Cystic Fibrosis Australia

Strategy 2026 - 2030

CYSTIC FIBROSIS Australia

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Our strategy on a page

Our strategy is focused on uniting partners to redefine possibilities for Australians impacted by Cystic Fibrosis through advocacy, awareness, research and quality care. It is underpinned by shared principles and supported by clear priorities, success measures and enabling capabilities to drive progress and uplift outcomes for the CF community.

Our purpose

"Uniting our partners through a national agenda to redefine the possibilities for all Australians impacted by Cystic Fibrosis"

Our principles

- Future-focused
- Collaborative
- Action-oriented
- Evidence-based
- Accountable
- Reliable

Our priorities

1. Effective advocacy for policy & funding

Advocate for policies, programmes and sustained funding through government, philanthropic support and collaboration with non-profits that improves outcomes for the CF community.

2. Elevating national awareness of CF and CFA

Raising compassion and support for the CF community by elevating awareness of the disease and CFA's role in supporting the CF community.

3. Accelerated research innovation

Accelerate Australian research and foster clinical and therapeutic innovation to reduce the burden of CF and advance progress towards transformative treatments.

4. Quality care outcomes

Ensure equitable, timely and consistent access to medications, devices and world-class quality care for every person living with CF, in all Australian jurisdictions and for all gene mutations.

Measures of success

Effective advocacy for policy & funding

- Policy & legislative influence
- Senior-level government engagement
- Advocacy funding & sustainability

Elevate national CF and CFA awareness

- National media exposure & digital reach
- Audience engagement & community growth
- Public understanding & awareness
- Collaborative campaign impact

Accelerated research innovation

- Supporting priority research funding and efforts
- Knowledge translation & impact

Quality care outcomes

- Ongoing updates of Standards of Care
- Expanding access to breakthrough therapies
- Improving quality of care for the CF community

Enablers

- Unity with national partners
- Communication and engagement
- Resourcing and investment
- Project management
- Governance and accountability
- Partnerships and alliances
- Australian Cystic Fibrosis Data Registry

Our purpose and principles

As the national voice for people in Australia with Cystic Fibrosis (CF), we unite the national CF community to lead effective advocacy, raise awareness of CF, accelerate research and ensure quality care outcomes. Our purpose is to ensure every Australian with CF leads a full life, unburdened by their disease.

Who we are:

Cystic Fibrosis Australia (CFA) is the national voice for Australians with CF. Our core purpose is to improve the longevity and quality of life for every person impacted by the disease, driving toward a future unburdened by CF.

We work tirelessly through four key pillars: (1) Effective advocacy for policy and funding, (2) Elevating national CF awareness, (3) Accelerated research innovation and (4) Quality care outcomes. Through these pillars, we support CF organisations across states and territories who provide invaluable, direct services to their CF communities. By uniting and strengthening these partners, we amplify our collective impact.

A central part of our mission is taking policy recommendations and research to government, industry and the health sector to ensure the challenges of those living with CF and caring for people with CF are understood. We ensure that these parties are enabled to provide support, services and care for the CF community. We are pursuing national health equity, working to ensure every person with CF has the same access to world-class care and treatment, no matter where they live.

With a new era of CF medication capable of transforming lives, our focus is clear: We will work to ensure quality lifelong management of CF is available to people of all life stages.

Our purpose:

"Uniting our partners through a national agenda to redefine the possibilities for all Australians impacted by Cystic Fibrosis"

Our principles:

Our principles are the values that shape the decisions we make and the actions we take.

Future focused

We anticipate change, adapt with agility and lead with purpose to shape a better future for the CF community.

Evidence-based

We rely on robust data, research and lived experience, guided by the Australian Cystic Fibrosis Data Registry and Australian Cystic Fibrosis Research Trust to influence government policy, funding for research and awareness of CF.

Collaborative

We work in genuine partnership with CF organisations and have the needs of the CF community front of mind when delivering programmes across advocacy, clinical improvement and research.

Action-oriented

We deliver measurable actions that reduce the burden on the CF community and their support networks.

Accountable

We focus on actions that improve life expectancy and quality of life, reporting outcomes transparently and building trust.

Reliable

We consistently provide trusted, expert-informed support that stakeholders can depend on, even in times of change.

Our strategic priorities

The strategic priorities outline our key focus areas, guiding our efforts and resources towards achieving our core purpose. They ensure our work remains targeted, impactful and aligned with the needs of the Australian CF community.

Initiatives

Strategic priority 1 – Effective advocacy for policy & funding

Advocate for policies, programmes and sustained funding through government, philanthropic support and collaboration with non-profits that improves outcomes for the CF community.

- **1.1 Influencing the Federal Government**
- **1.2 Developing a funding strategy for CFA's impact areas**

Strategic priority 2 – Elevating national CF and CFA awareness

Raising compassion and support for the CF community by elevating awareness of the disease and CFA's role in supporting the CF community.

- **2.1 Engaging Australians to increase CF awareness**
- **2.2 Enhance CFA's visibility**

Strategic priority 3 – Accelerated research innovation

Accelerate Australian research and foster clinical and therapeutic innovation to reduce the burden of CF and advance progress towards transformative treatments.

- **3.1 Leading the national research agenda**
- **3.2 Strengthening relationships with research partners**

Strategic priority 4 – Quality care outcomes

Ensure equitable, timely and consistent access to medications, devices and world-class quality care for every person living with CF, in all Australian jurisdictions and for all gene mutations.

- **4.1 Setting the standard for CF clinical care**
- **4.2 Leading the agenda for the future of CF care**

Initiatives and action plan (1/2)

We act as a powerful national voice, advocating directly to government and industry to secure better policies and access to treatments. This work is amplified by raising national awareness, ensuring the needs of our community are widely understood and supported.

Strategic priority 1
Effective advocacy for policy & funding

Initiative 1.1 - Influencing the Federal Government

Objective: To actively influence Federal policy by advocating for priorities and emerging needs identified by the Australian CF community.

Key actions:

- Conduct consultations with stakeholders and the Australian CF community to identify shared advocacy priorities.
- Advocate using insights from the ACFDR[1] to develop and submit evidence-based research, analysis and insights to Federal bodies including the Parliamentary Friendship Group.
- Coordinate targeted campaigns, engaging government representatives and mobilising the CF community.
- Maintain CFA's position as the national representative body and voice for people with CF.

Initiative 1.2 - Developing a funding strategy

Objective: To secure sustainable and diversified funding that enables CFA to advance its impact areas, while supporting effective advocacy for the Australian CF community.

Key actions:

- Identify potential funding channels, (e.g. government grants, corporate sponsorships and philanthropic partnerships).
- Advocate for alignment of funding from major bodies (e.g. NHMRC[2], MRFF[3]) with the community-led national priorities to maximise impact and reduce duplication.
- Develop a long-term funding strategy that ensures national coordination and sustainability for CFA's research and advocacy activities.

Strategic priority 2
Raising national CF and CFA awareness

Initiative 2.1 - Engaging Australians to increase CF awareness

Objective: To unify communications across CF organisations and engage Australians through coordinated, multi-platform outreach.

Key actions:

- Create a national digital toolkit with customisable resources (e.g. posters and social media templates) for stakeholders to use for collaborative outreach.
- Develop a nationally-aligned calendar that integrates marketing, engagement and educational events (e.g. National CF Awareness Month) in collaboration with stakeholders to deliver consistent, timely and impactful communication and raise public awareness of CF across Australia.

Initiative 2.2 - Enhancing CFA's visibility

Objective: To enhance visibility and understanding of our role and impact across the Australian CF community.

Key actions:

- Establish a "National Communications and Media Plan" that outlines target CF community audiences, key messaging and preferred media channels.
- Create and share materials (e.g. videos, testimonials, infographics) across our platforms that highlight our role as a leader within the CF community.
- Establish an annual "CFA Impact Report" that highlights measurable achievements in achieving strategic priorities.

[1]Australian Cystic Fibrosis Data Registry
[2]National Health and Medical Research Council
[3]Medical Research Future Fund

Initiatives and action plan (2/2)

We will ensure our community has access to the best care and breakthrough treatments available today. At the same time, we will drive the innovative research that will deliver the treatments of tomorrow.

Strategic priority 3
Accelerated research innovation

Initiative 3.1 - Leading the national research agenda

Objective: To establish and drive a unified national research strategy with the ACFRT[1] at its centre, ensuring investment is directed towards areas of greatest need and potential impact as defined by our community and experts.

Key actions:

- Lead a comprehensive, nationwide consultation process to develop and publish a "National CF Research Priorities" document.
- Establish an expert Research Advisory Committee, including researchers and consumer representation, to work with the ACFRT and oversee the implementation of the agenda and review research proposals.
- Expand the value of the ACFDR by exploring ways to develop data insights about the Australian CF community for CFA and its stakeholders.

Initiative 3.2 - Strengthening relationships with research partners

Objective: To establish and deepen formal partnerships with leading medical research institutes in Australia and internationally, to ensure high-quality research receives funding and leads to better therapies for people with CF.

Key actions:

- Launch partnered funding schemes, such as co-funded PhD scholarships and fellowships, to attract and retain new research talent in the CF field.
- Host the Australasian Cystic Fibrosis Conference that connects academic researchers with clinicians and the CF community to foster new, cross-disciplinary projects.
- Establish a collaborative research network to attract international research and clinical trials to Australia, helping overcome the challenges of a small and dispersed population of people with CF.

Strategic priority 4
Quality care outcomes

Initiative 4.1 - Setting the standard for CF care

Objective: To set and encourage the adoption of Australian standards of clinical care that serve as international benchmarks and drive continuous improvement in CF centres.

Key actions:

- Partner with leading clinicians through the peer review process to publish the national CF Standards of Care, incorporating new international evidence.
- Facilitate national peer-review processes and quality assurance programmes for CF centres.
- Champion the national integration of PROMs[2] to ensure patient experience is a core part of defining "world-class care".

Initiative 4.2 - Leading the agenda for the future of CF care

Objective: To identify and lead advocacy on the future issues that will impact the CF community, such as accelerating the approval and accessibility of emerging CF treatments and identifying future care requirements for the CF community.

Key actions:

- Actively monitor the global CF treatment pipeline to inform the CF community and healthcare providers on future therapies.
- Develop and lodge evidence-based submissions to PBAC[3] and other government bodies regarding access to new treatments in Australia for people with CF.
- Lead the national thought leadership on the future needs of the CF community that is living longer and healthier lives, including treatment of comorbidities and policies on insurance.
- Position Australia as an early adopter of emerging CF therapies and treatments by strengthening national research collaboration and trial readiness.

[1] Australian Cystic Fibrosis Research Trust
[2] Patient-Reported Outcome Measures
[3] Pharmaceutical Benefits Advisory Committee

With whom we work together

We support and advocate for people living with Cystic Fibrosis, their families and carers, through partnering with researchers, clinicians, governments and alliance partners to drive better outcomes, access and equity across the CF community.

Member organisations of CFA
How we work together: Provide data, shared tools and regular updates from us to strengthen advocacy, improve local service delivery and stay aligned with CF community priorities. Member organisations deliver direct services and support to their respective CF communities.

CF researchers
How we work together: Access to research funding, CF community insights and collaborative opportunities for international and joint venture collaboration to enhance the relevance and impact of their research.

CF clinicians and health professionals
How we work together: Foster collaboration and knowledge exchange to advance health outcomes, including the continuance of the Australian Cystic Fibrosis Data Registry Report and the Australasian CF Conference.

Government and agencies
How we work together: Demonstrate impact across research outcomes and care improvements, input into policy, accountable use of funding, facilitate collaboration with the broader healthcare sector and deliver equitable support nationwide.

The Australian CF community (the beneficiaries of our work)
How we work together: Provide timely and equitable access to emerging treatments, along with lifelong, holistic support in clinical and non-clinical environments.

Success measures and KPIs (1/2)

To create lasting change, we are committed to tracking our impact on both national policy and public perception. These indicators define our success, from securing access to medicines through the Pharmaceutical Benefits Scheme, to increasing the national understanding of Cystic Fibrosis.

Success factor 1: Effective advocacy for policy & funding			
ID	**KPI**	**Measures**	**Rationale / Links to Initiative(s)**
1.1	Policy & legislative influence	Number of CFA policy recommendations adopted or explicitly referenced in government reports, pre-budget submissions, or health department strategies.	A direct measure of our success in shaping the national policy agenda for the CF community. (Links to initiative 1.1)
1.2	Senior-level government engagement	Number of formal governance meetings held annually with Parliamentary Friendship Group, Ministers, Senior Advisors and Health Department Executives.	A lead indicator measuring the level of access and opportunity to influence key decision-makers. (Links to initiative 1.1)
1.3	Advocacy funding & sustainability	1. Achievement (%) of annual funding targets as defined in the funding strategy. 2. Percentage (%) of advocacy budget secured from diverse income streams.	Measures the financial health and capacity of CFA to deliver on its advocacy commitments. (Links to initiative 1.2)

Success factor 2: Elevating national CF awareness			
ID	**KPI**	**Measures**	**Rationale / Links to Initiative(s)**
2.1	National media exposure & digital reach	Total audience impressions (across broadcast, print, online, social) achieved through the national communications plan.	Measures the top-line success in getting the CF message in front of the Australian public. (Links to initiative 2.2)
2.2	Audience engagement & community growth	Year-on-year growth (%) of key digital engagement metrics (e.g., website users, social media engagement rate, mailing list subscribers).	Indicates how effectively CFA is building an active and engaged community of supporters online. (Links to initiatives 2.1 and 2.2)
2.3	Public understanding & perception	Positive trend (%) in biennial national survey results measuring unprompted public awareness and key message comprehension related to CF.	A critical long-term measure of whether awareness efforts are leading to deeper public understanding. (Links to initiatives 2.1 and 2.2)
2.4	Collaborative campaign impact	Number and reach of collaborative awareness campaigns co-delivered with member CF organisations and other partners.	Measures the success of leveraging partnerships to create a unified and more powerful national voice. (Links to initiative 2.1)

Success measures and KPIs (2/2)

Our success in accelerating innovation and delivering quality care outcomes is defined by tangible, measurable outcomes. These indicators track our performance against our core commitments, from improving access to medicines to funding life-changing research.

Success factor 3: Accelerated research innovation

ID	KPI	Measures	Rationale / links to initiative(s)
3.1	Supporting priority research efforts	Rolling 12-month growth (%) in the total value of funded research projects linked to the CFA-coordinated national research agenda.	Drives measurable progress towards research that will contribute to the increase in CF life expectancy. (Links to initiative 3.2)
3.2	Knowledge translation & impact	Number of peer-reviewed publications, citations and conference presentations resulting from research grants managed by the ACFRT and CFA and aligned to national priorities.	Assesses the influence and contribution of our research portfolio to the global scientific community. (Links to initiative 3.1)

Success factor 4: Quality care outcomes

ID	KPI	Measures	Rationale / links to initiative(s)
4.1	Ongoing updates of Standards of Care	Timeliness of Standards of Care documentation being updated after the emergence of new data and research recommendations on best-practice.	Ensures that key documents remain current, accurate and aligned with evolving best practices and community needs. (Links to initiative 4.2)
4.2	Expanding access to breakthrough therapies	1. Average time (in days) from TGA[1] registration to PBS[2] reimbursement for new CF medicines. 2. Percentage of PBAC[3] submissions for CF medicines receiving a positive recommendation.	Tracks the effectiveness of advocacy efforts in ensuring timely and equitable access to treatments. (Links to initiative 4.2)
4.3	Improving quality of care for the CF community	1. Engagement rates with CF community through the peer review process. 2. Annual survey score for patient confidence in CF self-management.	Quantifies the value and impact of our efforts to involve and empower the CF community to have better, healthier and longer lives. (Links to initiative 4.1)

[1]Therapeutic Goods Administration
[2]Pharmaceutical Benefits Scheme
[3]Pharmaceutical Benefits Advisory Committee

Our strategic enablers

To deliver on our strategic priorities, we require a set of core organisational enablers. These enablers are the foundations that will empower us and the members to execute the strategy effectively and drive meaningful change.

1. Unity with national partners

For a national strategy to be truly effective, the underlying operating structure of our members must foster collaboration, efficiency and unified impact. This requires aligning CFA and our state and territory members with the right resources, processes, technology and tools to achieve shared goals. Clarifying roles and presenting a cohesive front to government and the public is essential to harnessing our collective power and delivering the best outcomes for all Australians affected by CF.

Supports initiatives 1.1, 2.1, 3.1, 3.2, 4.1 and 4.2.

2. Resourcing and investment

To pursue an ambitious national strategy, we must secure the financial and human resources to realise our goals. This includes building a sustainable, diverse investment model that can fund multi-year research projects, power advocacy campaigns and attract and retain talent. The right mix of funding, people and resources is essential to enabling us to deliver impact at scale and pace.

Supports initiatives 1.2, 3.1 and 3.2.

3. Governance and accountability

As the national peak body, maintaining the trust of our members, donors, government partners and the entire CF community is paramount. Strong governance and accountability ensures ethical, transparent and strategic decision-making, ensuring every action is aligned with our purpose and that we are responsible stewards of the resources bestowed upon us.

Supports all initiatives.

4. Communication and engagement

Our national strategy cannot succeed from the top down; it must be built on a foundation of genuine, two-way dialogue. Clear, consistent communication builds alignment and fosters collaboration. By actively engaging our national partners and the broader CF community, we ensure their voices and experiences directly shape our priorities and strengthen our collective resolve.

Supports initiatives 1.1, 2.1 and 2.2.

5. Project management

A strategy is only as good as its execution. Effective project management provides the discipline to translate our strategic goals into a clear portfolio of initiatives with defined timelines and owners. This capability is critical for tracking our progress, managing dependencies and most importantly, rigorously measuring the impact of our work to prove the value of our investments and inform future decisions.

Supports all initiatives.

6. Partnerships and alliances

The challenges facing the CF community are too great for one organisation to solve alone. This enabler is a force multiplier for our mission. By building and strengthening strategic alliances with research institutions, philanthropic foundations, corporate partners and other CF organisations, we can access new expertise, share resources and amplify our voice to advance shared goals for the CF community much faster than we could alone.

Supports initiatives 1.1, 1.2, 2.1, 3.2, and 4.1.

7. Australian Cystic Fibrosis Data Registry

As a national, strategic asset, the ACFDR is central to delivering our priorities. It provides national-level clinical data that informs advocacy, policy, research, treatment safety and care improvements. The ACFDR empowers clinicians, supports evidence-based decision-making and offers people with CF and their families up-to-date insights through its annual report. Its breadth and impact make it an essential enabler of meaningful, lasting change for the CF community.

Supports initiatives 1.1, 3.1, 4.1 and 4.2.

Next steps

To realise the goals of our renewed strategy, we will work with stakeholders to communicate the strategy clearly, update our constitution, develop annual business plans and maintain stakeholder commitment through ongoing engagement and progress tracking.

01

Communicate the strategy
Description:
Through an effective engagement strategy, enable all stakeholder groups to understand CFA's strategic direction, priorities and intended impact.
Key Actions:
- Define core messages, audiences and channels for regular, two-way communication.
- Develop a calendar for internal and external communications.

02

Revise the constitution of CFA
Description:
Align governance documents with CFA's current strategy, ensuring that the constitution supports collaboration and effective decision-making.
Key Actions:
- Conduct review to identify gaps or outdated clauses.
- Engage members and stakeholders to co-design updates before formal changes.

03

Align CFA's operating model in light of the revised constitution
Description:
Review the current structure and operating model of CFA to ensure it enables the delivery of strategic priorities, supports collaboration and maximises existing capabilities.
Key Actions:
- Identify gaps where there is a lack of collaboration and siloed ways of working.
- Develop an ideal future state operating model aligned to the constitution that improves efficiency, alignment and impact.

04

Develop and implement annual operating plans
Description:
Translate strategic priorities into actionable annual operating plans that guide CFA's work and resource allocation.
Key Actions:
- Establish planning cycles and templates for operating plans.
- Develop an annual operating plan and gain approval from CEO and Board.
- Track progress against the identified measures in this strategy.

05

Maintain stakeholder commitment
Description:
Keep stakeholders informed and engaged throughout implementation to ensure transparency, shared ownership and sustained momentum behind the strategy.
Key Actions:
- Provide regular updates on progress aligned to stakeholder interests and strategic milestones and map them the annual operational plans where relevant.
- Create feedback loops to gather stakeholder input, address concerns and adapt programmes and operational plans as needed.

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