

ERKNet

The European Rare Kidney Disease
Reference Network

for patients

ERKNet ePAG satisfaction survey

January - February 2023

Results



Funded by
the European Union

Background

Aim of the survey

- To evaluate the participation and satisfaction with several activities of the Network (e.g. Working Groups, Guideline Development), as well as the collaboration and communication with the Central Office

Implementation

- Online survey via software SurveyMonkey
- Data collection period: 20.01. bis 09.02.23

Participation

- 12 ePAGs (total number of ePAGs: 19)



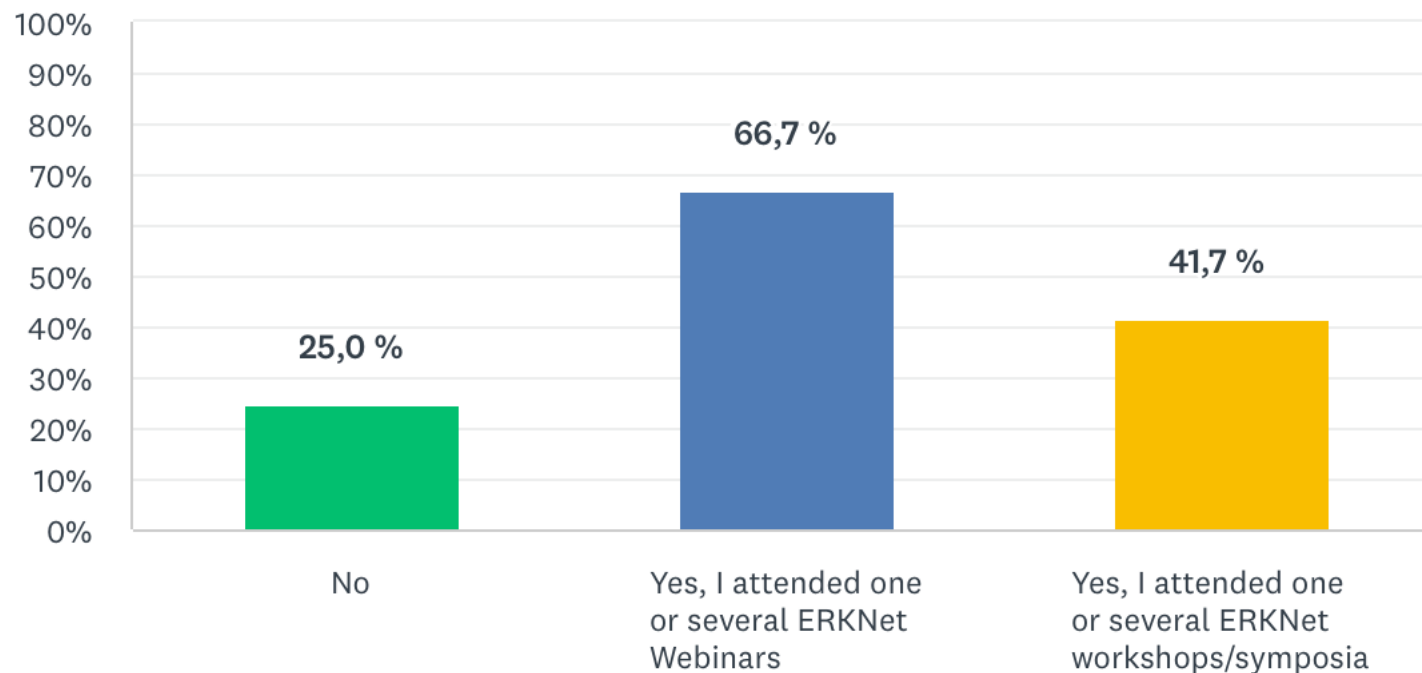


Education & Training

Education & Training

Did you ever participate in an ERKNet education & training activity?
(tick all that apply)

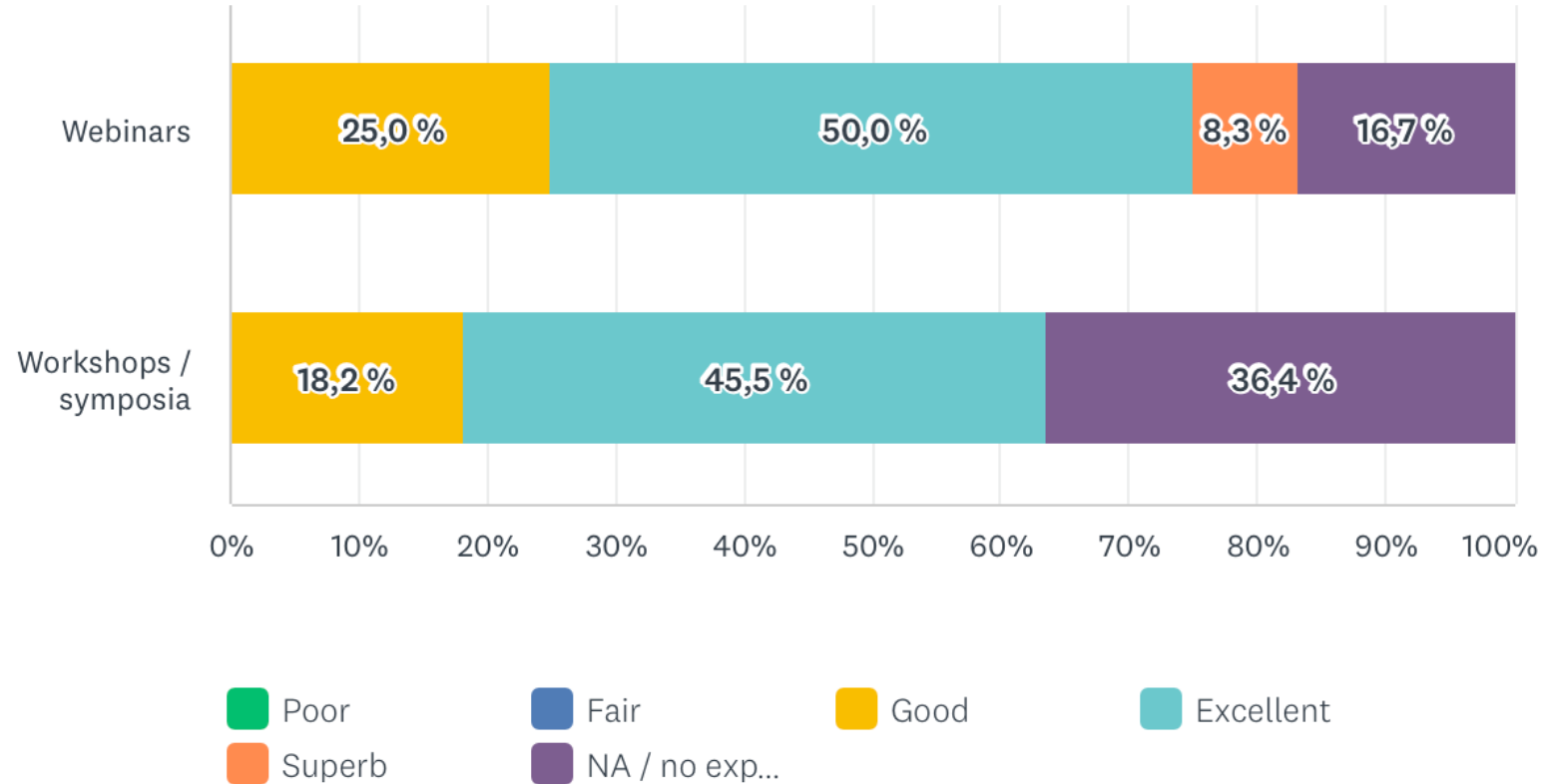
N=12



Education & Training

How would you rate the overall quality of the educational activities you attended?

N=12



WG Meeting



Working Groups

Working Groups

Are you participating in an ERKNet Working Group? (tick all that apply)

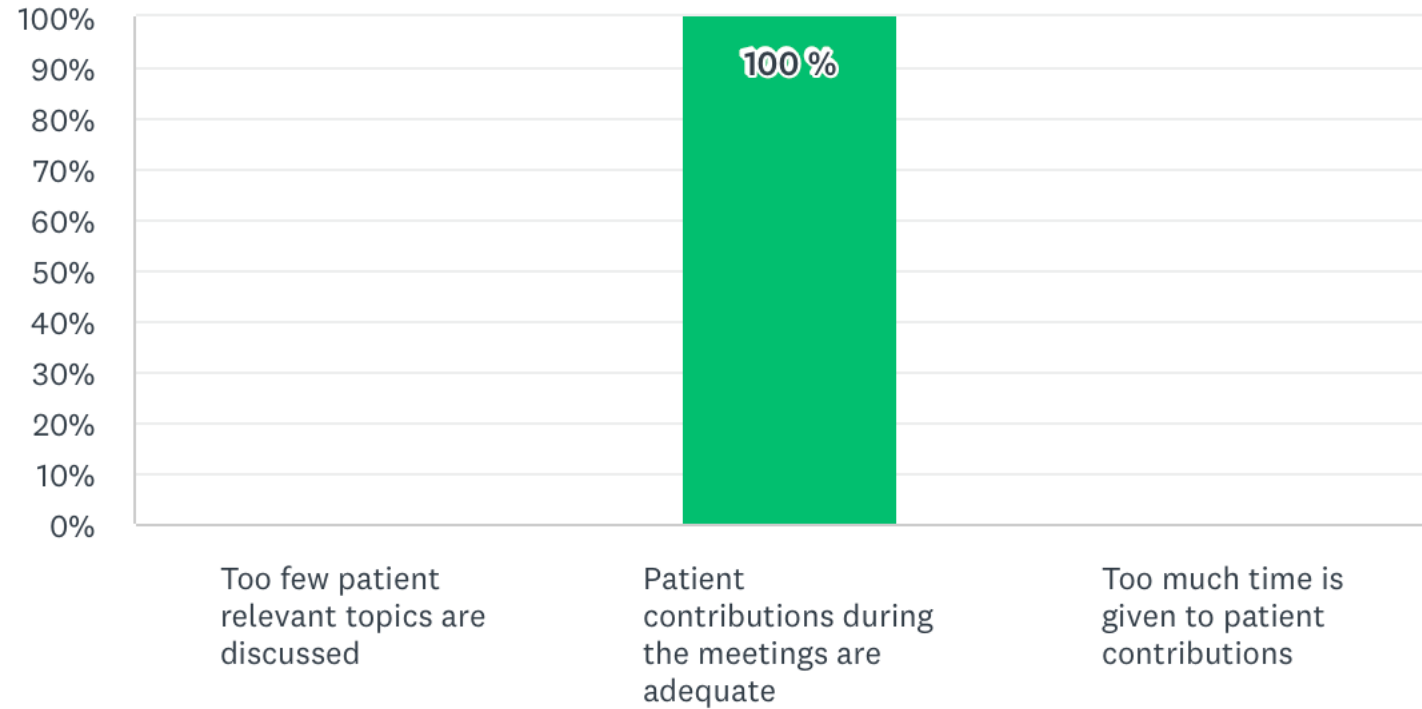
N=11

Yes, in the WG for Pediatric CKD	45,45 %	5
Yes, in the WG for Pediatric Kidney Transplantation	45,45 %	5
Yes, in the WG for Autosomal Dominant Structural Kidney Disorders	36,36 %	4
Yes, in the WG for Thrombotic Microangiopathies	27,27 %	3
Yes, in the WG for Tubulopathies	27,27 %	3
Yes, in the WG for Inherited Glomerulopathies	18,18 %	2
Yes, in the WG for Immune-Mediated Glomerulopathies	18,18 %	2
Yes, in the WG for CAKUT and Ciliopathies	18,18 %	2
Yes, in the WG for Metabolic Nephropathies and Stone Disorders	18,18 %	2
No	9,09 %	1

Working Groups

How do you rate the patient involvement during the Working Group meetings?

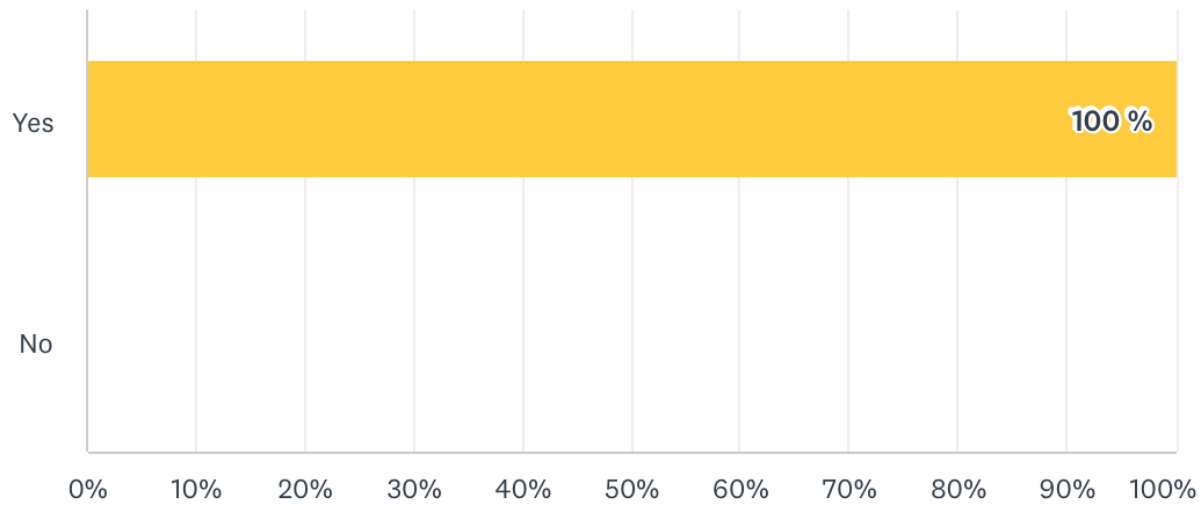
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Working Groups

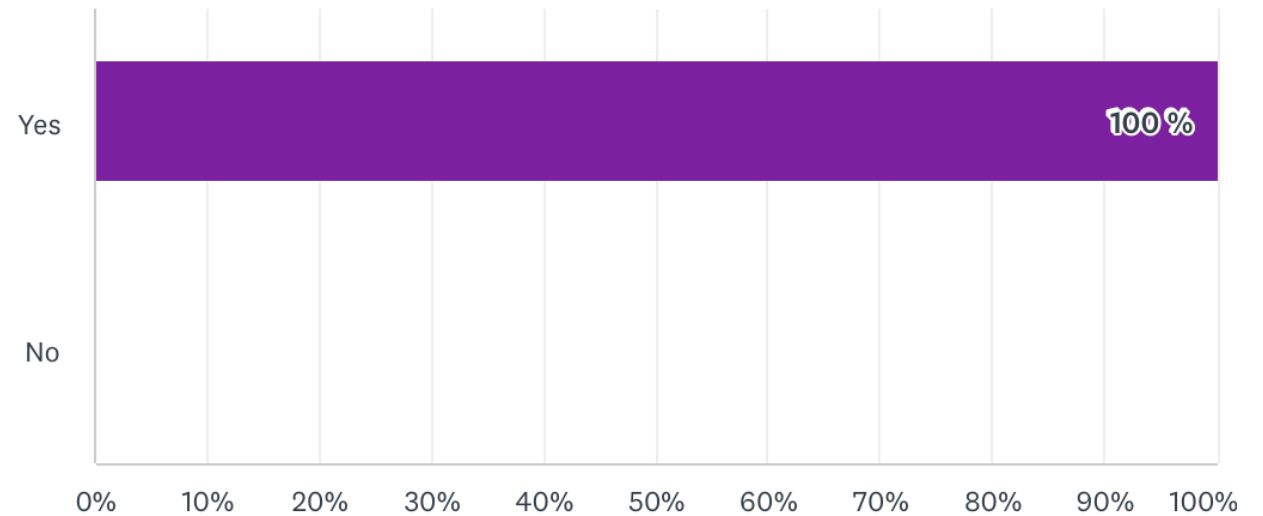
Did you know that we include Patient Voices in some webinars?

N=12



Do you think this initiative is useful?

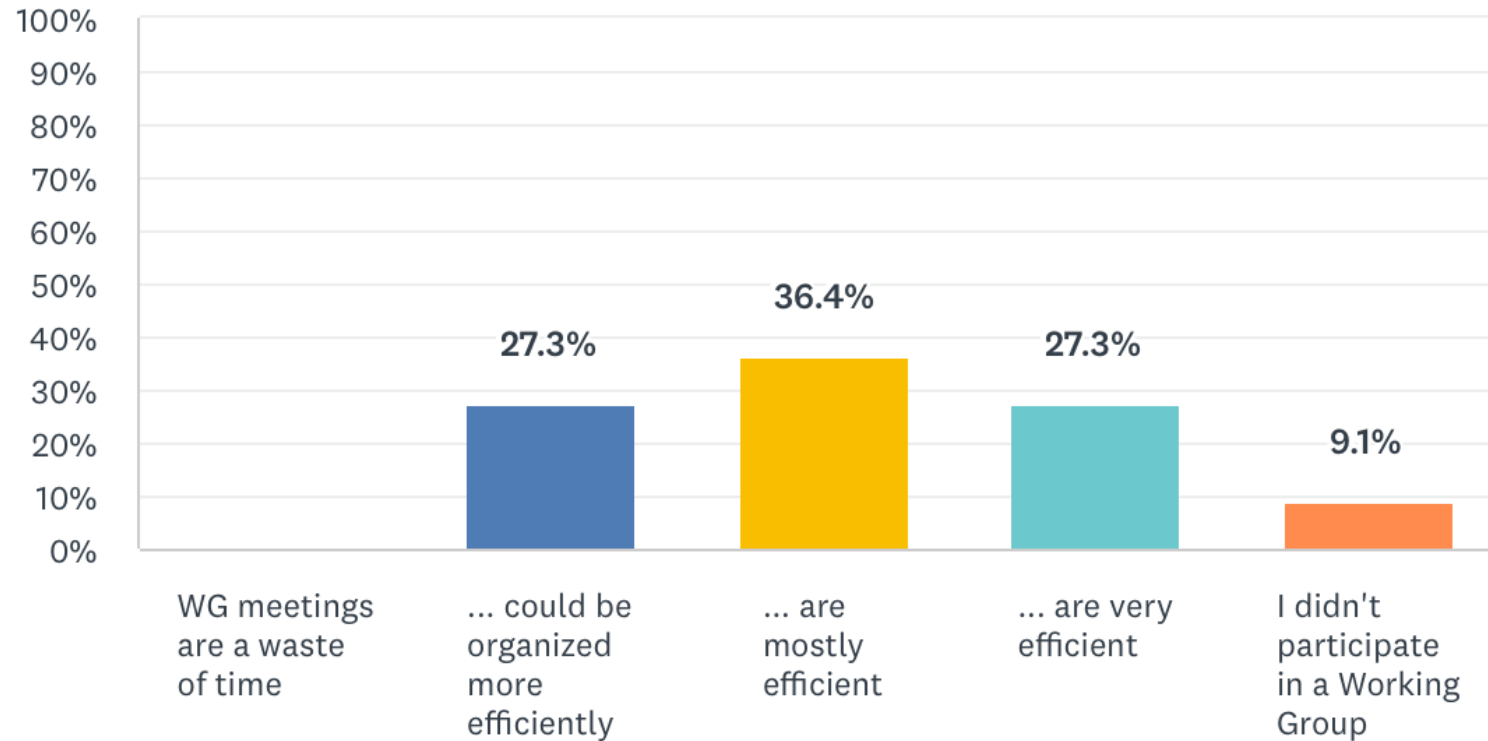
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Working Groups

How satisfied are you with the organisation and meeting frequency of the Working Groups?

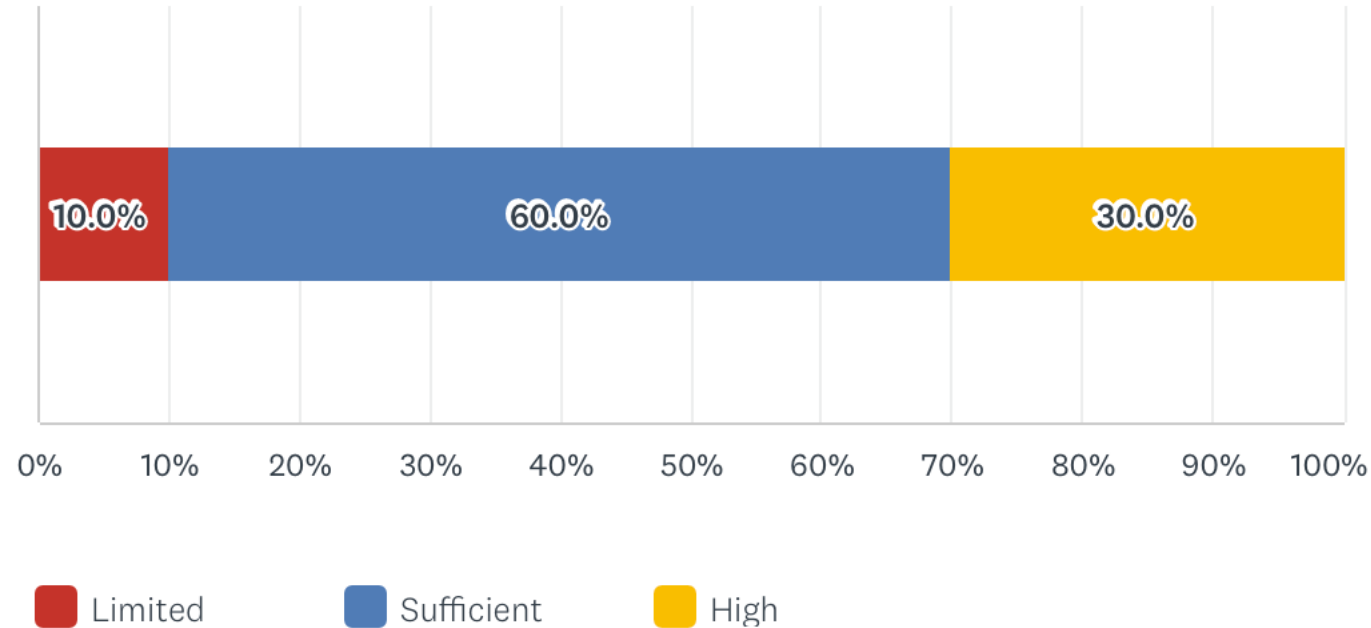
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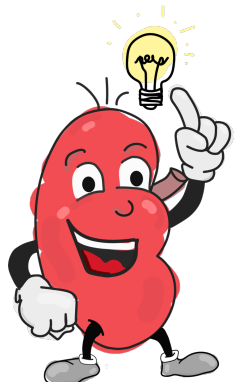
Working Groups

How do you rate the overall productivity of the Working Groups?

N=10



Suggestions for improvement: prioritising projects, closer contact with clinicians, desire for support of the Central Office for those WGs where patient participation is still insufficient



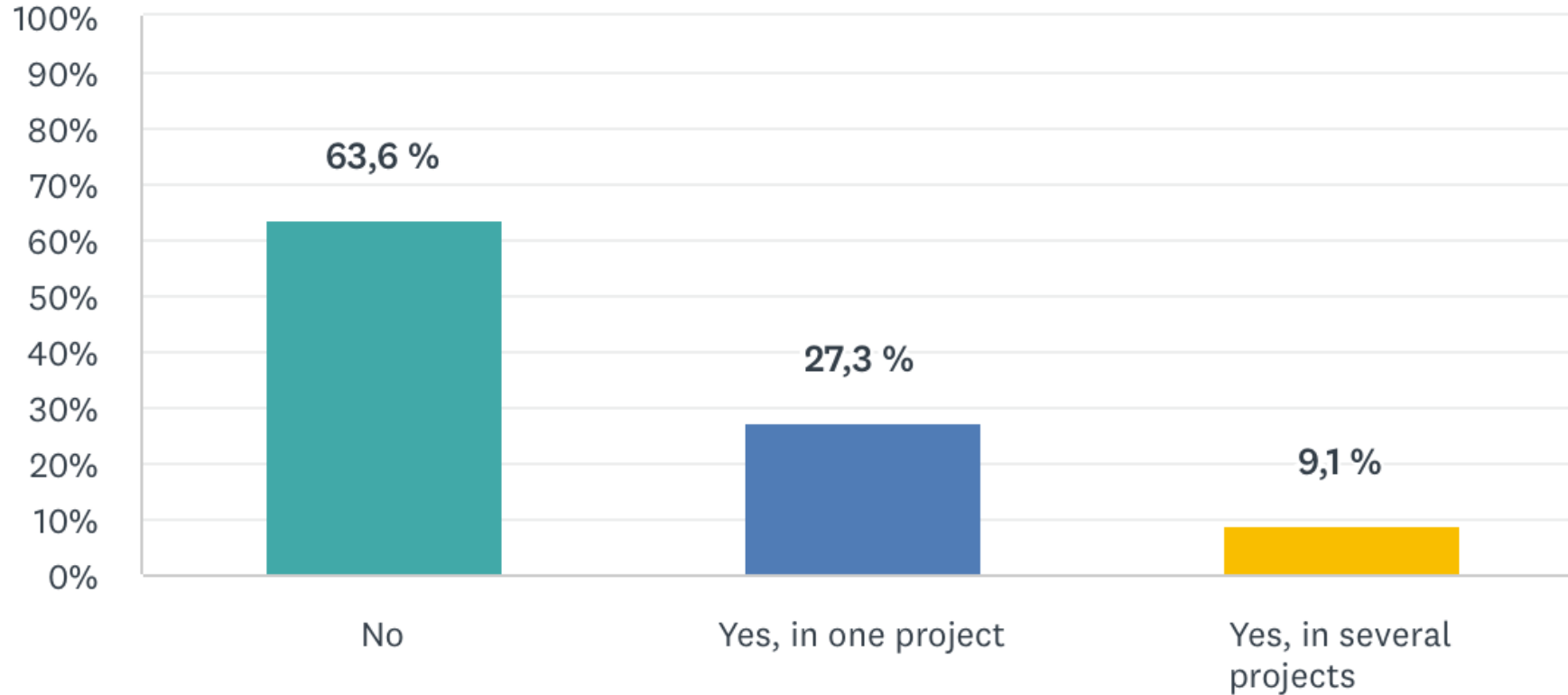
Development of Guidelines



Working Groups

Did you ever participate in a Guideline Project?

N=11



How did do you rate patient involvement in the Guideline Project(s)?

N=11

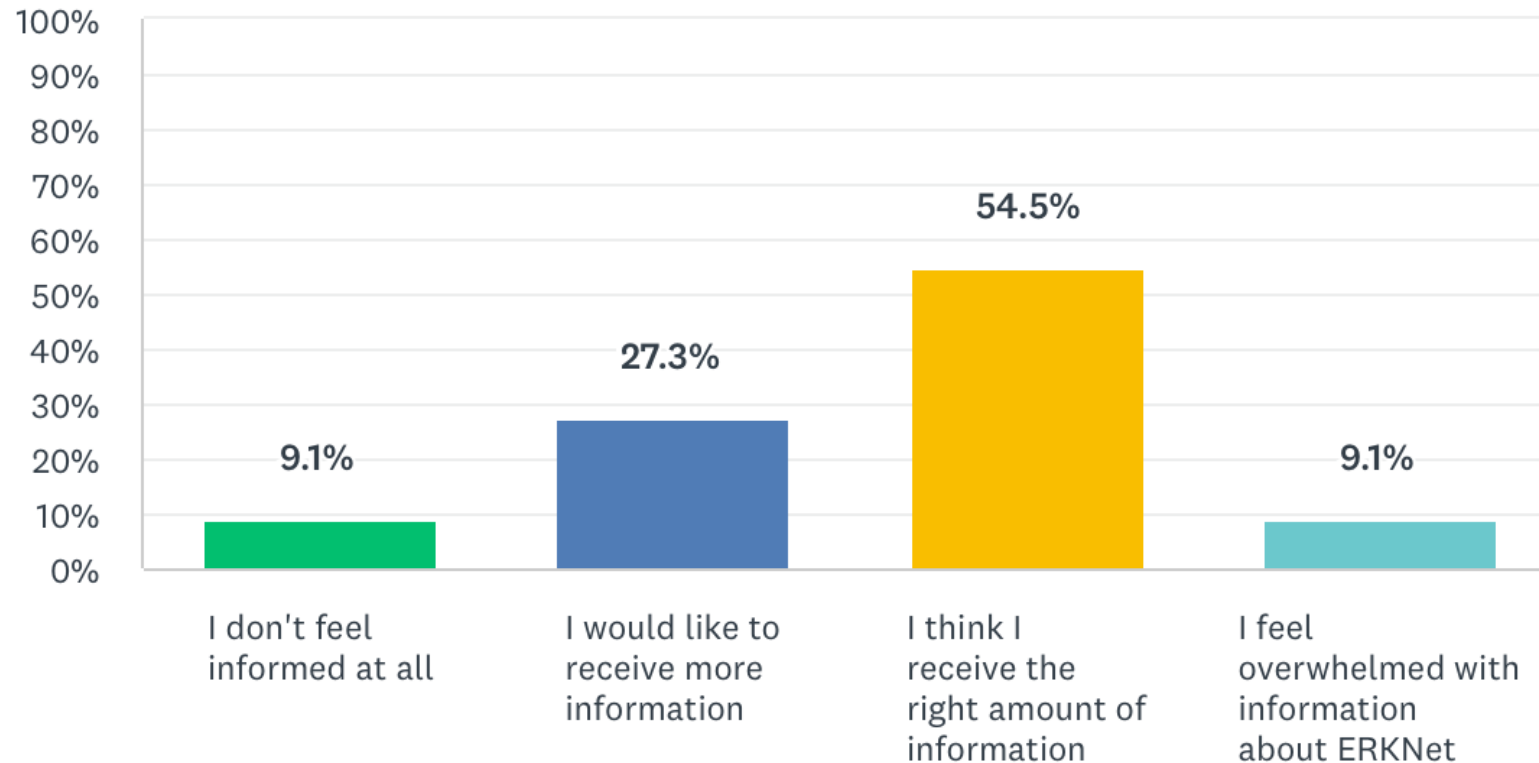
I can't recall any patient involvement	0,00 %	0
Patients were involved but their contribution was minor	18,18 %	2
Patients were involved and their contribution was appropriate	18,18 %	2
There was too much emphasis on patient involvement	0,00 %	0
I didn't participate	63,64 %	7



Communication & Dissemination

Generally, how well informed do you feel about ERKNet's activities?

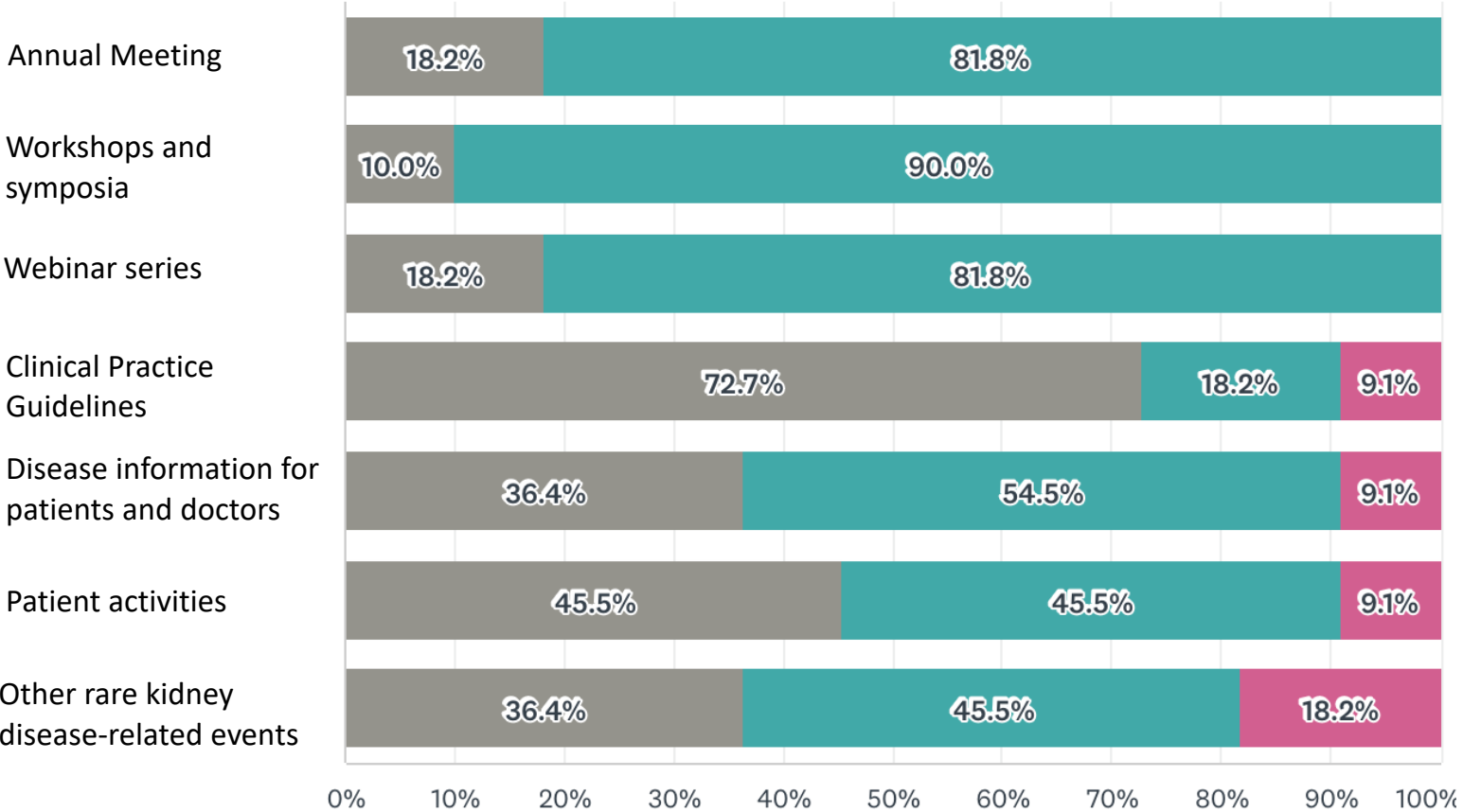
N=11



Communication & Dissemination

How well do you feel informed about each of the main ERKNet activities?

N=11

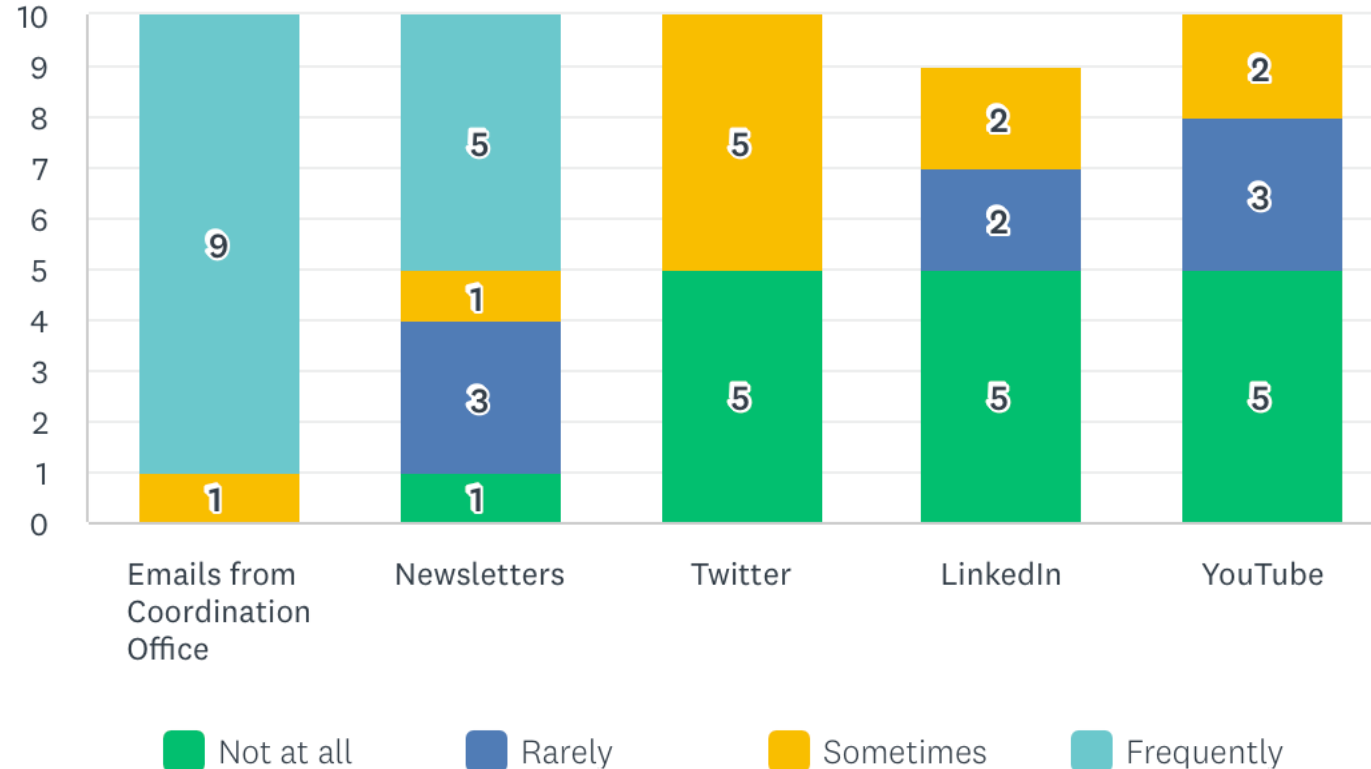


I would like to receive more information
I feel adequately informed
I receive too much/redundant information

Communication & Dissemination

Through which communication channels do you obtain information about ERKNet activities?

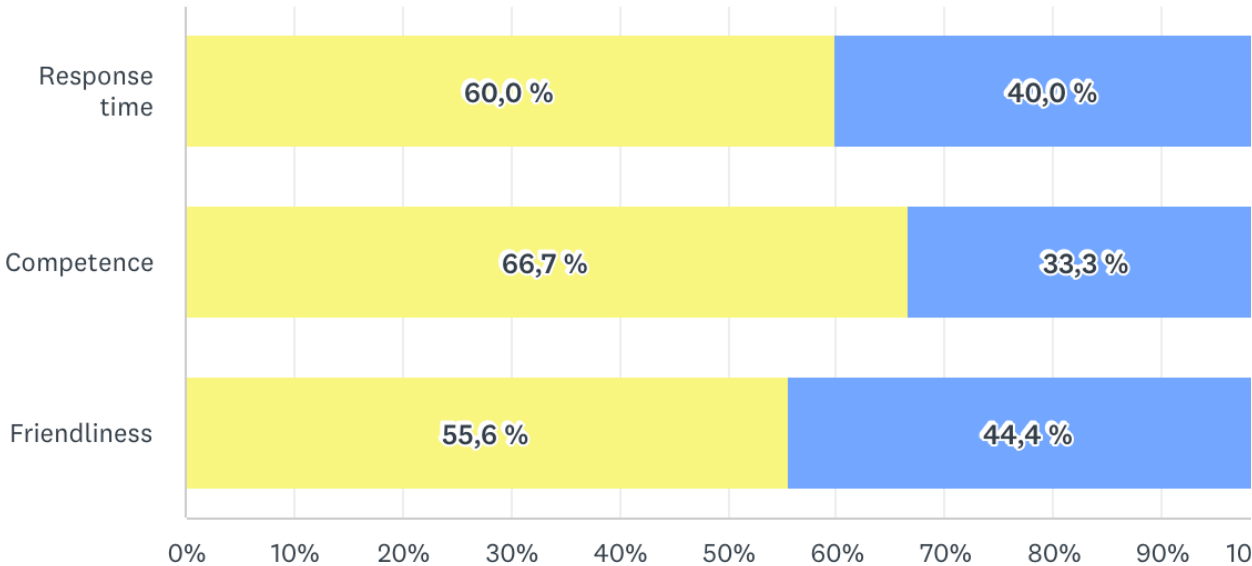
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Communication & Dissemination

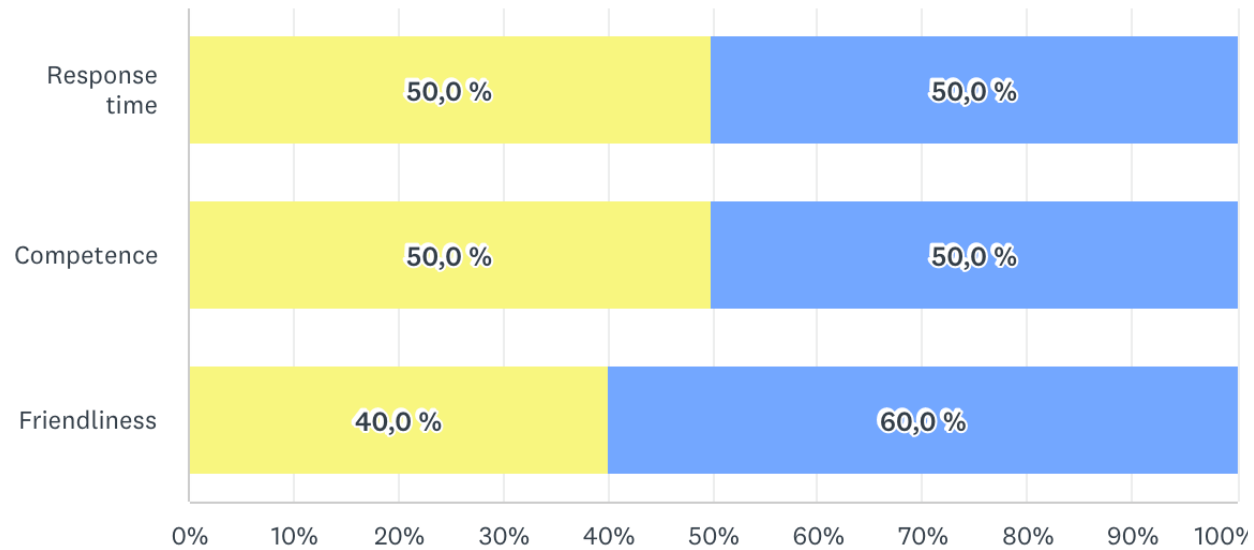
What is your personnel communication experience with the Coordination Office?

N=10



What is your personnel communication experience with the ePAG manager (Vera)?

N=10



Poor

Fair

Good

Outstanding

ERKNet
The European Rare Kidney Disease Reference Network



6th Annual Meeting
10/05/2022 - 12/05/2022

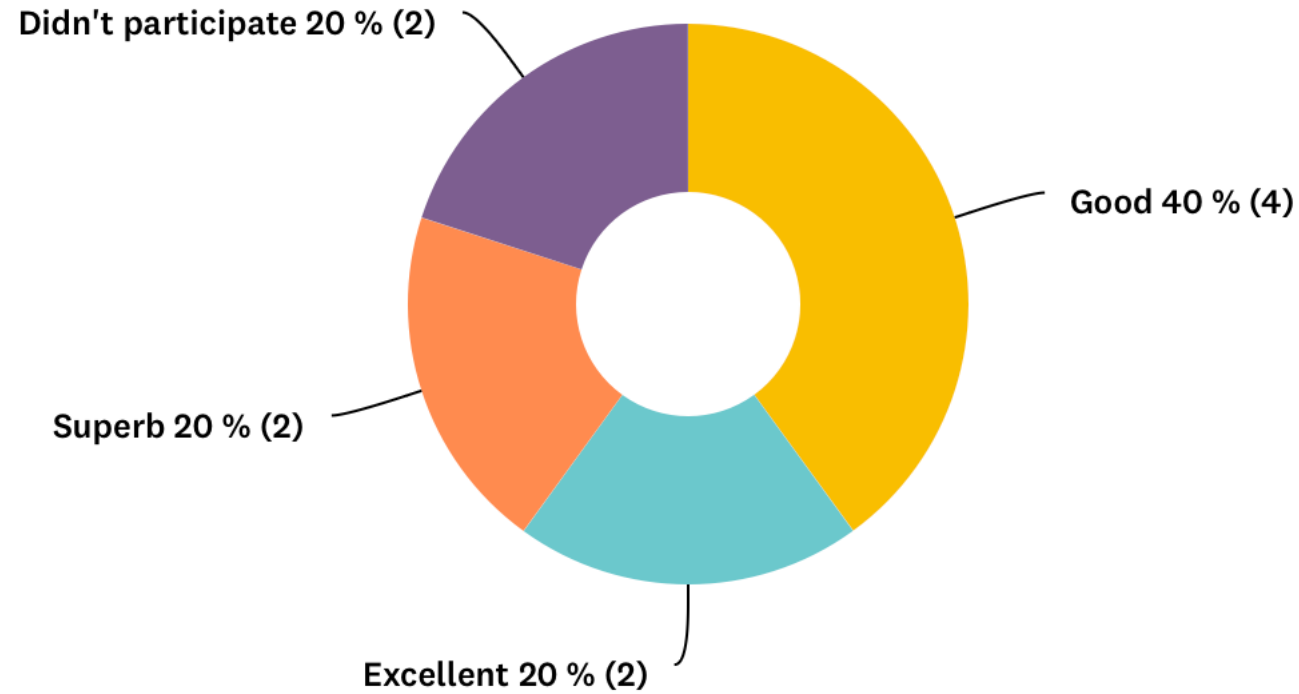
6th Annual Meeting 2022



**Funded by
the European Union**

How did you like the Annual Meeting?

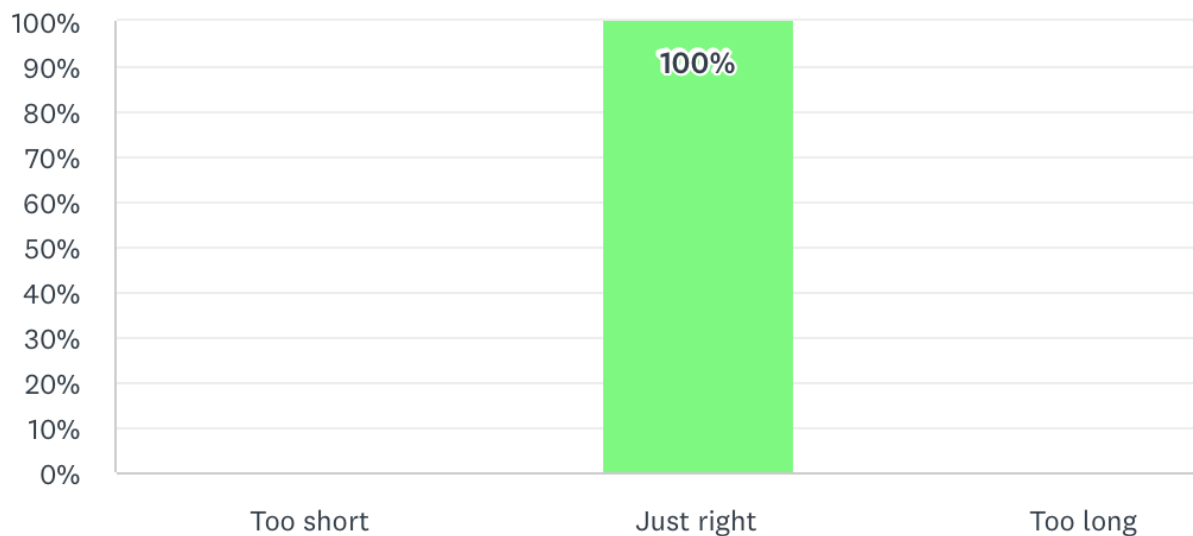
N=10



6th Annual Meeting 2022

Was the meeting duration (1.5 days) adequate?

N=8



Which format would you prefer for the next Annual Meeting?

N=9

