

3 June 2021



WE ARE LISTENING

Over the past 12 months we have surveyed the CF Community to ensure that Cystic Fibrosis Australia (CFA) and the Australian Cystic Fibrosis Trust (ACFRT) are working effectively to meet the community's needs.

The findings from the Research Priority Setting program have been enlightening and following the Think Tank, which is the final phase of the program, we will share what research we plan to fund in the future.

You have shared what matters to you and we are listening.

As a further check point, we have decided to offer 'Wild Card' research topic entries that will be considered at the Think Tank. This we hope will stimulate innovation and creative thinking and that is what is needed to overcome some of the CF hurdles we face.

'Wild Card' entries are the penultimate phase to the Research Priority Setting Survey. They can be a pet project that you would like to see funded or you can select from the list of Additional Research Priorities below.

Using this grid email your ideas to nickim@cfa.org.au by Friday, 18th June 2021.

WILD CARD Research Priority Entry					
Respiratory	Clinical Trials	Mental Health	Gastrointestinal	General Clinical Medical	Reproduction
I would like to participate in the Think Tank			YES/NO	Email:	

I have included the Research Priority Results from Survey Two and a list of extra priorities that did not make the top three list in each category. Your 'Wild Card' entry can change this.

Thank you for your insights and participation. We share a common commitment to consumer, researcher and clinician led research and I look forward to sharing the findings with you later in 2021.

Kind regards

A handwritten signature in black ink that reads 'Nettie Burke'.

Nettie Burke
CEO
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Australian Cystic Fibrosis Australia Trust

Research Priorities

Survey Two Results

April 2021

Overarching Research Priorities in preference order

% of people who ranked this as a Top Three Priority

1. Respiratory	69%
2. Clinical Trials	66%
3. Mental Health	64%
4. Gastrointestinal Tract Pancreas, Liver and Bile	51%
5. General Clinical and Medical	31%
6. Reproduction	19%

Top Three Issues

1. Respiratory
 - a. Infections and Antibiotic resistance
 - b. Sinus
 - c. Bacteriophages, phage's and macrophages
2. Clinical Trials
 - a. CFTR modulators
 - b. Precision Medicine/personalised solutions (Nof1, Organoids, Basket/Adaptive Trials)
 - c. Treatments for comorbidities
3. Mental Health
 - a. Coping strategies – CBT, IPT, ACT & Mindfulness
 - b. Psychological effects of a progressive disease
 - c. Early intervention to improve future outcomes
4. Gastrointestinal Tract Pancreas, Liver and Bile
 - a. Early diagnosis/detection, intervention and prevention
 - b. Relationships between GI complications and lung flares
 - c. Gut and Lung Microbiome relationship
5. General Clinical and Medical
 - a. Chronic Comorbidities
 - b. Infection Control
 - c. Standards of Care and CF Centre variability
6. Reproduction
 - a. CFTR Modulators impact on fertility
 - b. Mucosal health
 - c. Antibiotics and sexual health

As the penultimate phase to the Research Priority Setting Survey CFA is offering the CF Community the chance to nominate a 'Wild Card' research topic that would improve the lives of people with CF. You can select from the list below to create your own research focus. Email nickim@cfa.org.au by 18th June 2021.

WILD CARD Research Priority Entry

Respiratory	Clinical Trials	Mental Health	Gastrointestinal	General Clinical Medical	Reproduction

Additional Research Priorities		
1.	Treatment Burden	
	Chronic disease and learning difficulties	Physio options
	Support for job search	Steroid use – evidence and patient consultation
	Educational support	Fungal colonisation
	Adherence especially in children and adolescents	Mucus
	Support during hospitalisations	Pain
	Milestones and illness progression	Financial burden of the disease
2.	Diet	
	Weight management – adults and paed	Enzyme dosing in children
	Supplements & vitamins	Probiotics and CF
	Natural medicines and treatments	Constipation, diarrhea and associated pain
3.	Effect of CFTR Modulators	
	On physio	On anti-depressants
	On Weight management – adults and paed	On reproduction and pregnancy
	On pancreas	How to get the right one for me?
4.	Comorbidities and Models of Care	
	Infertility	CFRD and CFLD
	ADHD	Maternal health
	Spectrum disorders	Related cancers
	Food intolerances	Endometriosis
	Meconium ileus	Menopause
	Inflammation	Hormonal impacts – lung bleeds
	Asthma	Coronary heart disease
	Emphysema	Osteoporosis and osteopenia
5.	Digital Health and Models of Care	
	Use of biometrics to detect exacerbation	In home diagnostic tools
	Regional and remote (R&R) community outcomes	Wearables
	Standards of Care in R&R Clinics V's Metro	Tele/Video Standards of Care
6.	Infection	
	The effect of long term use of antibiotics	Optimising antibiotics
	Phages	Vaccine development
	Antimicrobial resistance	New Super Bugs
7.	Mental Health	
	Life changes after life changing drugs	Peer Support
	Family based therapy	Reducing burden of treatments
	ACT - Acceptance & Commitment Therapy	Gender differentials
	Family support and Respite	Life planning for adults with CF
	End of life anxiety	Transplant anxiety
	Needle phobia	Annual depression and anxiety checks for family