

2021-2026

# STRATEGIC PLAN



# EXECUTIVE SUMMARY

**Cystic Fibrosis Australia is the peak patient body in Australia and supports the broad cystic fibrosis community through advocacy, research, and clinical improvement.**

Cystic Fibrosis Australia is the voice of CF for government, industry, and the media.

We support Cystic Fibrosis Australia's members who provide valuable services to their cystic fibrosis communities. Our members include Cystic Fibrosis Western Australia, Cystic Fibrosis South Australia, Cystic Fibrosis Community Care, Cystic Fibrosis Queensland, Cystic Fibrosis Tasmania and Cystic Fibrosis Australian Capital Territory.

Working tirelessly to raise the profile of cystic fibrosis, we take key messages

to government, business, the health sector, and community to ensure that challenges faced by people with cystic fibrosis and their families are understood.

A new era of medications upon us, medications capable of targeting the basic defect in the cells of people with cystic fibrosis. These medications will have an unprecedented positive impact on the lives of people with cystic fibrosis.

**It is time to plan for the future.**



# OUR VISION & PRINCIPLES

## Our Vision

# Lives unaffected

BY CYSTIC FIBROSIS

## Our Principles



**Co-design:** Cystic Fibrosis Australia brings consumers, clinicians, and healthcare managers together to support the design, assessment and implementation of all advocacies, clinical improvement, and research projects.



**Collaboration:** Cystic Fibrosis Australia is committed to partnering with its members and a wide range of global and Australian stakeholders to drive innovation, programs, and services.



**Action-oriented:** All programs, projects and services are focused on reducing the burden on those with cystic fibrosis, their families, and their extended networks.



**Evidence-based advocacy:** Cystic Fibrosis Australia is committed to an evidence-based approach that is underpinned by the Australia Cystic Fibrosis Data Registry and activities of the Australian Cystic Fibrosis Research Trust.



**Reliability:** Using leading subject matter experts to inform our actions.



**Accountability:** Cystic Fibrosis Australia focusses on a defined set of programs that deliver improved life expectancy and quality of life for people with cystic fibrosis.



# OUR STRATEGIC PRIORITIES



**Access to a wide range of high-quality treatments to reduce the burden of the disease.**

Cystic Fibrosis Australia will work with our members, partners, and other stakeholders to enable access to the best high-quality medications and devices at affordable prices and opportunities to access financial supports.

## Key actions

- Secure medicines and treatments that are available overseas but not yet in Australia as was the case with Trikafta
- Attract clinical trials to Australia and establish the Clinical Trial Alliance
- Advocate to reduce national barriers to health and social services (e.g., diabetes support)

## Measures of success

- Registration of Trikafta on the Pharmaceutical Benefits Scheme for all age groups informed by evidence on safety and efficacy
- Increase in new treatments registered on the Pharmaceutical Benefits Scheme
- Increase in the number of Australians with cystic fibrosis involved in clinical trials Improved Government policies relating to rare and chronic diseases
- Extended life expectancy from 47 to 55 years by 2026

## Looking ahead

- Explore new medicines and devices and management/care techniques on the horizon
- CF has gone from a disease with a high mortality to a chronic illness. Improvements in clinical care and highly effective medicines and treatments mean that people with CF are living longer, have better quality of life and generally suffer from less severe infections
- The need to drive change in the hospital and primary care sectors to ensure cystic fibrosis models of care are appropriate for the needs of greater diversity of age and disease severity.
- Our health technology assessment processes will need to change to ensure they are 'fit for purpose' and embrace new clinical trial designs and precision medicine.



## Delivery of world-class clinical care with Australian standards setting international benchmarks.

Australians should experience continuous clinical improvement and the highest standard of care regardless of location.

### Key actions

- Advocate to ensure quality and standardisation of care across all Australian jurisdictions
- Promote the redevelopment of National Standards of Care including Infection Control Guidelines
- Facilitate peer review of clinical care
- Continued engagement and the establishment of partnerships with other health and medical science organisations (e.g., establishing standards of testing for diabetes and colorectal cancer)

### Measures of success

- Adoption of National Standards of Care by all Cystic Fibrosis centres
- Implementation of peer review Mk2 in all Cystic Fibrosis centres
- Incorporation of patient-reported outcome measures and patient-reported experience measures in programs aligned to the Australian Cystic Fibrosis Research Trust or Australian Cystic Fibrosis Data Registry.

### Looking ahead

- Increased use of outpatient care and treatment in the home
- Increased support and care for CF-related comorbidities found in aging patients
- The number of adults will continue to increase so innovative changes in clinical care will be needed
- The move from acute care to outpatients involving Multidisciplinary Teams (MDT) is underway
- There will need to be access to cystic fibrosis appropriate diversified health services, including mental health services, direct HITH support and home physiotherapy, telehealth, and support with antibiotics etc.



## Enhancing the capability and capacity of research and innovation in Australian into cystic fibrosis.

Australian CF research will change the lives of people with CF and reduce their treatment burden.

### Key actions

- Specific programs aimed at raising funding for the Australian Cystic Fibrosis Research Trust
- Increase the scope of research towards improved outcome and reduced burden of CF
- Cutting edge information accessible through CF research and CFA's online platforms

### Measures of success

- Increase the number of scientists, researchers, doctors, and clinicians dedicated to improving respiratory health and outcomes in Australians with cystic fibrosis
- CF funding for key Australian programs
- Increase usage of Australian Cystic Fibrosis Data Registry and Clinical Trial Alliance processes

### Looking ahead

- Encourage the sense of a united, cooperative CF research community
- **Promote** research and investigation into changing models and standards of care for treating CF
- **Encourage** new modulator and gene therapies
- **Seek** support and promotion for innovation, such as new styles of clinical trials
- Research into management of genetically modified organisms and exploring novel treatments (phage therapies) will be paramount



