

Cystic Fibrosis Queensland 2019 Survey

This year our survey received 149 respondents:

- 66 parents of children with cystic fibrosis
- 50 adults with cystic fibrosis
- 3 partners of cystic fibrosis adults
- 2 teenagers with cystic fibrosis
- 10 cystic fibrosis clinicians
- 14 parents and grandparents of adults with cystic fibrosis
- 2 siblings of people with cystic fibrosis
- 1 didn't nominate

Information was collected on a number of key areas including:

- General information (region, age, Cystic Fibrosis Queensland memberships, life challenge)
- Supportive networks
- Overall health conditions (transition, comorbidity)
- Cystic Fibrosis Queensland level of services understanding and satisfaction
- National Cystic Fibrosis advocacy understanding

1. Region

	Percentage	Number
Brisbane - City or surrounding postcodes	45.95%	68
Gold Coast	9.46%	14
Sunshine Coast/Wide bay	13.51%	20
Toowoomba/Darling Downs/Granite Belt	6.76%	10
Central Queensland	5.41%	8
North Queensland	5.41%	8
Far North Queensland	5.41%	8
Northern NSW	2.03%	3
Northern Territory	1.35%	2

46 % of the respondents live in Greater Brisbane, 13.51% live at the Sunshine Coast and Wide Bay and 9.46% live at the Gold Coast. A small percent of respondents are from Toowoomba/Darling Downs/Granite Belt, Central Queensland, North Queensland, Far North Queensland, Northern New South Wales and the Northern Territory.

2. Clarified respondents

	Number	Percentage
Adult with CF (18-35 years)	29	20.86%
Adult with CF (over 35 years)	20	14.39%
Parent with CF children (0-11 years)	53	38.13%
Parent with CF children (11-18 years)	13	9.35%
Partner of a CF adult	3	2.16%
Teenager with CF (12-18 years)	2	1.44%

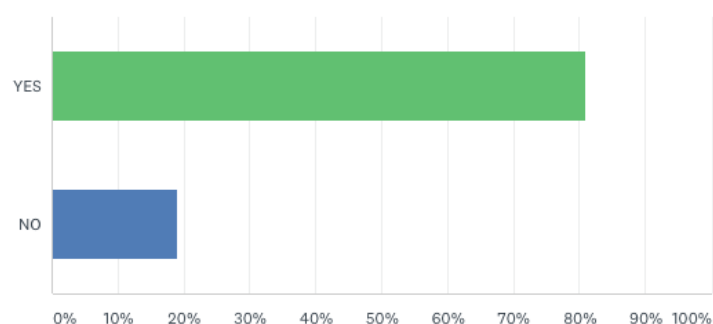
The 67 children represented in the survey ranged from the age of 0 -18 years (52 children ranged from the age of 0-11 years, 15 children in ranged from the age of 12-18 years). Of the 52 adults represented in this survey, three people identify as cystic fibrosis partners. 60% of the cystic fibrosis adults, fall into the range of 19-35 years and 40% identified themselves as over 35 years.

Clinicians

	Respondents	Percentage
Social worker	0	0%
Cystic fibrosis clinician (medical)	0	0%
Cystic fibrosis nurse practitioner	2	33.33%
Dietician	0	0%
Physiotherapist	3	50%
*Other	1	16.67%

Of the 10 clinicians, two are cystic fibrosis nurse practitioners, three are physiotherapists, one is a respiratory scientist and four did not clarify.

3. Membership

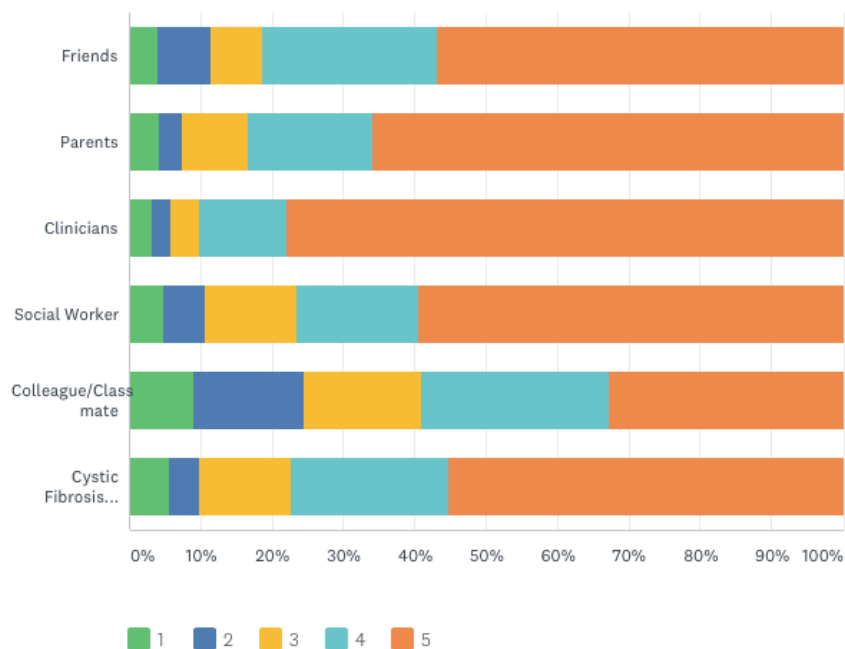


	Number	Percentage
Yes	107	80.06%

No	25	18.94%
----	----	--------

107 people identify themselves as a member of Cystic Fibrosis Queensland and 25 people responded that they were not a Cystic Fibrosis Queensland member. The number one reason (5 of 21 respondents) people provided was that they were unaware of membership. Some of the other reasons provided for not being a member were: relatives are members, financial issues, membership has expired.

4. Support network



	Number	Average score
Friends	123	4.23
Parents	120	4.38
Clinicians	122	4.59
Social worker	123	4.20
Colleague/Classmate	122	3.58
Cystic Fibrosis Queensland staff	123	4.17

For people living with cystic fibrosis, they are most comfortable talking about their health with friends, parents, clinicians, social workers and Cystic Fibrosis Queensland (average score 4.32 out of 5) as opposed to colleagues and classmates (average score 3.6 out of 5). The role Cystic Fibrosis Queensland plays in educating the broader public and raising awareness about the disease remains important to the community as it lessens the burden of people having to personally explain the condition and treatment.

5. Comorbidity

Responses from CF parents, CF partners, CF adults and CF teenagers:

	Number	Percentage
Autism spectrum	3	6.25%
Bronchiectasis	10	20.83%
Cerebral palsy	0	0%
Diabetes	25	52.08%
Osteoarthritis	3	6.25%
Osteoporosis	5	10.42%
Renal failure	2	4.17%
Others	23	47.92%

More than 50% of cystic fibrosis respondents (48) said that they are suffering from diabetes. 37% of cystic fibrosis people 12 years and over experience chronic insulin-dependent diabetes. Diabetes is 4.9% of the entire Australian population making it 10.2 times more prevalent in people with Cystic Fibrosis.

The second highest comorbidity is Bronchiectasis as this is experienced by 10 out of 68 of the respondents, accounting for 14.7%.

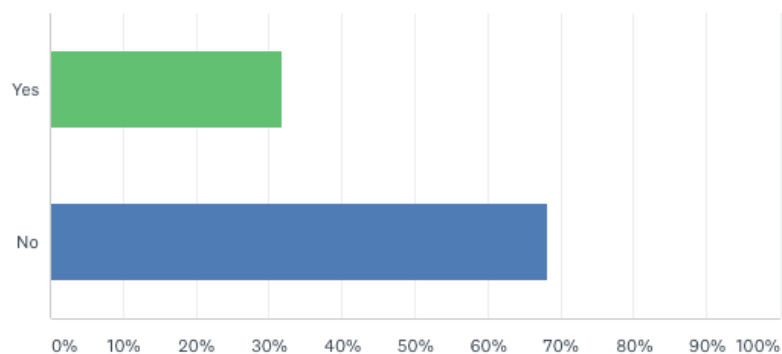
10.42% of respondents mentioned that they suffer osteoporosis. Compared with the entire population in Australia it is more than 2.74 times prevalent in people with cystic fibrosis (only 3.8% of people are living with osteoporosis in Australia).

Clinician responses

	Respondents	Average score
Autism spectrum	4	3.00
Bronchiectasis	4	3.00
Cerebral palsy	3	2.33
Diabetes	4	3.25
Osteoarthritis	3	4.00
Osteoporosis	3	3.00
Renal failure	4	3.50
Others	2	3.50

Due to the low number of clinical responses, it is not possible to use the data collected in the survey as a reflection of the cystic fibrosis population. The Australian Cystic Fibrosis Data Registry is to remain the primary source of information.

6. Difficulty maintaining clinical adherence



	Respondents	Percentage
YES	37	31.9%
NO	79	68.1%

30.7% of people living with cystic fibrosis are struggling to maintain clinical adherence but 69.3% of this cohort are maintaining a positive attitude about their ability to maintain clinical adherence. This suggests that while clinical adherence presents a challenge, people are aware of the importance and do all that they can to maintain adherence.

**Specific areas which difficult to maintain clinical adherence for people with cystic fibrosis:
Respond (112 response) from CF parents, CF partners, CF adults and CF teenagers:**

	Respondents	Average score
Diet	107	4.85
Exercise	106	4.75
Time management	104	4.10
Financial issues	105	3.91
Work issues	102	3.97
Mental health and wellness concerns	106	3.59
Conversations regarding your child's health (parent only)	81	3.42

Respond (4 response) from CF clinician, which are most difficult for people with CF to maintain.

	Respondents	Average score
Diet	4	3.25
Exercise	4	3.50
Time management	4	3.75
Financial issues	2	2.50
Work issues	3	3.33
Mental health and wellness concerns	4	3.75
Conversations regarding your child's health (parent only)	2	3.50

Majority of people living with cystic fibrosis (average score above 4.00) are struggling to manage diet and exercise as well as time management for treatment which impacts on work. Their overall mental health and concerns about wellness rate higher than their concerns about their financial issues (average score 3.93). Clinicians tended to reflect this and also rated financial issues as a low challenge for people living with cystic fibrosis (2.50/5).

In the National Health Survey 2017-18, more than one in eleven people (10.4%) reported having the symptoms of depression or feelings of depression; 3.2 million Australians (13.1%) had an anxiety-related condition. Parents of cystic fibrosis children are especially struggling to maintain their mental health and overall wellbeing (3.59). This is 71.8% of all respondent (112 responses) and was at a much higher level than the majority of Australians.

Clinicians rated diet (3.25/5) and time management (3.75) among the biggest adherence challenges for people with Cystic Fibrosis.

7. Cystic Fibrosis Queensland Support Programs

Awareness of Cystic Fibrosis Queensland programs

	YES	%	NO	%	Respondents
E-newsletters	89	94.58%	5	5.32%	94
Physical Activity Subsidy (\$150 per year)	82	87.23%	12	12.77%	94
In-hospital Program for children–Boredom Buster Bag	79	84.95%	14	15.05%	93
Airway Clearance Equipment via hospital physio referral	76	81.72%	17	18.28%	93
Loan Equipment (Oxygen concentrators/ Nebulisers, Positive Expiratory Pressure devices)	71	75.53%	23	24.47%	94
Hospital Parking Subsidy (\$75 per year)	65	68.42%	30	31.58%	95
Newly Diagnosed Support	63	67.02%	31	32.98%	94
Trampolines for Children (when a grant is available)	62	65.96%	32	34.04%	94
Concessions and Benefits- Help with Support Letters, Forms	61	64.89%	33	35.11%	94
Nebuliser subsidy (Provided every three years when a grant is available)	57	60.64%	37	39.36%	94
Discounts at Cystic Fibrosis Queensland Bookshop	56	59.57%	38	40.43%	94
Cleaning Subsidy (either parent of CF child or CF parent- \$200 per year provide when a grant is available)	49	52.13%	45	47.87%	94
Advocacy	46	50.55%	45	49.45%	91
Cystic Fibrosis Queensland Forum and Expo (annual event)	48	51.06%	46	48.94%	94
Education –CF Smart	45	48.91%	47	51.09%	92

Education – in-hospital tutoring	37	39.78%	56	60.22%	93
Little Day Out (\$150 per year provided when a grant is available)	36	38.71%	57	61.29%	93
In-hospital program for adults-Supermarket vouchers (\$20 up to four times per year)	28	29.79%	66	70.21%	94
No interest Loan Scheme (NILS)	26	28.26%	66	71.74%	92

The e-Newsletter is one of the most well-known programs and the No Interest Loan Scheme (NILS) is the lowest awareness of the respondents.

The Physical Activity Subsidy, Boredom Buster Bag, Airway Clearance Equipment, Loan Equipment, Hospital Parking Subsidy, Newly Diagnosed Support, Trampolines for Children, Concessions and Benefits, Nebuliser subsidy all have over 60% awareness across all groups. There is definitely an opportunity for continued promotion and reminders about all Cystic Fibrosis Queensland programs.

The 2018 survey identified that less than 25% of people were aware of advocacy. In the 2019 survey, more than 50% of respondents answered that they are aware of the advocacy programs. This has been a good improvement but there is still a way to go towards raising awareness.

However, only the minority respondents are familiar with programs introduced in 2019, (Little Day Out 38.71%, In-hospital program for adults 29.79%, In-hospital tutoring 39.78%). With consistent promotion, awareness should grow among members.

When asking people how donations should be spent there was a distinct difference between philosophical positions of common good versus individual need.

The top 10 programs which benefit an individual and where money should be spent are:

1. Concessions and Benefits - Help with Support Letters, Forms
2. Advocacy
3. Airway Clearance Equipment via hospital physio referral
4. Hospital Parking Subsidy
5. Loan equipment (Oxygen concentrators/ Nebulisers, Positive Expiratory Pressure devices)
6. Research
7. Education –CF Smart
8. Newly Diagnosed Support
9. In- hospital Program for children – Boredom Buster Bags
10. Physical Activity Subsidy

Individual

	Respondents	Score
Advocacy	73	16.63

Career Development Services	68	12.37
Cystic Fibrosis Queensland Forum and Expo (annual event)	71	11.61
Concessions and Benefits- Help with Support Letters, Forms	84	16.77
Discounts at Cystic Fibrosis Queensland Bookshop	67	10.16
Education –CF Smart	72	13.74
Education – tutoring	70	12.97
Hospital Parking Subsidy	84	16.20
Airway Clearance Equipment via hospital physio referral	85	16.44
In- hospital Program for children – Boredom Buster Bags	81	13.51
In-hospital program for adults-Supermarket vouchers	77	12.55
Loan equipment (Oxygen concentrators/ Nebulisers, Positive Expiratory Pressure devices)	88	15.31
Meet-ups for parents and partners	72	9.22
Newly Diagnosed Support	84	13.61
E-Newsletters	76	7.78
No interest Loan Scheme (NILS)	74	7.96
Physical Activity Subsidy	89	13.28
Trampolines for children	80	9.30
Research	84	13.92
Nebuliser Subsidy	84	12.17
Cleaning Subsidy	76	7.39
Little Day Out	73	5.07

The top 10 programs which benefit the community are:

1. Advocacy
2. Concessions and Benefits- Help with Support Letters, Forms
3. Airway Clearance Equipment via hospital physio referral
4. Hospital Parking Subsidy
5. Education –CF Smart
6. Cystic Fibrosis Queensland Forum and Expo (annual event)
7. Education – tutoring
8. In- hospital Program for children – Boredom Buster Bags
9. Career Development Services
10. Loan equipment (Oxygen concentrators/ Nebulisers, Positive Expiratory Pressure devices)

Common Good

	Respondents	Score
Advocacy	57	18.21

Career Development Services	46	14.59
Cystic Fibrosis Queensland Forum and Expo (annual event)	46	14.85
Concessions and Benefits- Help with Support Letters, Forms	56	16.43
Discounts at Cystic Fibrosis Queensland Bookshop	43	11.56
Education –CF Smart	52	15.94
Education – tutoring	51	14.65
Hospital Parking Subsidy	57	16,02
Airway Clearance Equipment via hospital physio referral	52	16.04
In- hospital Program for children – Boredom Buster Bags	54	14.59
In-hospital program for adults-Supermarket vouchers	48	12.57
Loan equipment (Oxygen concentrators/ Nebulisers, Positive Expiratory Pressure devices)	60	14.22
Meet-ups for parents and partners	48	9.25
Newly Diagnosed Support	60	13.60
E-Newsletters	49	8.71
No interest Loan Scheme (NILS)	48	7.96
Physical Activity Subsidy		12.19
Trampolines for children	52	8.90
Research	65	13.65
Nebuliser Subsidy	60	11.90
Cleaning Subsidy	46	4.46
Little Day Out	47	5.49

All respondents agreed that: Advocacy, Concessions and Benefits - Help with Support Letters and Forms, Airway Clearance Equipment via hospital physio referral, Hospital Parking Subsidy, Education – CF Smart, Loan equipment (Oxygen concentrators/Nebulisers, Positive Expiratory Pressure devices) and in-hospital program for children – Boredom Buster Bags are all in top 10 support programs. 70% of the top 10 support programs that benefit the individual and the broader community are the same.

Support programs to help maintain clinical adherence

	YES	%	NO	%	TOTAL
Concessions and Benefits - help with support letters, forms	39	50.65%	38	49.45%	77
Hospital Parking Subsidy	43	54.43%	36	45.47%	79
Airway Clearance Equipment via hospital physio referral	42	53.85%	36	46.15%	78

Loan Equipment (Oxygen concentrators, Compressors/Nebulisers, Positive Expiratory Pressure devices)	22	29.73%	52	70.27%	74
Physical Activity Subsidy	59	71.95%	23	28.05%	82
Trampolines for children	28	38.36%	45	61.64%	73
Nebuliser subsidy	39	50.65%	38	49.35%	74
Cleaning subsidy	11	14.86%	63	85.14%	74
Little Day Out	15	20.83%	57	79.17%	72

The most useful program delivered by Cystic Fibrosis Queensland is the Physical Activity Subsidy. More than 70% people think it is extremely useful for people with cystic fibrosis to maintain clinical adherence.

Respondents think the following programs are useful (approximately 50% useful, and 50% not very useful) to maintain clinical adherence: Concessions and Benefits - help with support letters and forms, Hospital Parking Subsidy, Airway Clearance Equipment via hospital physio referral and Nebuliser subsidy.

Loan Equipment (Oxygen concentrators, Compressors/Nebulisers, Positive Expiratory Pressure devices), trampolines for children, cleaning subsidies for single parents and Little Day Out were deemed to be are not very useful. This is justified as these programs target psychosocial needs, home physiotherapy, welfare and of course, assist people awaiting transplant or at end of life stage.

The strength of Cystic Fibrosis Queensland programs

Respondents rated 3.7 out of 5 stars regarding their satisfaction with Cystic Fibrosis Queensland programs. The strength of Cystic Fibrosis Queensland programs are the subsidy services, outreach, education, communication support and advocacy.

Suggestions about what programs provided by other Cystic Fibrosis State and Territory members of the Federation would like to see delivered by Cystic Fibrosis Queensland.

1. Siblings days
2. Mothers' retreats and more parent meet ups

Cystic Fibrosis Queensland did hold a range of parent dinners and meets up both this year and last, they all drew very low attendance and therefore cost prohibitive. As this has been identified as a need, Services will contact specific respondents for further information as to what they are seeking.

8. Advocacy:

Awareness of Cystic Fibrosis Queensland's Advocacy

	YES	%	NO	%	Total
Prince Charles Hospital Adult Cystic Fibrosis Centre	33	39.29%	51	60.71%	84
State support for the Federal Orkambi campaign	61	73.49%	22	26.51%	83
State support for the Federal Kalydeko campaign	54	65.85%	28	35.15%	82
Mental Health Roadshow- state forums	23	27.71%	60	72.29%	83

73.49% knew about the Orkambi campaign and 65.85% of respondents knew about the Kalydeko campaign. More work is to be done about raising awareness of the state success which has occurred i.e. the refurbished adult ward at The Prince Charles Hospital.

The advocacy areas that people would like the Cystic Fibrosis Federation of Australia to focus on

	Respondents	Score
Health Care Card of all people with cystic fibrosis	85	3.49
National Diabetes Services Scheme for all people with cystic fibrosis	83	1.94
Access to Symdeko	84	2.44
Free hospital parking provided by the Government for outpatient visits	85	2.13

Most respondents hope the Cystic Fibrosis Federation of Australia can improve the health care card access for all people with cystic fibrosis. Next in turn is access to Symdeko (which has already commenced in Australia).

9. Specific questions for parents who have a child with cystic fibrosis

	Respondents	Score
Maintaining my child's clinical adherence	54	3.65
Supporting my child with their mental health challenges	56	3.96
Helping my child to overcome the challenges of living with cystic fibrosis while still being able to enjoy their childhood	55	2.96
Ensuring that my child is motivated to exercise	55	3.75
Ensuring that my child follows their recommended diet	58	3.43
Developing my child's sense of agency independence and being positive about their future	59	2.93

Supporting my child with their mental health challenges was the highest concern for most parents (3.96 of 5) followed by maintaining their child's clinical adherence (3.65), ensuring that their child is motivated to exercise (3.75), and ensuring that their child follows their recommended diet (3.43). This followed a very similar pattern to the 2018 and 2017 survey.

The stress level of looking after a child with cystic fibrosis (level 1 to level 5)

Parents rated themselves as extremely anxious – 4 out of 5. This is the same result as previous surveys and reiterates the importance of mental wellbeing and the mental health programs being created across the Cystic Fibrosis Australian Federation.

References:

Australian Bureau of Statistics (ABS) 2017–18 National Health Survey (NHS)

Australian Cystic Fibrosis Data Registry 2017

Cystic Fibrosis Queensland 2019 Survey