

Priority Setting Survey One Results – September 2020

Cystic Fibrosis is thrilled to share findings from the initial phase of our Research Priority Setting program and we would primarily like to thank the 154 people who took the time to complete the survey.

Two thirds of respondents were consumers and 79% of respondents were aged between 25 – 54 years. 67% of respondents live in metro areas while 25% live in the regions. 8% did not answer this survey. There was great representation from each State and Territory (TAS – 6%, WA – 17%, SA – 11%, VIC – 21%, ACT – 4%, NSW – 27% and QLD – 14%).

94% of consumer respondents have at least one F508del gene mutation and 17+ nationalities are represented (Australian Euro; English; Asian; Irish; NZ; Welsh; Spanish; German; French; Estonian; Polish; Indian; Dutch; Italian; Maltese and Indigenous) which mirrors the wonderful multicultural society that we live in.

Thanks must also go to the 56 people who have asked to participate in the Think Tank being held in 2021. In the new year we will begin the selection process. We need to have comparable numbers of consumers, MTD team members, medical specialists and researchers.

The first Research and Advocacy Priority Setting survey had nine medical sections and they are ranked below in order of respondent priority.

1. Respiratory

Respiratory issues were seen as most important for people with cystic fibrosis (CF) gaining 73% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. Early detection and eradication of infections
2. Antibiotic resistance
3. Sinus
4. Lung infections - Bacteriophages, Phages and Macrophages

2. Clinical Trials and Personalised Medicine

Clinical trials were seen as the second most important issue for people with CF gaining 61% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. '2nd Corrector' CFTR modular medications
2. Personalised solutions for rare CF mutations using N of 1, organoids, basket and adaptive trials
3. Phage therapy
4. Mental health - Cognitive Behavioural Therapy, Interpersonal Therapy (IPT) and Mindfulness

3. Mental Health

Mental health was the third most important issue for people with CF gaining 46% of support across the two pillars of research and advocacy. Research Priorities included ...

1. Coping strategies like Cognitive Behavioural Therapy, Interpersonal Therapy (IPT) and Mindfulness
2. Psychological effects of a progressive disease
3. Early intervention of mental health supports to improve future outcomes
4. Needle and procedural phobias.

4. General Clinical

General clinical issues were numerous and fourth on the respondents' most important issue list, gaining 33% of interest across the two pillars of research and advocacy. This section also highlighted a number of concerns about the clinical environment. Research Priorities included ...

1. Management of Infection Control in CF Centres
2. CF-targeted physiotherapy and exercise regimes
3. Adherence by patients
4. Airway clearance and physical activity and fitness programs.

5. Pancreas

Research and advocacy issues relating to the pancreas were seen as important for people with CF by 32% of respondents. Research Priorities included ...

1. Early detection and interventions for CFRD
2. Nutrition and impaired pancreatic function
3. Hormonal changes and impaired pancreatic function
4. Therapies for pancreatitis including effects of CFTR modulators.

6. Gastro Tract

The gastro tract causes significant issues for people with CF and gained 32% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. Relationship between gastro-oesophageal reflux and lung flares
2. The Gut Microbiome and its relationship to the Lung Microbiome
3. Non-invasive strategies for relieving blocked digestion and constipation
4. Weight gain supplements and procedures.

7. Liver and Bile

Liver and bile complications gained 30% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. Early diagnosis
2. Prevention of disease, scarring and inflammation
3. Complications including cancer
4. Restoration of normal bile function.

8. General Medical

A number of research priorities were identified in the General Medical section and two patient centric advocacy priorities were captured. General Medical gained a rating of 22% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. Chronic conditions (Osteoporosis), immune health conditions (arthritis and celiac) and comorbidities
2. Complications from infection disease i.e. COVID-19 and influenza
3. Modulators and changes in effectiveness of Chloride Channel (salt balance)
4. Abdominal pain therapies.

9. Reproduction

Reproduction was an important section for young people with CF and parents of children with cystic fibrosis, gaining 22% of interest across the two pillars of research and advocacy. Research Priorities included ...

1. Restoration of restoring mucosal health to the uterine wall
2. Inhaled antibiotics to alleviating symptoms of candidiasis
3. IVF support.

The list above only includes the most popular Research Priorities and we know there are many more research opportunities. There is still scope for you to have your say and now is the time to go to the second Research Priority Setting survey <https://www.surveymonkey.com/r/7BKJFYL>.

This Survey will be open until **13 November 2020**. There is also still the opportunity to register your interest in being part of the Research Priority Setting Think Tank in early 2021.

Thank you for taking the time to shape cystic fibrosis research and advocacy for the next five years.

Regards

Nettie Burke

CEO

Cystic Fibrosis Australia

0404 034 294

nettieb@cfa.org.au