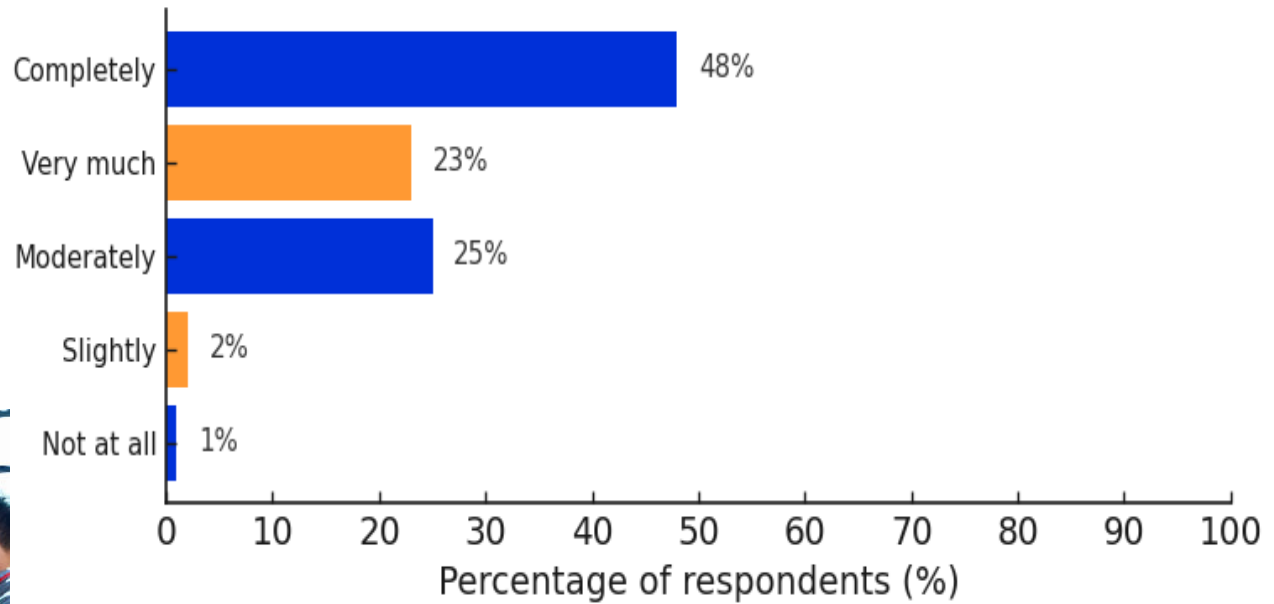


# How was the Co-Design Experience?





Q9. Did you feel your input was valued by the research team?



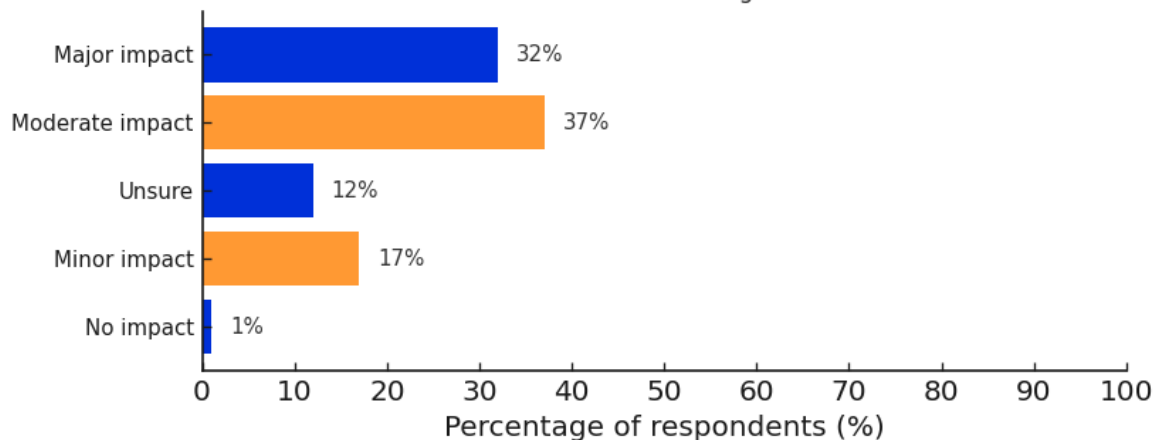
# Was Your Input Valued?



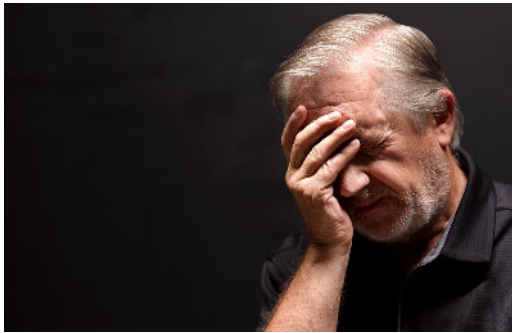
# Impact of Involvement in Co-Design



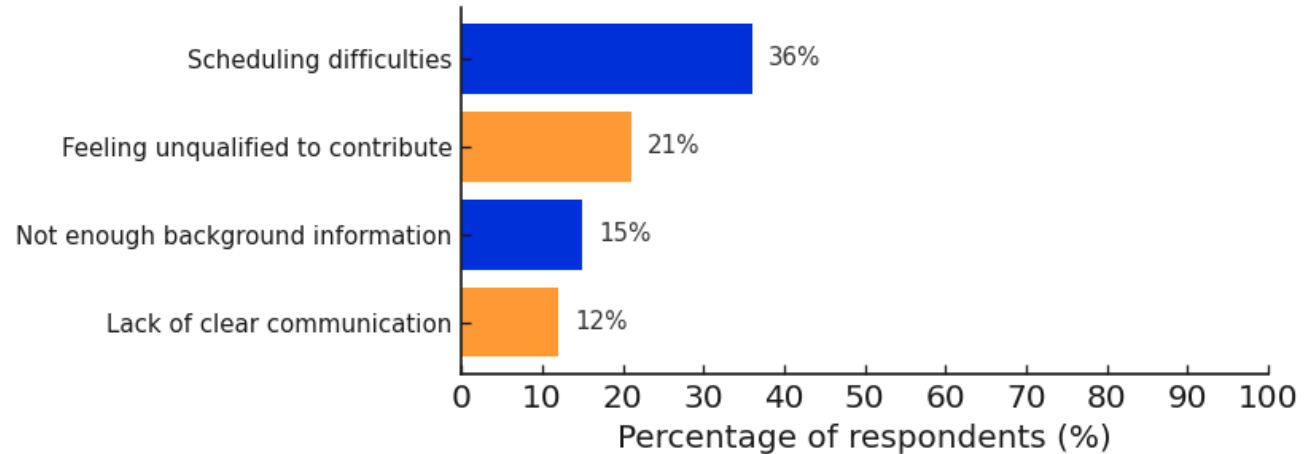
Q10. What impact do you think your involvement had on the clinical trial design?



# What challenges did you experience?



Q11. What challenges did you experience during the codesign process? (Select all that apply)



# What Would Improve the Co- Design Experience for Patients?

- **More flexible scheduling & locations** – home/remote options, virtual meetings, time accommodations (~22 % of respondents).
- **Clear, easy-to-understand information & education** about the study and the codesign process (~19 %).
- **Broader, more representative patient participation** (include people with first-hand disease experience, varied backgrounds) (~18 %).
- **Earlier involvement and greater transparency** so patients see how their input is used (~17 %).
- **Better ongoing communication & feedback loops** – regular updates, reminders, acknowledgement of contributions (~9 %).

