

“Contribution of Rare Disease Patient Organizations to Medical Education in Germany”

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Overview

- The Project
 - Background
 - Project Design
- Preliminary Results
 - Characteristics of Patient Organisations (PO)
 - Contribution of PO to Medical Education
 - Recommendation
- Conclusions

The Project

Background

- Project funded by German Ministry of Health, carried out at the Charité Universitätsmedizin, Berlin.
- Part of a larger project (2009 - 2011) dealing with the “interface” between patient organizations and doctors.

The Project

Project Design

- Phase 1: Data collection and analysis
 - Questionnaire-based e-mail survey of 90 member organizations of German umbrella organization for rare disease patients (ACHSE)
 - Excellent response rate of 58%, i.e. 52 patient organizations (Schulenburg study: 47%)
- Phase 2: Implementation of recommendations and support of selected activities of PO

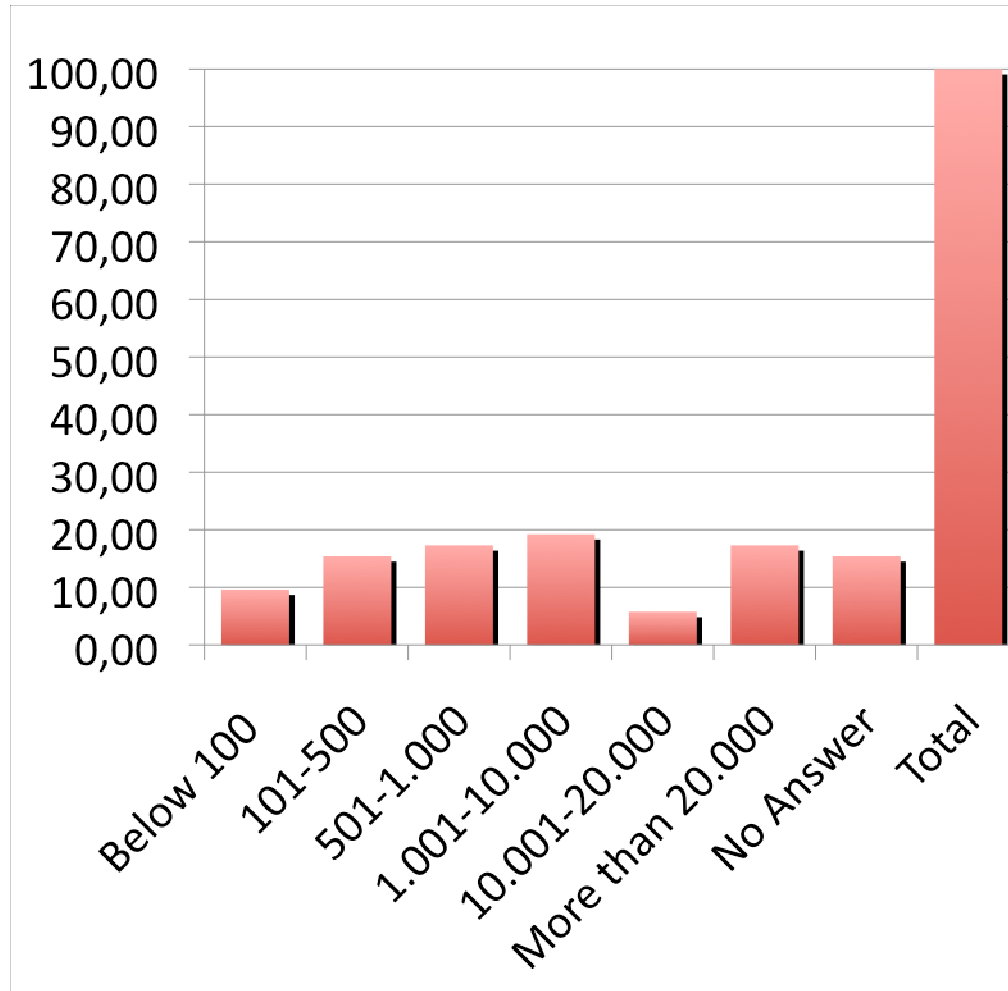
Preliminary Survey Results

Characterics of participating PO

- 50 disease specific patient organizations with patient members
- 2 foundations without patient members
- Total: 52 Member organizations of ACHSE

Characteristics of PO

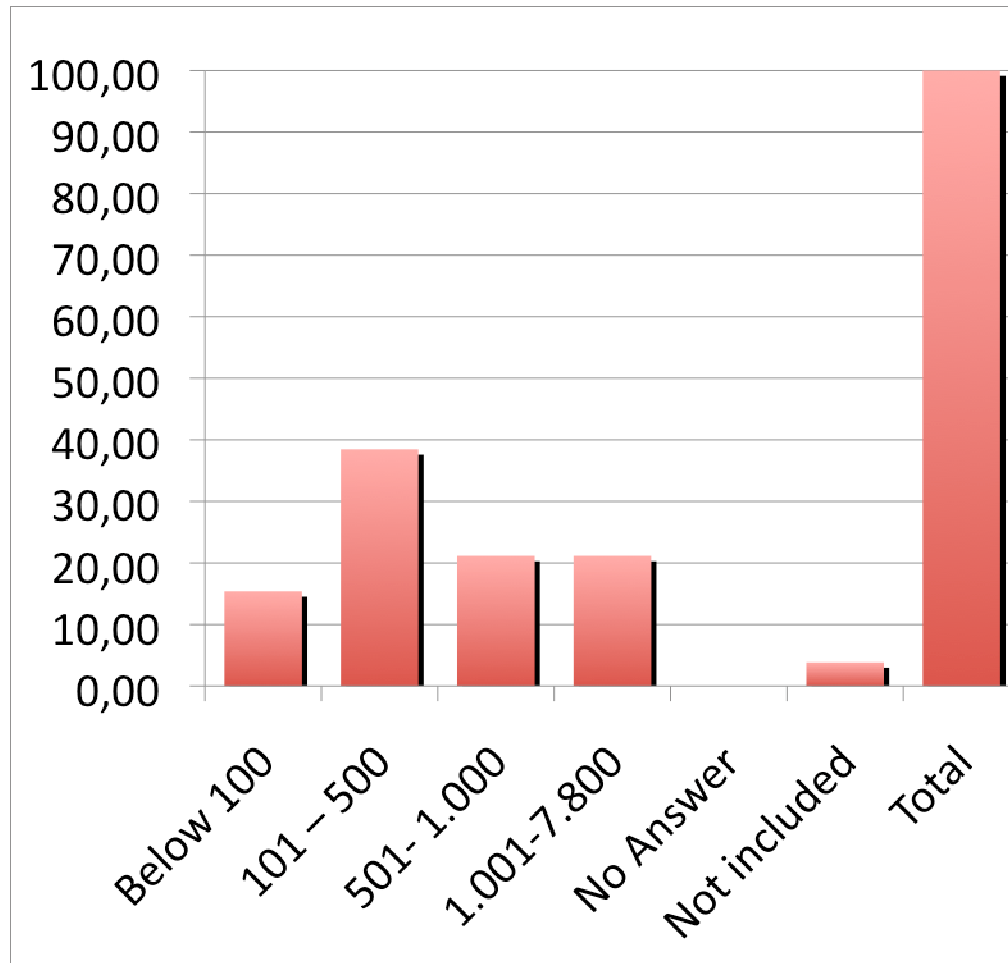
Estimated number of patients in Germany



Estimated number	Absolute	Percent
Below 100	5	9,62
101-500	8	15,38
501-1000	9	17,31
1001-10.000	10	19,23
10.001-20.000	3	5,77
More than 20.000	9	17,31
No Answer	8	15,38
Total	52	100,00

Characteristics of PO

Number of members

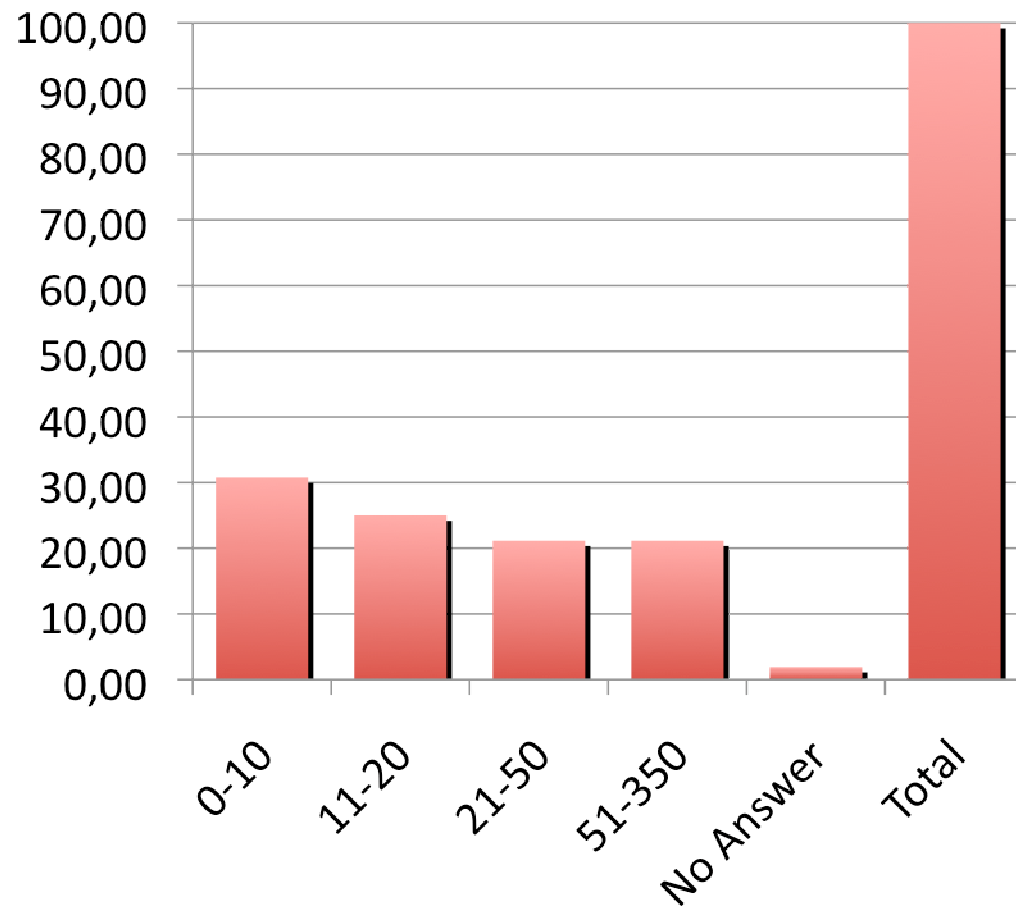


Number of members	Absolute	Percent
Below 100	8	15,38
101 - 500	20	38,46
501 - 1.000	11	21,15
1.001 - 7.800	11	21,15
No answer	0	0,00
Not included*	2	3,85
Total	52	100,00

*Selbsthilfegruppe Ektodermale Dysplasie: 185 Families; Proteus-Syndrom e. V.: 16 Families

Characteristics of PO

Active members



Active Members	Absolute	Percent
0-10	16	30,77
11-20	13	25,00
21-50	11	21,15
51-350	11	21,15
No Answer	1	1,92
Total	52	100,00

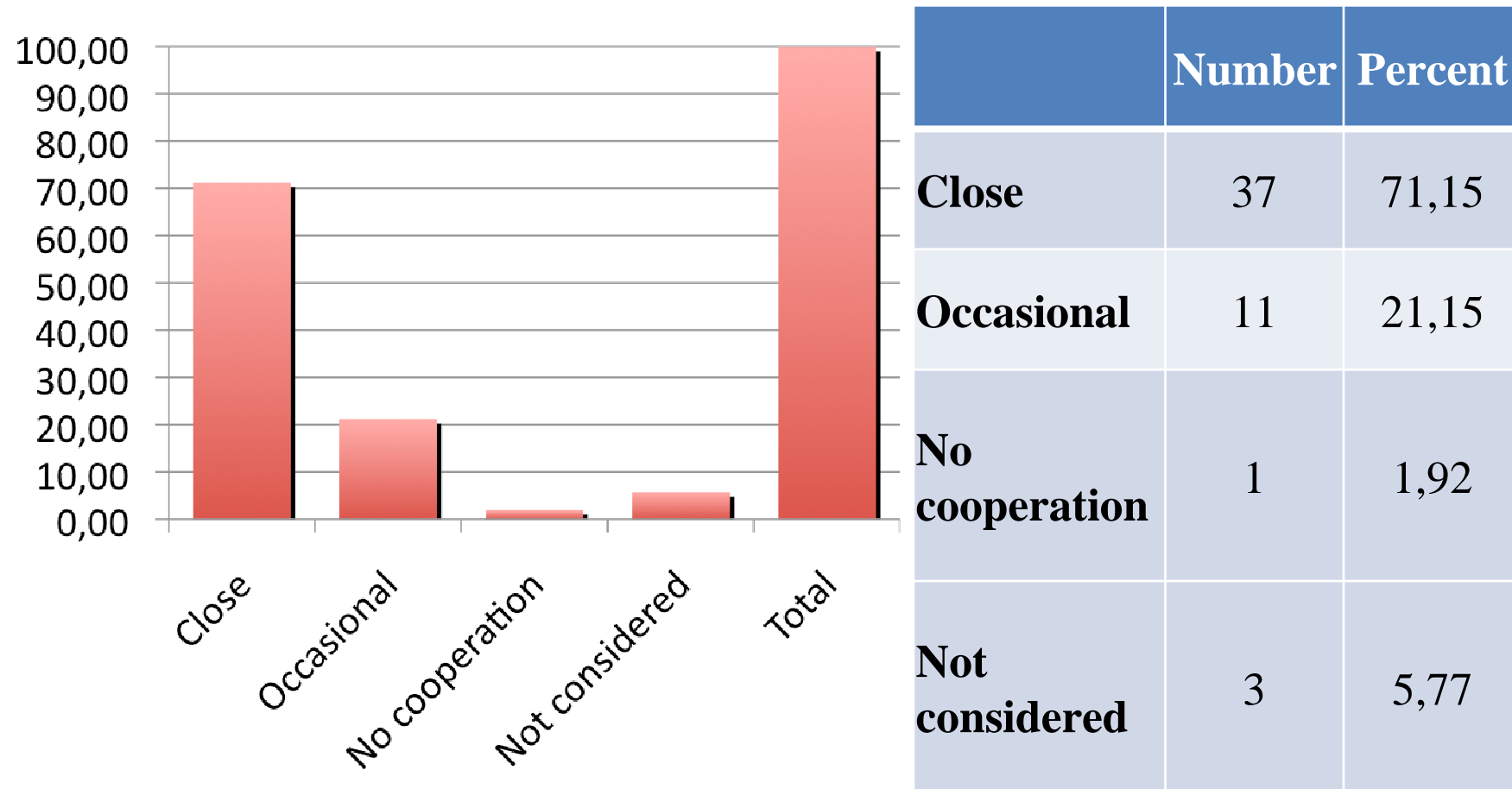
Characteristics of PO

Website with disease-specific information

- All PO except one have a website with disease-specific information (N=51).

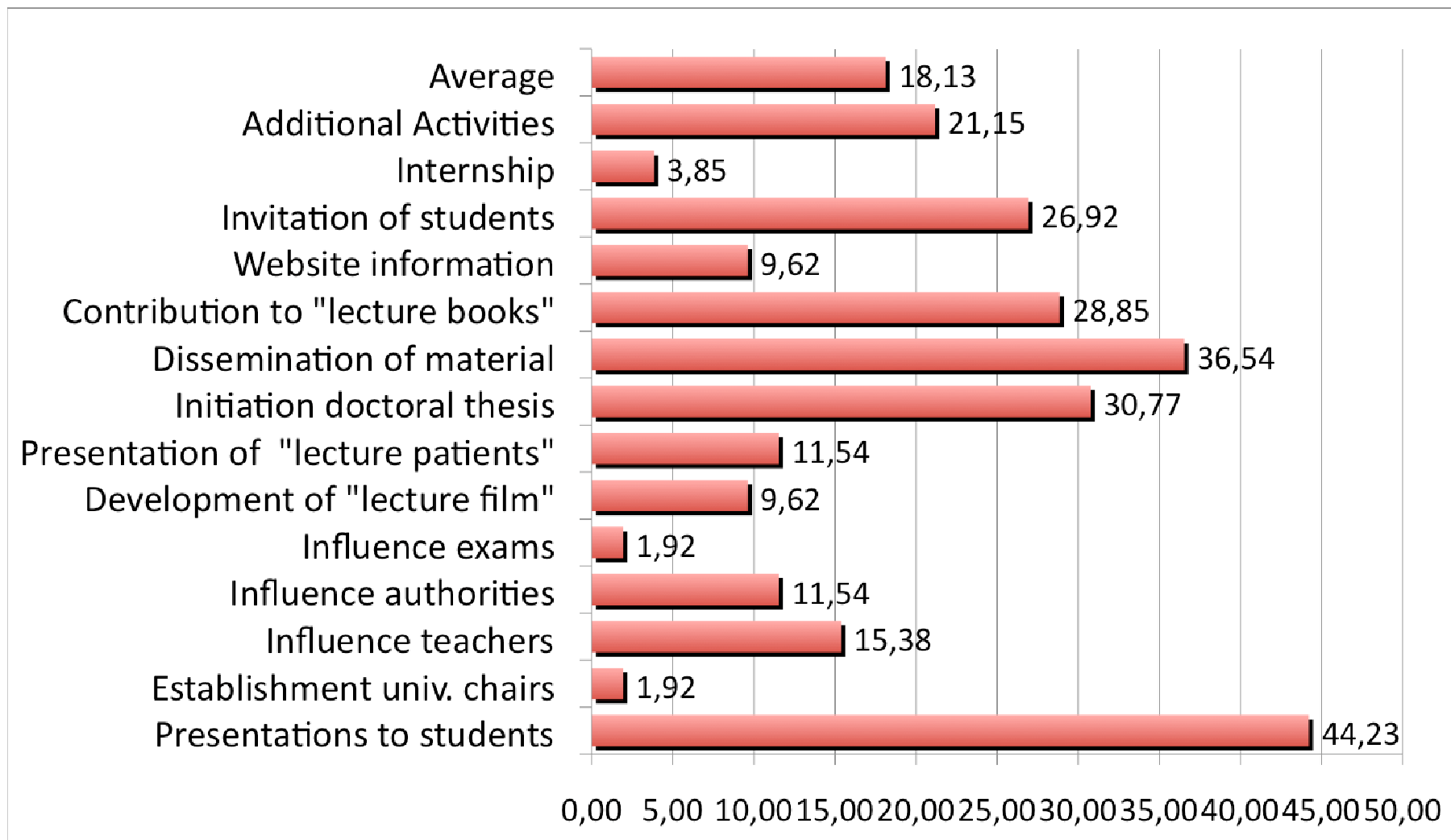
Characteristics of PO

General cooperation with doctors



Contribution of PO to medical education

Overview of training-related activities



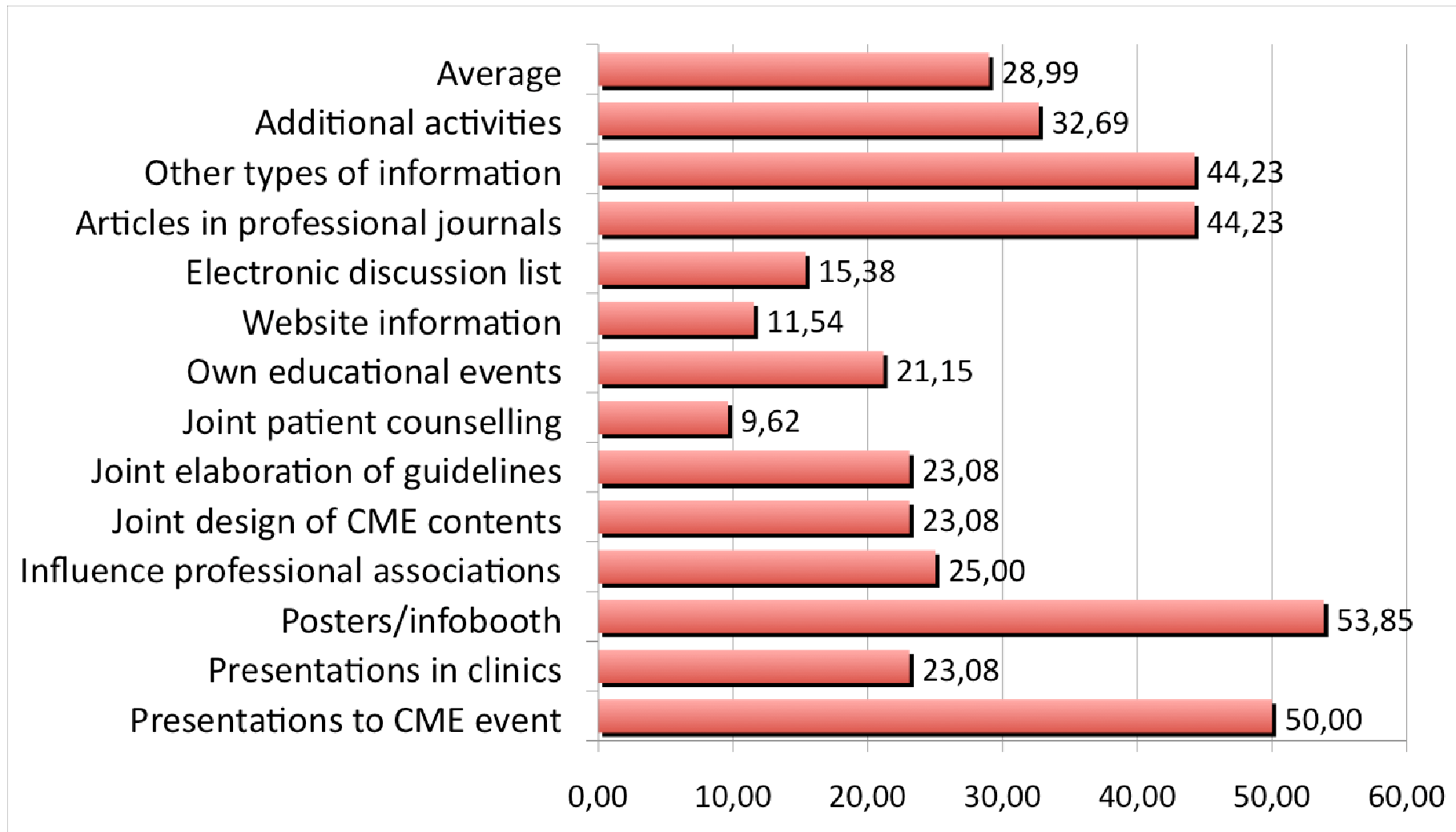
Contribution of PO to medical education

Most important training related activities

Training-related Activity	Number of contributing PO	Percentage
Presentation to students	23	44,23
Dissemination of information material	19	36,54
Initiation of doctoral thesis	16	30,77
Contribution to lectures/lecture books	15	28,85
Invitation of students	14	26,92

Contribution of PO to medical education

Overview of activities related to CME



Contribution of PO to medical education

Most important CME-related activities

CME-related activities	Number of contributing PO	Percentage
Poster/infobooth at professional CME-related events	28	53,85
Presentation to CME-related events	26	50,00
Articles in professional journals	23	44,23
Other materials for doctors	23	44,23
Cooperation with professional associations	13	25,00

Contribution of PO to medical education

Two Innovative Examples

Example 1: Morbus Wilson

→ *Competition among medical students for best disease description*

- Literary, scientific, lectural, personal perspective
- Participation of 50 students
- Three prizes awarded by jury
- Doctoral theses included

Contribution of PO to medical education

Two Innovative Examples

Example 2: Pro Retina

→ *Annual „Potsdam Meeting“ for young European Researchers*

- Participation of young and senior researchers, clinicians, patient representatives (about 150)
- Senior and junior speakers
- Poster prize awards
- Funding: DFG, Pro Retina, HOPE project

Contribution of PO to medical education

Two Innovative Examples

Objective of both Examples:

- Raise interest for specific disease area among postdocs, doctors and researchers
- Inform about research and clinical aspects of respective disease

Major preliminary recommendation

- Establishment of data base for CME-related activities of rare disease patient organizations:
 - General characteristics of educational event (format, contents, participants etc.).
 - Information about patient-doctor interface. (cooperation, special subevents, certification)
 - Access Data (website, contact partner etc.).

Conclusions

- Rare disease patient organizations, although small in size and infrastructure, are major carriers and service providers for CME-related activities in their specific fields of disease.
- Most resources of RD-PO are invested into CME-related activities, like self-organised educational events (conferences, symposia, patient days).
- Training-related activities are less important than CME related activities. Potentially high innovative impact.
- The establishment of a database on CME-related activities of rare disease patient organizations would be useful for all interested stakeholders.

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