

Appendix 2. Number of responders to each question (Q).

Question	Responders No.	Skipped No.	Missing No.
Q 1-4: name, disease, city, role	280		
Q 5: participated in clinical research	280		
Q 6: in what clinical research activities the association was involved <i>optional to q. 5</i>	136 (+ 2 responding "I don't know or not at all" to Q5, not included in the analysis of Q6)	142	
Q 7: is your association aware about the topic?	280		
Q 8: circumstances in which the association discuss this topic? <i>optional to q. 7</i>	144	136	
Q 9: having an official position <i>optional to question 7</i>	139	136	5
Q 10: group's position <i>optional to question 9</i>	57	79	3
Q 11: explain reasons supporting your group's view <i>open question</i>	49		231
Q 12: who can have access? <i>optional to q. 7 and 10</i>	131	2	11
Q13: aspects to guarantee a fair and secure process <i>optional to q. 7 and 10</i>	131	2	11
Q 14, 15, 16: risks and advantages of IPD sharing	258		22
Q 17 Number of group's members	238		42
Q18 Who are members of the executive board	238		42
Q 19 In which activities has been involved your group <i>Three options: yes, to some extent, no</i>			
Education and dissemination/information	239		41
Financial support for research	232		48
Lobbying at the institutional level (local and central)	231		49
Fund-raising	235		45
Health and social support	234		46
Surveys about health services quality	231		49
Q 20: which of the following financial sources have mainly supported your group	239		41
Q 21: association's work mainly local, regional, national	239		41
Q 22: involved in European or international networks	239		41