

Table: Demographic characteristics of individuals who responded to the cystic fibrosis survey

Characteristic group	Cystic fibrosis survey (n =295)		Characteristic group	Cystic fibrosis survey (n =295)	
	n	%		n	%
Stakeholder type			PWCF gender		
PWCF	137	49.4	Male	113	38.3
Parent of a child <18 years with CF	97	32.9	Female	175	59.3
Parents of a child with CF ≥ 18 years	33	11.2	Other	2	0.7
Other*	28	9.5	Unknown	5	1.7
Respondent age (years)			Country		
<15	0	0	Australia	3	1
16-19	13	4.4	Belgium	5	1.7
20-29	62	21.0	Brazil	1	0.3
30-39	98	33.2	Canada	27	9.2
40-49	60	20.3	France	5	1.7
50-59	32	10.8	ROI	46	15.6
60-69	17	5.8	Israel	11	3.7
70+	5	1.7	New Zealand	3	1
Unknown	8	2.8	UK	47	15.9
Respondent gender			South Africa	25	8.5
Male	67	22.7	Sweden	1	0.3
Female	222	75.3	UAE	12	4.1
Other	2	0.7	USA	107	36.3
Unknown	4	1.4	Unknown	2	0.7
PWCF age (years)			Continent		
<10	69	23.4	Africa	25	8.5
10-15	27	9.2	North & South America	135	45.8
16-19	23	7.8	Europe	104	35.3
20-29	67	22.7	Australia & Oceania	6	2.0
30-39	66	22.4	Asia	23	7.8
40-49	28	9.5	Unknown	2	0.7
50-59	7	2.4	English is an official language		
60-69	3	1	Yes	258	87.5
70+	2	0.7	No	35	11.9
Unknown	3	1	Unknown	2	0.7

PWCF, person with cystic fibrosis; CF, cystic fibrosis; ROI, Republic of Ireland; UK, United Kingdom; USA, UAE, United Arab Emirates; United States of America.

*caregivers, CF charity workers, family, friends, other.

Notes:

Given the voluntary nature of the survey, none of the questions asked in the questionnaire were mandatory and as such, data is expressed (%) in terms of those individuals who answered the individual questions. Due to the small representation of some countries, they were grouped into continents for the purposes of statistical analysis. Similarly, parents were split into two groups; those with children <18 years old and those with children ≥ 18 years old. This is due to the fact that legally a child becomes an adult at age 18, therefore the groups reflected parents of adults and children.