

Cystic Fibrosis Queensland Annual Survey – 2021

This year Cystic Fibrosis Queensland's annual survey received 77 responses:

- 3 Parents/Guardians of a newly diagnosed child with cystic fibrosis (0 to 12 months)
- 38 Parents/Guardians of a child with cystic fibrosis (12 months to 18 years)
- 3 Teenagers with cystic fibrosis (13 to 17 years)
- 12 Adults with cystic fibrosis (18 to 35 years)
- 20 Adults with cystic fibrosis (over 35 years)
- 1 Clinician to a patient with cystic fibrosis

General Questions

Region

Central Queensland	2
Gold Coast	9
Greater Brisbane	28
Northern NSW	3
North Queensland	3
Northern Territory	0
Sunshine Coast/Wide Bay	9
Toowoomba/Darling Downs/Granite Belt	4
Other	12

Postcodes listed in the other region were noted as 4415, 4306, 2400, 4509, 4285, 4152, 4304, 2400, ACT, 4825.

Parents/Guardians of children living with cystic fibrosis

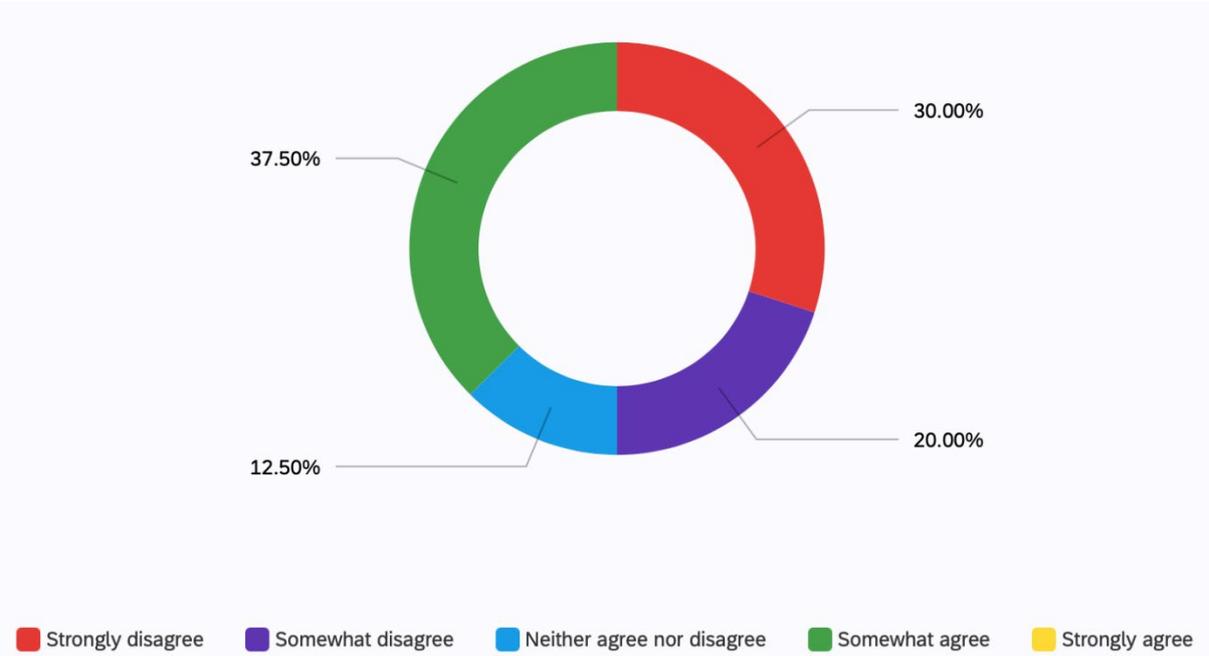
92.5% of parent respondents were mothers of children living with cystic fibrosis and 7.5% were fathers. No grandparents or guardians answered the survey.

10% of parent respondents had children aged within 0 to 12 months (newly diagnosed), while 90% had children aged between 12 months to 18 years.

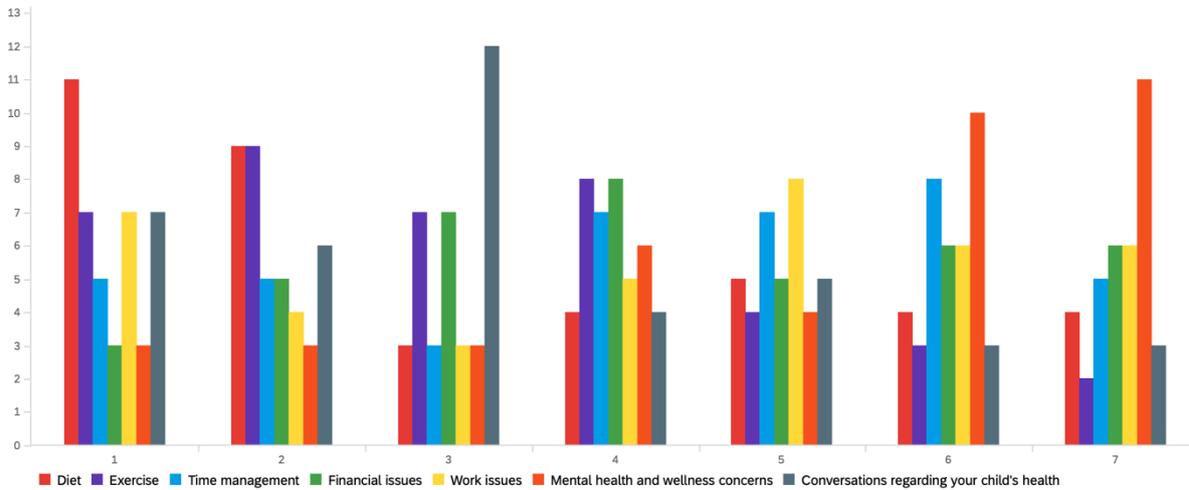
90% of parents have only one child living with cystic fibrosis within their care, while 10% have two or three children within their care.

97.5% of parents did not know that they were a carrier of the cystic fibrosis gene before their child was first diagnosed with cystic fibrosis.

45% of parents who have a child/ren without cystic fibrosis (in addition to their cystic fibrosis child/children) know if their child is a carrier of the cystic fibrosis gene, while 32.5% do not know.

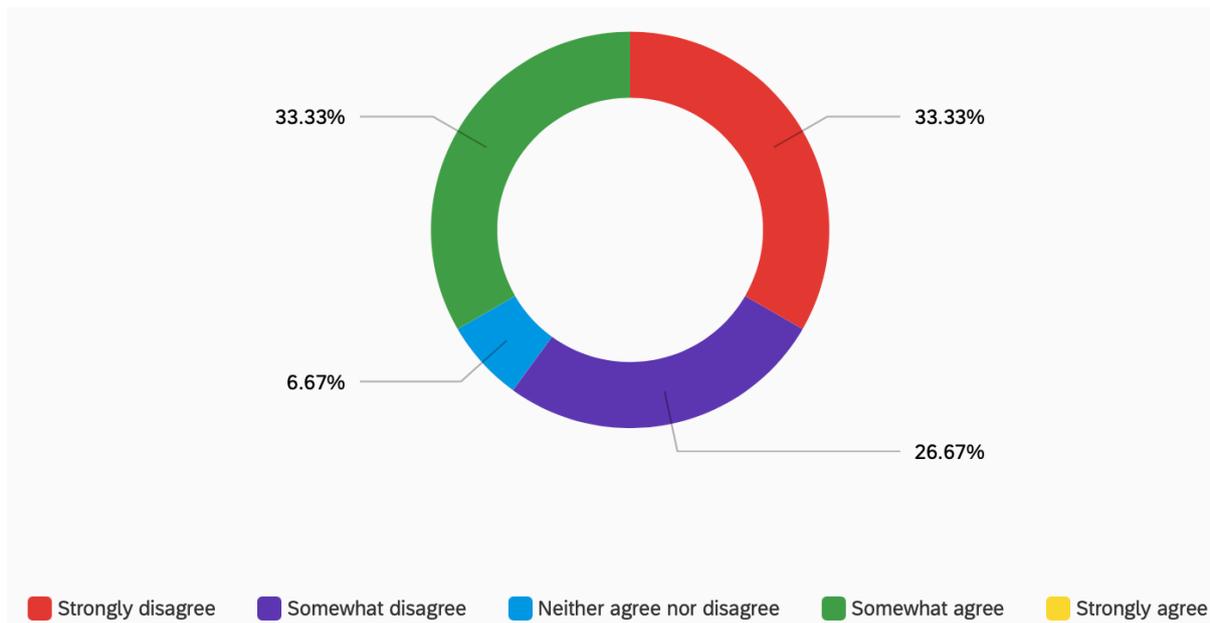


37.50% of parent respondents somewhat agreed it was difficult to adhere to their child's clinical treatments. 30% of parent respondents strongly disagreed to this statement.

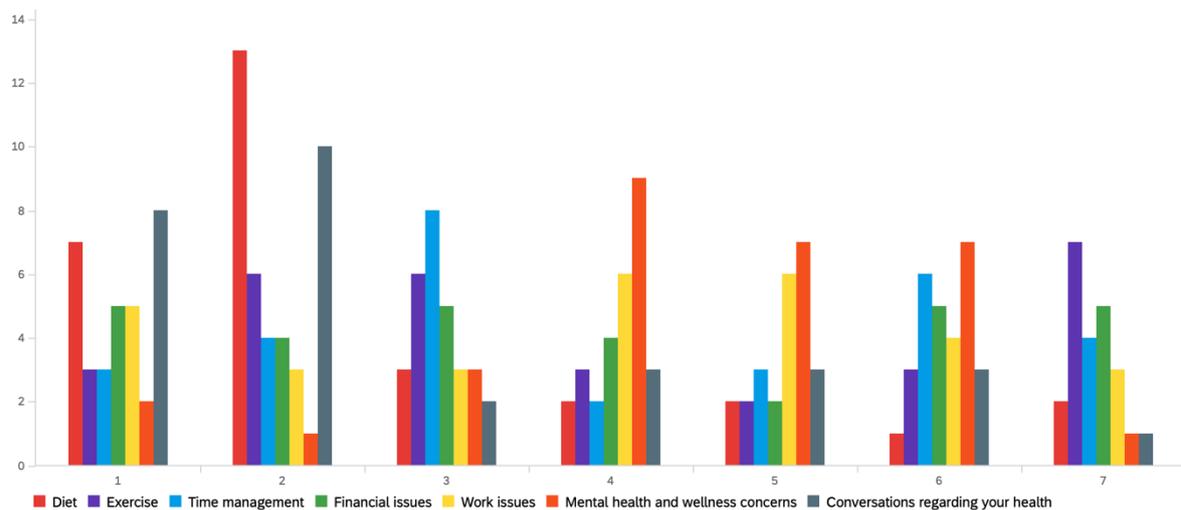


For parents of children living with cystic fibrosis, diet and exercise were ranked as the easiest clinical treatments to adhere to, while mental health and wellness concerns and time management were ranked as the most difficult clinical treatments to adhere to.

Teenager and adults living with cystic fibrosis



Like the parents of children living with cystic fibrosis, 33.33% of respondents somewhat agreed it was difficult to adhere to their clinical treatments. 33.33% of respondents strongly disagreed to this statement.



For teenagers and adults living with cystic fibrosis, diet and conversations regarding their health were ranked as the easiest clinical treatments to adhere to, while exercise, mental health and wellness concerns and time management were ranked as the most difficult clinical treatments to adhere to.

4 respondents had received a transplant. Those who had a transplant, manage their cystic fibrosis through a transplant team and their general practitioner. It was suggested that Cystic Fibrosis Queensland can assist people post-transplant through food delivery services and financial support for exercise. The charity's members does include post-transplant therefore there is opportunity to promote support and services.

Cystic Fibrosis Queensland programs

All respondents were members of Cystic Fibrosis Queensland. Respondents listed financial support from subsidies and grants, and equipment as the two most valuable aspect of their membership. Other listed aspects include the support network, education, awareness, and guidance.

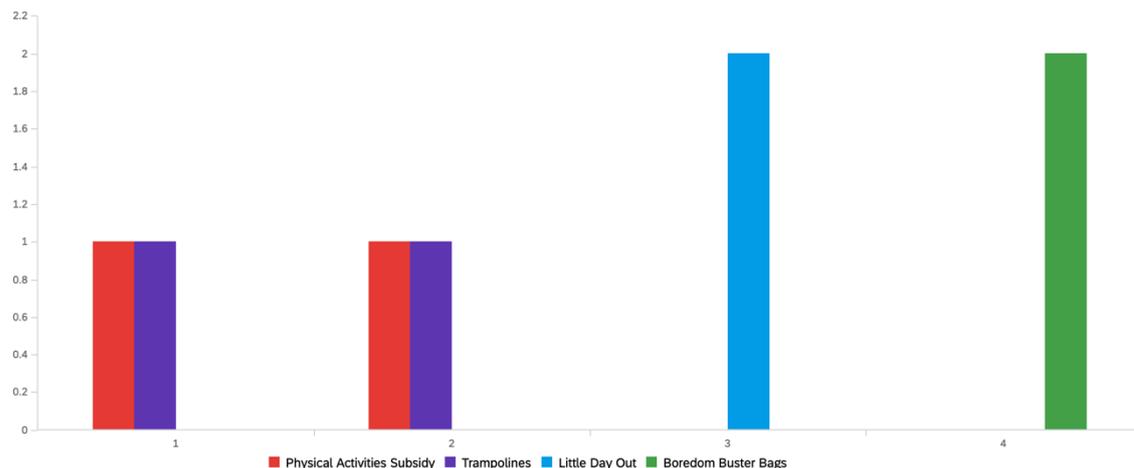
Newly diagnosed kits

Of the respondents within the newly diagnosed category, 66.67% of parents received a newly diagnosed kit, however, only 50% found this kit valuable. The most valuable aspect of the kit for this category was the information booklet. It was suggested that references to further readings (case studies), expectations for hospital visits and links to established support groups could have improved the kits.

Of the respondents with children aged 12 months to 18 years, 62.61% did recall receiving a newly diagnosed kit upon their child's initial diagnosis. 75% of respondents found this newly diagnosed kit valuable. The most valuable aspects of the kit for this category were the trusted source of information and connection to other people with cystic fibrosis. The ability to pass the booklet onto family and friends was also listed as a valuable aspect. It was suggested that forecasts of potential costs, childcare education information, list of available government payments and subsidies and a list of established support groups or other new parents could have improved the kits.

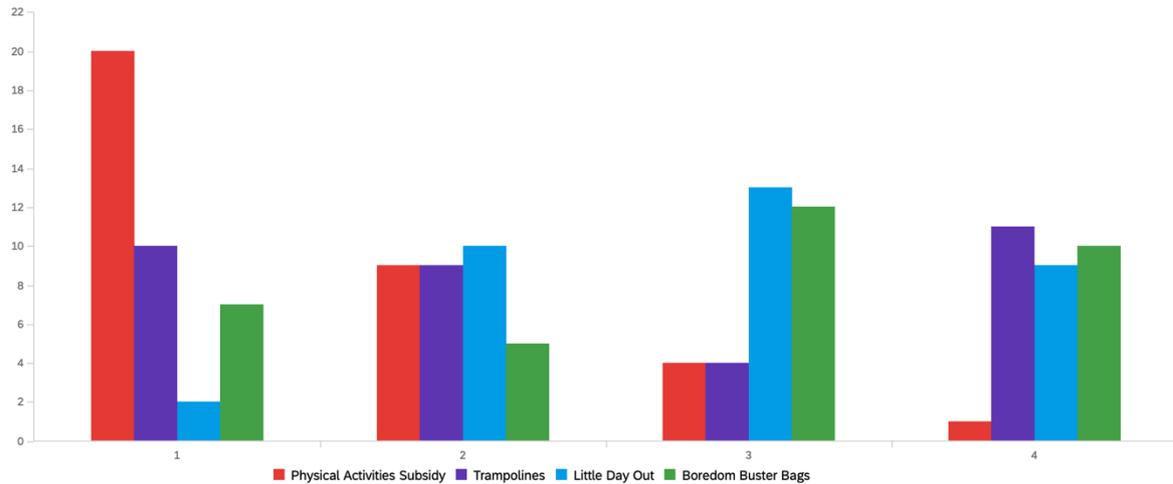
Health and Wellness programs

Within the parent of newly diagnosed category, 2 physical activity subsidies, 1 trampoline and 1 little day out have been utilised.



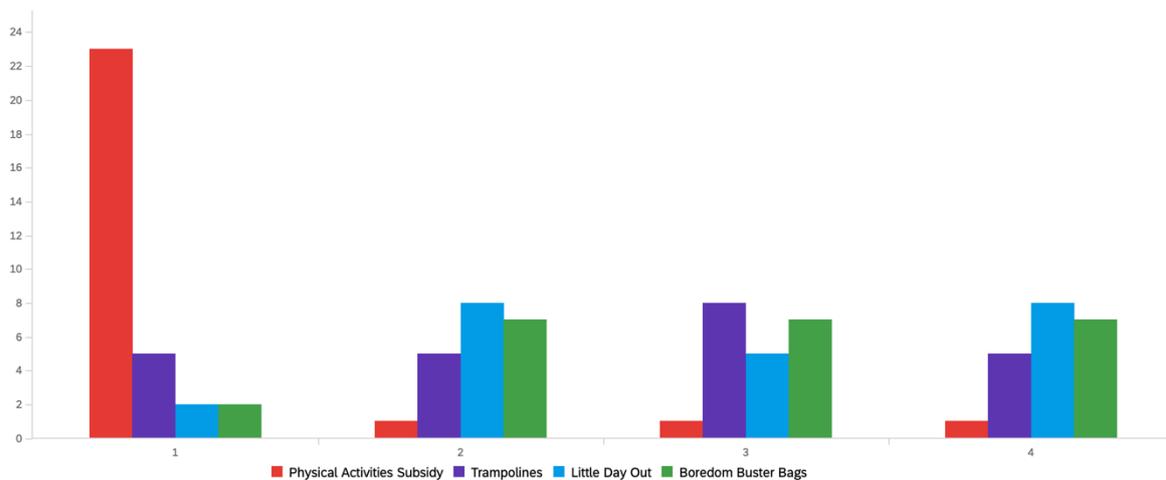
The physical activity subsidy and trampolines were equally ranked of highest importance, followed by little day out and boredom buster bags.

Within the parent of children aged 12 months to 18 years category, 26 physical activity subsidies, 21 trampoline, 22 little day out and 22 boredom buster bags have been utilised.



The physical activity subsidy was ranked of highest importance, followed by trampolines, boredom buster bags and little day out.

Within the teenagers and adult's category, 21 physical activity subsidies, 1 trampoline, 7 little day out and 4 boredom buster bags have been utilised.



The physical activity subsidy was ranked of highest importance, followed by trampolines, little day out and boredom buster bags

Equipment programs

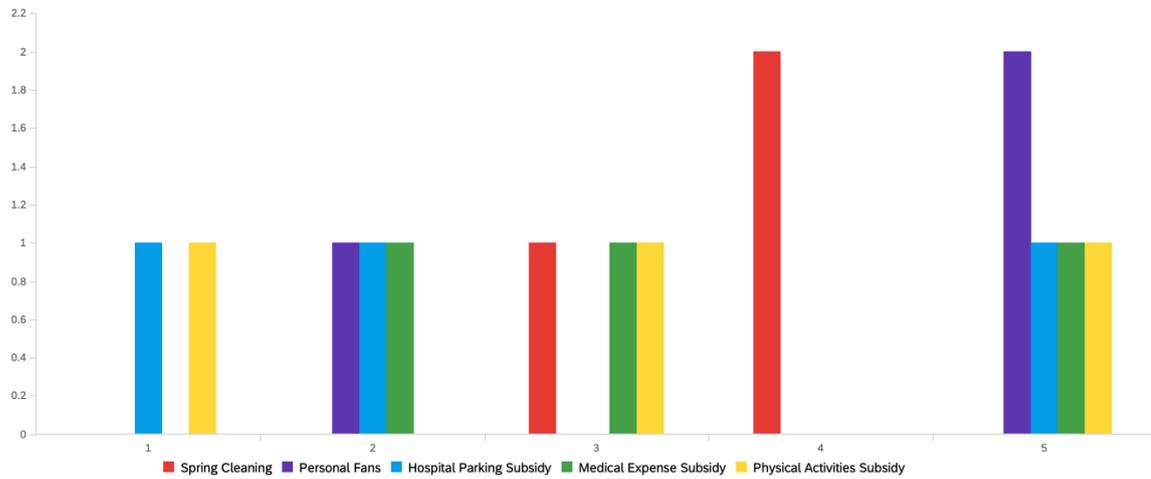
Within the parent of newly diagnosed category, none of the equipment programs have been utilised.

Within the parent of children aged 12 months to 18 years category, 31 personal nebulisers, 6 airways clearance equipment, 5 spirometers and 1 oxygen concentrators have been utilised.

Within the teenagers and adult's category, 17 personal nebulisers, 11 airways clearance equipment, 13 spirometers and 1 oxygen concentrators have been utilised.

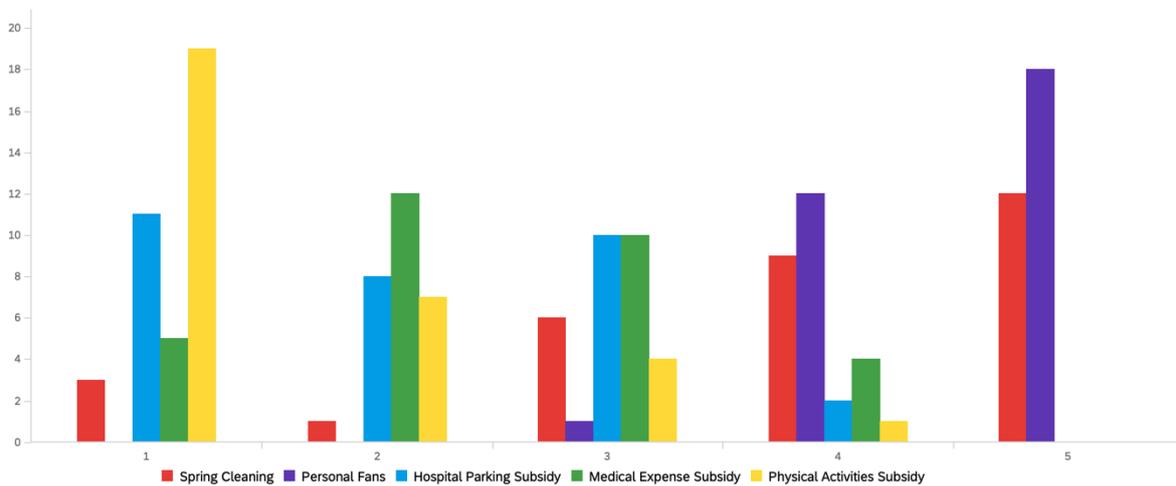
Welfare programs

Within the parent of newly diagnosed category, 3 hospital parking subsidies, 2 medical expense subsidies and 1 physical activity subsidy have been utilised.



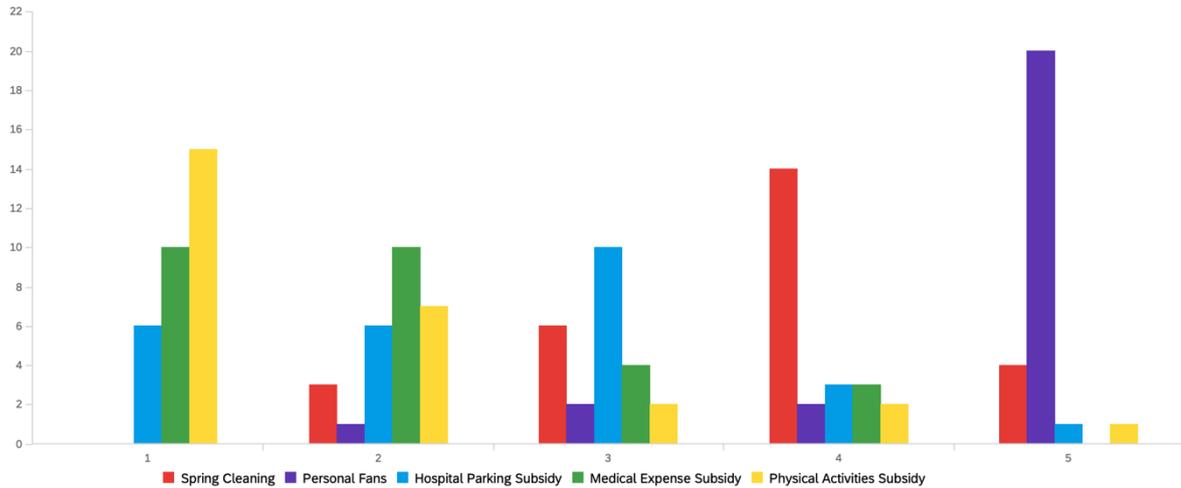
The physical activity subsidy and hospital parking subsidy were equally ranked of highest importance, followed by medical expense, personal fans, and spring cleaning.

Within the parent of children aged 12 months to 18 years category, 22 hospital parking subsidies, 13 medical expense subsidies, 26 physical activity subsidies, 10 personal fans and 3 spring cleanings have been utilised.



The physical activity subsidy, hospital parking subsidy and medical expenses subsidy were ranked of highest importance, followed by spring cleaning and personal fans.

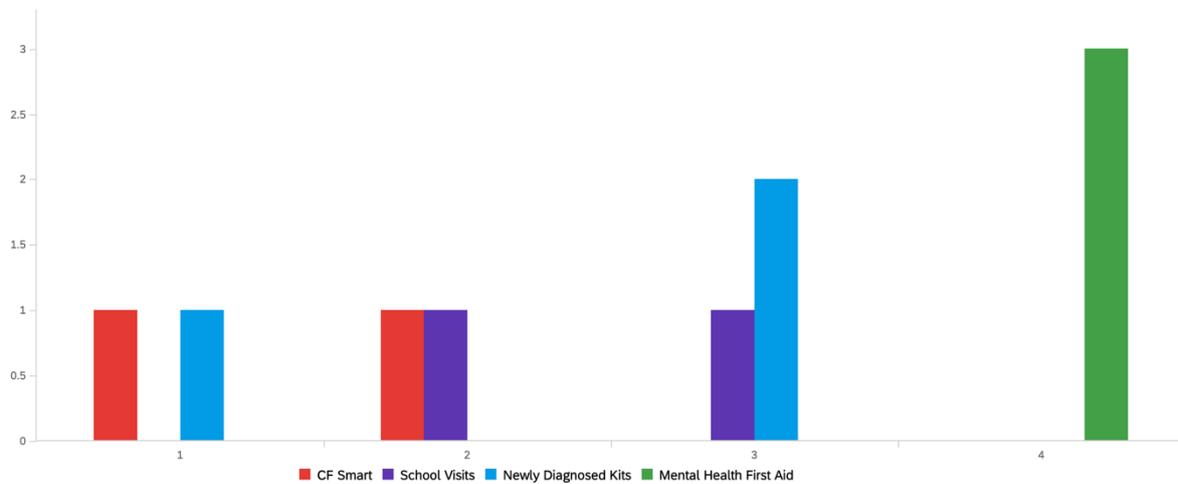
Within the teenagers and adult's category, 16 hospital parking subsidies, 10 medical expense subsidies, 19 physical activity subsidies, 4 personal fans and 8 spring cleans have been utilised.



The physical activity subsidy, medical expense subsidy and hospital parking subsidy were ranked of highest importance, followed by spring cleaning and personal fans.

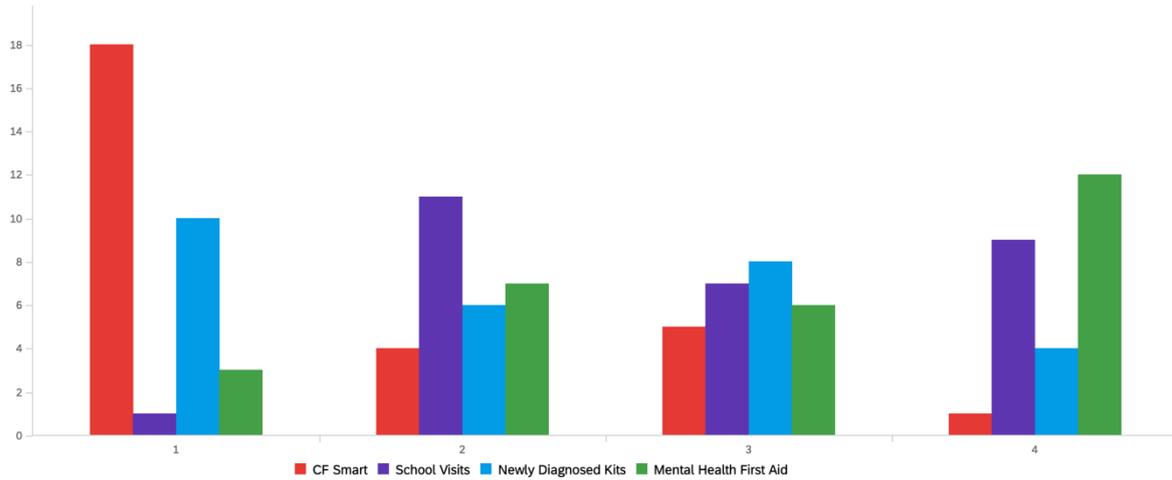
Education programs

Within the parent of newly diagnosed category, 1 CF Smart, 3 Newly diagnosed kits and 1 mental health first aid were utilised.



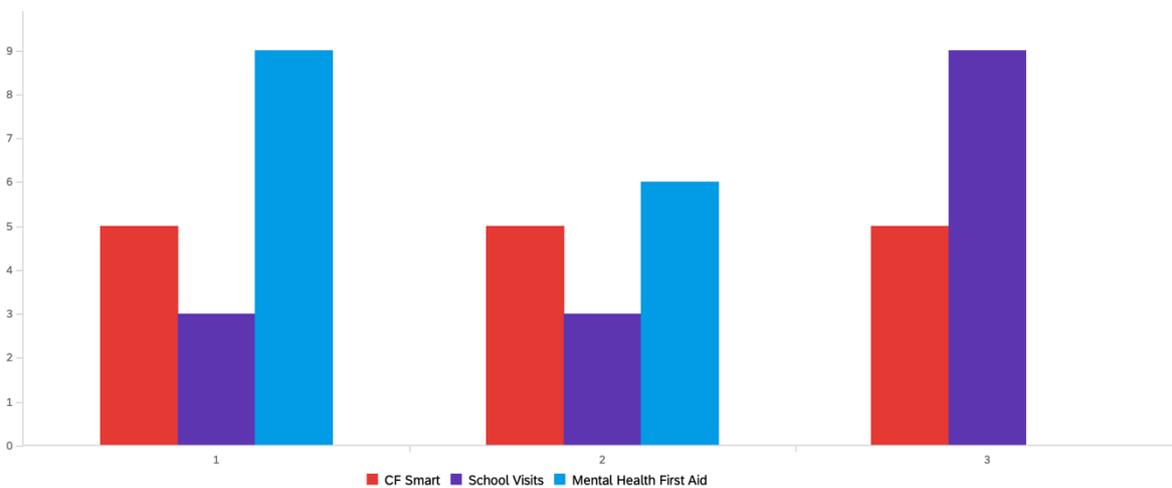
The CF Smart and Newly diagnosed kits were equally ranked of highest importance, followed by school visits and mental health first aid.

Within the parent of children aged 12 months to 18 years category, 21 CF Smart, 1 school visit and 13 newly diagnosed kits were utilised.



The CF Smart and Newly diagnosed kits were ranked of highest importance, followed by school visits and mental health first aid.

Within the teenagers and adult's category, 1 CF Smart and 2 mental health first aid were utilised.



The Mental health first aid was ranked of highest importance, followed by CF Smart and school visits.

NDIS

Only 1 respondent has access to NDIS funding, 1 is in the process, while 66 respondents did not. 5 respondents were able to obtain NDIS funding through cystic fibrosis, while 3 respondents were able to obtain funding through another comorbidity.

63.2% of respondents did not know that Cystic Fibrosis Queensland is a national NDIS provider. There is still a lot of awareness work to be done.

Cystic Fibrosis Queensland Community Advisory Committee

48.5% of respondents knew of Cystic Fibrosis Queensland's Community Advisory Committee, while 51.5% of respondents did not know.

Only 12.5% of respondents had attended one of the online support forums.

Respondents ranked the suggested topics to be covered by these forums of importance as follows:

1. Mental Health Challenges and how to overcome them
2. Conversations with your School
3. Challenges from transitioning from Paediatric Clinics to Adult Clinics
4. What to look for in your Day Care Centre
5. Planning for the future - attending university

Further suggestions of information to be covered by these forums included:

- Career advice and entering new workplaces (i.e., jobs that require pre-medical, rights and disability discrimination)
- General lifestyle and living with cystic fibrosis (i.e., medications, medical appointments etc.)
- Talks to pre-teens and teenagers about importance of compliance to medication and treatments
- Cystic fibrosis women becoming mothers (lead into a virtual mother's support group)

Cystic Fibrosis Queensland Bookshop

80% of respondents had previously heard about the Cystic Fibrosis Queensland Bookshop, although 66.80% of respondents have not ever visited the bookshop.

65.15% of respondents were not aware of the discounts received by Cystic Fibrosis Queensland members at the Bookshop. There is opportunity for continued awareness about the bookshop to our members.