



## CFWA Strategic Plan 2017-2020

Prepared for: Cystic Fibrosis Western Australia

Prepared by: Catalyse Pty Ltd

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In Western Australia, Lotterywest has played an increasingly important role for community organisations in funding capacity building exercises such as this strategic plan.

This has enabled the whole sector to grow and improve its governance, operational efficiencies, transparency and professionalism. Never has this been more important than now, as we in WA transition from the resources led boom.

In developing this plan, we realised the value of our last strategic plan; achieving around 90% of what we set out to do. The models we employed to deliver services and raise funds did a great job. They enabled us to become one of the most successful CF Associations in Australia. They were however, a product of their time and as our environment and the wants and needs of our clients have changed, these models were clearly going to be incapable of supporting our continued growth.

Our new perspective is 'profit for purpose' and we are developing new fundraising strategies to reflect that whilst leveraging technology to re-design service delivery models to deliver an even bigger range of services with greater efficiency.

In the most exhaustive research yet which underpins this plan, we have gained a visceral understanding of our environment, the changing needs of our clients, supporters and particularly our major funder (the Health Department of WA) as they themselves have transitioned from an output based contracting framework to an outcomes based framework.

We have retained our vision of lives unaffected by CF as this accurately portrays our vision of the future, a world where a person can achieve their full potential unaffected by the disease.

We have re-focused our mission to identify CFWA as a social enterprise that funds **critical research** and **essential support services** to improve the lives of children and adults affected by cystic fibrosis. Our stretch goals for the next three years are aligned to this mission.

Our 2017-2020 plan makes explicit a clear strategy which CFWA will employ to meet the needs and expectations of the wider CF community. These goals are something we are all striving towards. I would like to invite you the reader, to accompany us on our journey.

We are grateful to Lotterywest for providing funding and to CATALYSE for guiding the organisation through the decision making process which has culminated in this plan.

I strongly endorse this Plan and on behalf of the Board, I commend the Plan to all of CFWA's stakeholders.



Richard Simons  
President



Richard Simons  
President

## 2 Overview of our Strategic Purpose

<b>Vision</b>	Lives unaffected by CF.
<b>Mission</b>	CFWA is a social enterprise that funds <b>critical research</b> and <b>essential support services</b> to improve the lives of children and adults affected by cystic fibrosis.
<b>Value Proposition</b>	When you support CFWA you're investing into <b><i>lives unaffected by CF</i></b> .
<b>2020 Goals</b>	<ol style="list-style-type: none"> <li>1. Improved quality of life for people affected by CF. In 2017, 42% of people affected by CF in WA were classified as 'thriving' vs 62% in the Australian general public. CFWA will work towards closing this gap.</li> <li>2. \$1m contribution towards CF research per annum to develop and deliver clinical benefits for people with CF.</li> <li>3. New drugs are approved in line with global standards.</li> <li>4. Member support to be maintained at high levels (CFWA Value Index Score &gt; 80).</li> <li>5. CFWA is financially sustainable. We are working towards having 12 months of operational reserves in the form of cash reserves and securities.</li> </ol>
<b>Strategic Priorities</b>	We will achieve our 2020 goals by addressing seven strategic priorities:
<b>SP1 Fundraising</b>	<ul style="list-style-type: none"> <li>• Agree on a portfolio of high margin products, services and experiences.</li> <li>• Develop a Marketing Plan for each 'offer' to attract and retain customers.</li> <li>• Explore opportunities to partner with Telethon Kids Institute on a 'Care Today, Cure Tomorrow' fundraising joint venture.</li> </ul>
<b>SP2 Member Support</b>	<ul style="list-style-type: none"> <li>• Provide valued support services to meet members' needs.</li> <li>• Form a CF Adult Taskforce and a CF Regions Taskforce.</li> <li>• Improve access to mental health services.</li> <li>• Review subsidies annually.</li> <li>• Develop an Outpatient Hospital Parking Strategy.</li> <li>• Improve access to education resources and support to assist students with CF.</li> <li>• Host the 2019 Australasian CF Conference</li> </ul>
<b>SP3 Advocacy</b>	<ul style="list-style-type: none"> <li>• Encourage adoption of the Advocacy Development Protocol among the Federation.</li> <li>• Support CFA to be a strong and effective advocate to address national priorities.</li> <li>• Be a strong and effective advocate for local and state priorities.</li> </ul>
<b>SP4 Research</b>	<ul style="list-style-type: none"> <li>• Support critical CF research projects for children and adults by contributing to the ACFRT and funding five PhD top up scholarships.</li> <li>• Collaborate with Telethon Kids Institute to support Little Lungs, Big Futures (LLBF).</li> <li>• Promote adult CF research being conducted at the Institute for Respiratory Health through the ACFRT process.</li> <li>• Inform members of critical CF research projects for children and adults that are being conducted locally, nationally and internationally.</li> </ul>
<b>SP5 Community Education</b>	<ul style="list-style-type: none"> <li>• Increase awareness and understanding of CF in schools, workplaces, etc.</li> <li>• Advocate for CF to be included in the teaching curriculum in relevant fields of study.</li> <li>• Collaborate with the Federation/CFQ to develop and adopt a National PR Strategy.</li> <li>• Collaborate with funding partners to write and share stories about CF.</li> </ul>
<b>SP6 Brand and Communications</b>	<ul style="list-style-type: none"> <li>• Review CFWA's brand and IP strategy.</li> <li>• In collaboration with the Federation develop a national CF Brand Strategy.</li> <li>• Develop a Third Party Endorsement Policy.</li> <li>• Develop and implement a Communications Plan.</li> <li>• Develop and maintain a Customer Relationship Management (CRM) database.</li> <li>• Develop and maintain an effective website.</li> </ul>
<b>SP7 Resourcing and partnerships</b>	<ul style="list-style-type: none"> <li>• Develop a key stakeholder management strategy.</li> <li>• In collaboration with the Federation, review and agree on CFA's role.</li> <li>• Review the HR strategy to ensure alignment with the Strategic Plan.</li> <li>• Develop a pro bono resourcing strategy to address professional skill gaps.</li> <li>• Develop a digital business strategy to support business improvement initiatives.</li> <li>• Conduct annual OHS and risk assessments.</li> </ul>

CFWA has been striving to achieve its vision of “lives unaffected by cystic fibrosis” (CF) for over 40 years.

CF is the most common recessive genetic disease affecting Australians today. It manifests itself primarily in the lungs and digestive system. People with CF develop an abnormal amount of excessively thick and sticky mucus within the lungs, airways and the digestive system. The mucus causes impairment of the digestive functions and the pancreas and traps bacteria in the lungs resulting in recurrent infections which lead to irreversible damage.

Lung failure is the major cause of death in CF.

On average one in 25 people carry the CF gene, around 1 million people in Australia. As carriers of CF show no symptoms, most carriers are unaware that they carry the gene. Two carrier parents have a 1 in 4 chance of having a child with CF with each pregnancy.

In Australia, one in 2,500 babies are born with CF; one every four days.

**Currently, there is no cure for CF.**

From birth, a person with CF undergoes constant medical treatments and physiotherapy.

CFWA was formed in the 1970s when several parents of children living with cystic fibrosis (CF) came together. The group was formally incorporated under the Associations Act of WA on 29 June 1976.

In the 1990s, CFWA developed links with cystic fibrosis clinics based at PMH and SCGH and gained funding from the Department of Health WA to begin a comprehensive homecare service that continues today.

CFWA is a consistent contributor to CF research in Australia through the Australian Cystic Fibrosis Research Trust (ACFRT) and contributes to the national CF agenda through support of Cystic Fibrosis Australia and its work in areas such as the Australian CF Data Registry, national advocacy and Standards of Care.

**We strongly believe in the power of collaboration.**

With the support of our members, the State Government of Western Australia, Lotterywest and Telethon, many sponsors, volunteers and donors, and CF Federation members across Australia, CFWA continues to make a real and positive impact on the lives of people affected by CF.

Our collective contributions were recognised in 2016 when CFWA won the inaugural charity section of the WA Telstra Business Award.

## 4.1 International and national landscape

Similar to CFWA, CF organisations around the world share a focus on the following strategic priorities:

- **Research** - supporting researchers to develop innovative therapies, medication and treatments and to discover a cure.
- **Support** - providing access to treatment, personalised care, services and information to improve quality of life.
- **Advocacy** - providing a voice for people in the CF community and effectively lobbying government, hospitals, etc for positive change.
- **Communication** - raising awareness, knowledge and understanding of CF and keeping members well informed about what's happening.
- **Attracting funding** - through grants, sponsorship, individual giving, bequests, etc.
- **Capacity building** - attracting, retaining and building engagement among staff, volunteers and donors.
- **Digital activation** - using technology (social media, apps, web-based tools, etc) to improve CF services, support and communication.
- **Leadership and governance** - operating with the best people, culture, infrastructure, policy, systems and procedures to support members.
- **Collaboration** - getting key stakeholders to work together, including clinicians, researchers, business, politicians and other CF organisations.

## 4.2 PEST-M Analysis

PEST-M analysis highlights the following key issues for CFWA to consider.

POLITICAL / LEGAL + ECONOMIC	MEDICAL
<ul style="list-style-type: none"> <li>• Tight economic market with increased competition for funding.</li> <li>• Need to consider alternative income streams.</li> <li>• National Disability Insurance Scheme (NDIS)</li> <li>• ACNC's increased focus on accountability.</li> <li>• Cystic Fibrosis Federation (CFF) Agreement and strategic direction taken by CFF members.</li> <li>• Movement towards greater collaboration and consolidation across the sector, and how the CF NSW + CF VIC merger will impact CFWA.</li> </ul>	<ul style="list-style-type: none"> <li>• Strong competition for funding for CF research projects between paediatric and adult CF researchers, and WA versus other states.</li> <li>• Increased availability of Kalydeco.</li> <li>• 13 new CFTR modifiers in the drug development pipeline and their listing on the PBAC including Orkambi. These new small molecules bring hope but also raise complex issues related to costs, royalties and conflict of interest.</li> <li>• Dependence on CFA's advocacy success with the Federal Government.</li> </ul>
SOCIAL	TECHNOLOGY
<ul style="list-style-type: none"> <li>• Need for mental health and wellbeing support for people affected by CF.</li> <li>• Better CF treatment and medication is contributing to increased life expectancy and greater demand for services by adults with CF.</li> <li>• Shift in culture and focus within patient care models to 'patient centric' approach.</li> <li>• Mixed views about whether CF is, or should be, recognised as a disability.</li> <li>• Saturation of peer to peer fundraising.</li> </ul>	<ul style="list-style-type: none"> <li>• Digital disruption.</li> <li>• High cost of acquiring and adopting new technology.</li> <li>• Shift to digital marketing, communications and fundraising.</li> <li>• Growing expectations for personalised and customised communication and services.</li> <li>• Telehealth and other technology innovations improving access to services across regional WA.</li> <li>• Increasing concerns with cyber security and protecting private data.</li> </ul>

### 4.3 Stakeholder Needs

Key stakeholders have a collective need for CFWA to improve overall quality of life for people affected by CF, understand and address key issues and challenges for people affected by CF, continue to provide meaningful, high value services and support, and to remain financially sustainable.

#### Quality of Life

Overall, people associated with CFWA experience **lower quality of life**. The 'thriving' score among people with CF was only 42 compared to a national average among the general population in Australia of 62.

#### Key issues and challenges facing people affected by CF

The key issues and challenges for people affected by CF mainly relate to concerns with mental health, and maintaining general health and wellbeing in order to lead as 'normal' a life as possible. Mental health issues affecting the CF community include stress, fear of death, grief, isolation, anxiety, deterioration of relationships, body image issues, missing out, guilt, and bullying.

Specific concerns with isolation, loneliness and missing out tend to be mentioned more often by carers (mentioned by 9% of people with CF versus 19% of carers). Isolation appears to be a larger concern among carers of children aged 0-5 years (mentioned by 36% of carers in this group) and in regional WA (14% metro versus 25% regional WA).

Table 1: Main issues and challenges facing people with CF and their carers

<b>Main issues for people with CF</b> <ul style="list-style-type: none"><li>• Mental health issues – 50% of respondents</li><li>• Maintaining health to lead a normal life – 50%</li><li>• Maintaining routines – 32%</li><li>• Work related issues – 32%</li><li>• Support networks – 18%</li></ul>	<b>Main issues for carers of children aged 0-5 years</b> <ul style="list-style-type: none"><li>• Mental health issues – 64% of respondents</li><li>• Maintaining routines – 55%</li><li>• Hospital related issues - 36%</li><li>• Concerns with isolation – 36%</li><li>• Community knowledge and understanding – 36%</li></ul>
<b>Main issues for carers of children aged 6-12 years</b> <ul style="list-style-type: none"><li>• Maintaining routines – 53% of respondents</li><li>• Maintaining health to lead a normal life – 53%</li><li>• Mental health issues – 47%</li><li>• Hospital related issues - 21%</li><li>• Financial challenges - 21%</li><li>• Issues specific for carers – 21%</li></ul>	<b>Main issues for carers of children aged 13+ years</b> <ul style="list-style-type: none"><li>• Mental health issues – 82% of respondents</li><li>• Maintaining routines – 45%</li><li>• Financial challenges – 45%</li><li>• Maintaining health to lead a normal life – 36%</li><li>• Hospital related issues – 27%</li></ul>

*“Sometimes, when you are different from the mainstream, it is difficult to find your place, so diminishes your lifestyle.”*

*“Thinking of death as might not reach 35 as that's the normal age.”*

*“Isolation. From the point of view of a mother with a CF baby. Isolated from other CF people... hard to share experiences.”*

*“A lonely stressful life at home without this opportunity for employment with too much time on hands to dwell on it.”*

*“Keeping as healthy as possible, so they can get the maximum benefit from hoped-for breakthroughs in CF treatment.”*



## 4.4 Current performance

### Overall Value

CFWA is **highly valued by all stakeholders**. Among people with CF, the Value Index Score is 82 out of 100. This means that on average, people with CF rated CFWA as providing high to very high value.

*Just an absolutely fabulous team.*

*Compassionate caring long term employees.*

*In every way fantastic support not only for the CF patient but also parents, siblings and extended family.*

Respondents mostly value CFWA for the **support** provided, in particular, the support provided with organising and providing in-home services, such as physiotherapy, medical support and cleaning.

Stakeholders also value CFWA's education programs, both the programs to educate and inform people with CF, and the programs to raise the profile and level of understanding about CF in schools and the general community.

As shown in the table below, carers were more likely to mention that they value CFWA's fundraising efforts to support CF research, in particular those who care for younger children or older children. Carers with primary school aged children were more likely to value subsidies and the provision of medical equipment.

People who live in regional WA were more likely to value CFWA for providing moral and emotional support, and for the organisation's fundraising efforts.

Table 2: Most valued aspects of CFWA

	CFWA Member	A person with CF	Related to a person with CF	A carer for a person with CF	Care for child aged 0-5 years	Care for child aged 6-12 years	Care for child aged 13+ years	Perth Metro	Regional WA
<i>Number of survey respondents (n)</i>	80	20	35	39	11	19	9	88	11
Organising & providing in-home support (physio, medical, cleaning etc.)	★	★	★	★★	★★	★★	★★	★	
General support for people with CF	★	★	★	★		★	★	★	★
Education and awareness raising in schools and the general community	★		★	★	★	★	★	★	
Providing information and education for people affected by CF				★		★	★	★	
Moral and emotional support					★				★
Support for research							★		
Fundraising for CF				★	★		★		★
Support for carers and families of people with CF							★		
Connecting CF community / creating networks / holding events				★	★		★		
Subsidies e.g. travel, sport etc.						★			
Provision of medical equipment						★			

★★ Very high value – 40%+ of respondents spontaneously mentioned that they value this area.

★ High value – 20%+ of respondents spontaneously mentioned that they value this area.



## Member Performance Ratings

CFWA is performing well across the organisation. For key performance areas, the Performance Index Score was 75 or higher in most areas. Please refer overleaf for a chart showing member ratings for key performance areas.

CFWA has recognised **strengths** among its members in the following areas (all scoring 80+):

- Keeping members informed about what's happening at CFWA
- Access to loan equipment (i.e. nebulisers)
- Managing the organisation effectively (people, policies & procedures)
- Home care treatment and assistance for people with CF

A perceived **weakness**, with the lowest score of 68, was:

- Access to information and support in relation to mental health and wellbeing for people affected by CF and their carer.

## Communication and Education

CFWA is achieving excellent communications reach among its members. Over the past 12 months, 93% of members read Red Magazine, 79% read CFWA's enewsletter, 73% visited CFWA's website and 48% engaged with CFWA through social media<sup>1</sup>.

Moving forward, members would prefer to receive communications from CFWA by enewsletter (87%), followed by the Red Magazine (78%). While Facebook is fairly popular with 45% of members saying they would prefer to receive information this way, other forms of social media (such as Twitter, Instagram and YouTube) were much less popular (7% or fewer mentions). Around 25% would like to receive text messages<sup>1</sup>.

With education, around 33% of members had attended a CF educational seminar over the past 12 months and 7% of members had participated in a CF webinar<sup>1</sup>. Based on preferences, CFWA will need to continue to provide members with choice as 37% would prefer to attend seminars, talks or expos in person, 35% would prefer to read research and education papers in their own time, and 20% would prefer to take part in online webinars<sup>2</sup>. Overall, 96% of members expressed interest in engaging in educational activities with CFWA.

## Stakeholder Advocacy

The Net Promoter Score (NPS) is an advocacy score that can range from -100 to +100. It is an indication of how likely people are to recommend CFWA to others. The average NPS for Australian Charities is 27<sup>3</sup>. This is high relative to other sectors. CFWA's NPS is very high at 54 for members, 78 for volunteers and 82 for board members and staff.

## CULTYR Employee and Volunteer Scorecards

Results from the CULTYR Employee and Volunteer Scorecard indicate CFWA is a high performance organisation. The overall performance index score was 93 out of 100 among employees and 91 among volunteers.

The Commitment Index Score is a measure of how likely employees and volunteers are to remain with the organisation over the next three years. There is very high commitment to CFWA, with a Commitment Index Score of 93 among employees and 94 among volunteers.

The Workplace Net Promoter Score (NPS), which measures employee and volunteer's willingness to recommend CFWA as place to work or volunteer, is very high at 71 among employees, 63 among volunteers.

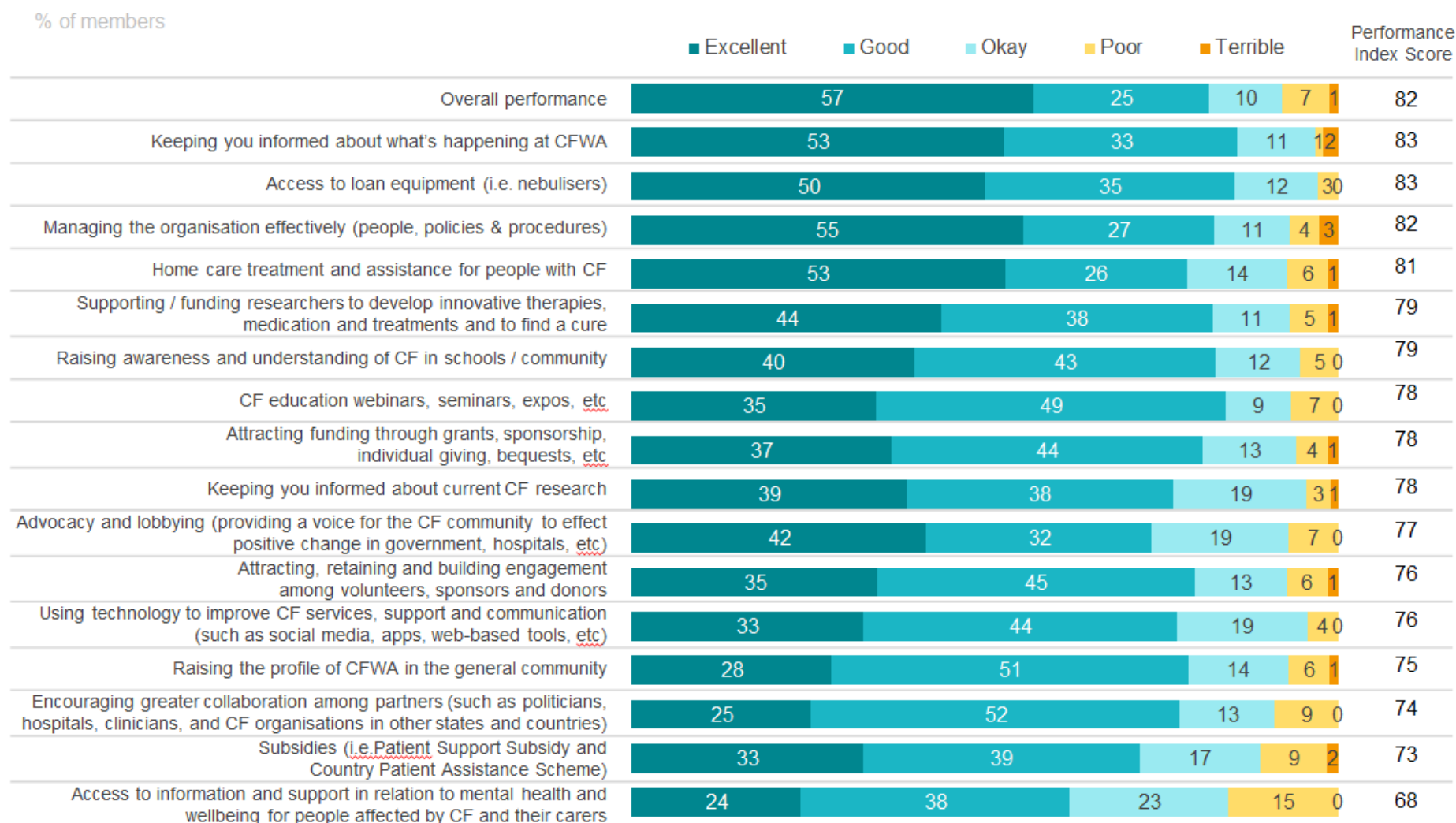
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<sup>1</sup> Results are based on a sample of 91 members.

<sup>2</sup> Results are based on a sample of 89 members.

<sup>3</sup> Australia NPS® Benchmarking February 2017, Perceptive Research

**Chart: Member Ratings in Key Performance Areas**



Base: Members (all respondents, excludes unsure and no response, n ranges from 67 to 91)

## 4.5 SWOT Analysis

In the words of key stakeholders:

*"I have so much respect for CFWA"*

*"CFWA is going from strength to strength. They are growing in professionalism."*

*"They are patient focused and passionate about what they do. They genuinely care about their clients. Not just ticking a box."*

The following SWOT analysis reflects the collective views of CFWA's stakeholders. Around 180 stakeholders were consulted in total, covering members, volunteers, donors, sponsors, researchers, government partners, staff and board members. The SWOT analysis covers the main perceived strengths, weaknesses, opportunities and threats as described by CFWA's stakeholders.

Please refer to the full report for a comprehensive list of suggestions.

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> <li>• Strong track record established over 40 years</li> <li>• 2016 Telstra Business Award winner</li> <li>• Highly valued by members</li> <li>• Strong communications reach (members)</li> <li>• High staff and volunteer engagement</li> <li>• Strong partnerships in WA – highly respected and trusted</li> <li>• Considered to be a leading organisation with model of care, consumer programs and outcomes based reporting</li> <li>• Strong, stable financial performance</li> </ul>	<ul style="list-style-type: none"> <li>• CFA / CFWA have a low public profile</li> <li>• Website</li> <li>• Disjointed national marketing and fundraising</li> <li>• Small organisation / limited capacity</li> <li>• Communications reach among key stakeholders (sponsors, partners, etc)</li> <li>• Visibility and communication around how research and health support service funding is being allocated (research outcomes, who is benefiting, availability of health service funds, how to apply, etc)</li> </ul>
OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> <li>• Greater support for research projects, such as Little Lungs, Big Futures.</li> <li>• "Care today; cure tomorrow" a co-branded fundraising initiative between Telethon, Telethon Kids Institute, PCH, SCGH and CFWA</li> <li>• Increase collaboration with CFF members to benefit from synergies and economies of scale (marketing, fundraising, technology, etc)</li> <li>• Greater collaboration with all CF partners, locally and internationally to advance the cause of people whose lives are affected by CF</li> <li>• Explore alternative funding models (NDIS, Bulk Billing, Fee for Service, diversifying memberships, products or services, etc)</li> <li>• Adopt telehealth and other digital innovations to improve regional access to services</li> <li>• Capitalise on a shift to profit for purpose perspective</li> <li>• Capitalise on growing shift towards corporate volunteering</li> </ul>	<ul style="list-style-type: none"> <li>• Poor awareness and understanding of CF in general community.</li> <li>• The CF Federation model not working effectively.</li> <li>• Uncertainty around CF Victoria and CF NSW merger and what this will mean for CF Federation/CFWA.</li> <li>• Reduced role clarity between CFA and CFWA creating confusion and conflict.</li> <li>• Growing competition for government grants for health support services and increasing need to demonstrate competitiveness/value for money</li> <li>• Increasing competition for sponsorship and fundraising dollars with greater choice of causes and activities, and saturation in peer-to-peer fundraising</li> <li>• Lack of support for LLBF from other CFF members</li> <li>• Perceived risks associated with CFA's proposal to provide online medical advice.</li> </ul>

## 4.6 Member Priorities

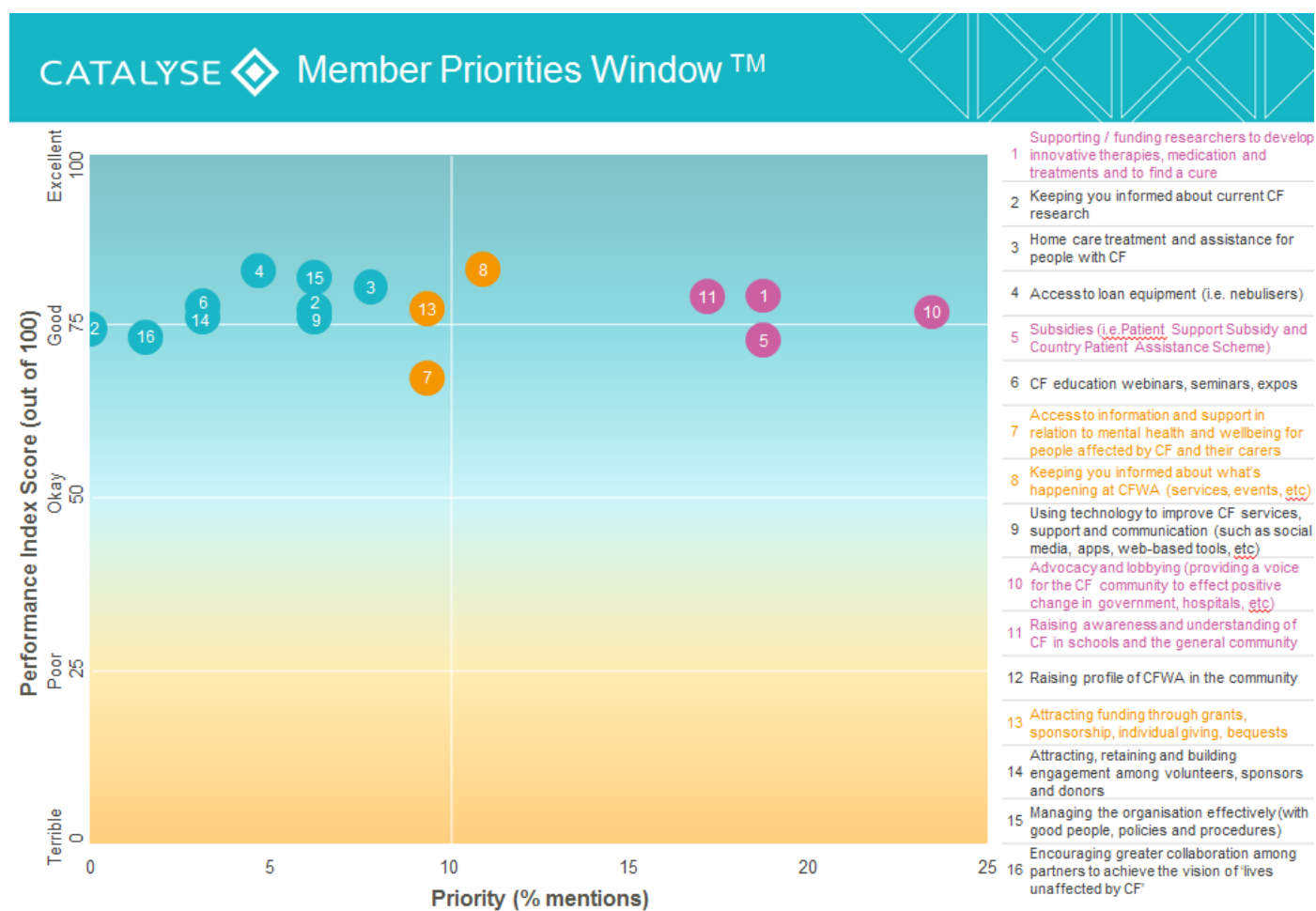
When members were asked to describe the areas they would mostly like CFWA to focus on doing, achieving or improving, they were most likely to mention the following priorities:

- Advocacy and lobbying
- Access to subsidies
- Support research to develop innovative therapies, medication and treatments and to find a cure
- Raise awareness and understanding of CF in schools and the general community

Secondary priorities include:

- Keeping members informed about what's happening at CFWA (services, events, etc)
- Access to information and support in relation to mental health and wellbeing
- Attracting funding through grants, sponsorship, individual giving, bequests

These priorities are mapped below in the CATALYSE Member Priorities Window.



It is important to note that, while member support services, including home care treatment and providing access to loan equipment, are not coming through as high priorities, this is not because they are unimportant. In fact, in-home care and support, is the area that CFWA members value the most. It is more likely that home care treatment and access to loan equipment are not coming through as higher priorities because CFWA has recognised strengths in these areas. Members are happy for current service levels to be maintained.

## 5 Our Strategic Direction

### Vision

Lives unaffected by CF.

### Mission

CFWA is a social enterprise that funds **critical research** and **essential support services** to improve the lives of children and adults affected by cystic fibrosis.

### Value Proposition

When you support CFWA you're investing into ***lives unaffected by CF***.

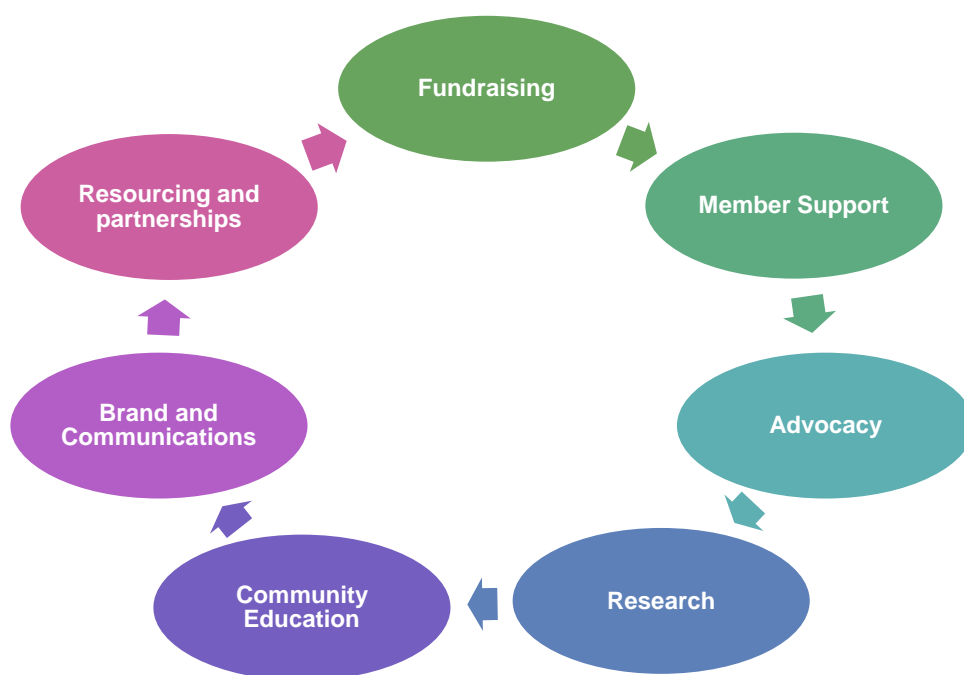
### Goals

CFWA will aim to achieve the following goals by 2020:

1. Improved quality of life for people affected by CF. In 2017, 42% of people affected by CF in WA were classified as 'thriving' vs 62% in the Australian general public. CFWA will work towards closing this gap.
2. \$1m contribution towards CF research per annum to develop and deliver clinical benefits for people with CF.
3. New drugs are approved in line with global standards.
4. Member support to be maintained at high levels (CFWA Value Index Score > 80).
5. CFWA is financially sustainable. We are working towards having 12 months of operational reserves in the form of cash reserves and securities.

### Strategic Priorities

To achieve our vision, we have identified seven strategic priorities:



### Resources Key

CEO of CFWA	Services Manager	Fundraising and Marketing Manager	Business and Finance Manager	Chair LLBF Committee	CEO CFA
NMB	KP	KDL	RR	FS	AB

## Our aspirations

CFWA has a portfolio of *profit for purpose*<sup>4</sup> products, services and experiences that are valued and preferred by a growing number of customers. We have connected our products to customers in a way that maximises reach, engagement and fundraising, while minimising the burden on our members, customers, volunteers, partners and staff.

Actions	Who	When
Review and agree on a <b>portfolio of high margin products, services and experiences</b> , using planning tools such as the BCG Matrix and Directional Policy Matrix to assess opportunities. Evaluate a range of options, including bequests, sponsorships, donations, events, workplace giving, corporate volunteering, fee for service, social enterprise concepts, and others.	KDL/NMB/RR/KP	Dec 2017
<ul style="list-style-type: none"> <li>Maintain and innovate existing, high performing products, services and experiences ('stars' and 'cash cows'), including bequests and workplace giving.</li> </ul>	KDL/KP	2017-2020
<ul style="list-style-type: none"> <li>Develop a strategy to improve or retire low performing products, services and experiences ('dogs').</li> </ul>	KDL/KP	2017-2018
<ul style="list-style-type: none"> <li>Research, develop and launch new 'stars', including securing a corporate sponsor and exploring fee for service options.</li> </ul>	KDL/NMB/KP	2018-2020
<ul style="list-style-type: none"> <li>Lead the development of one major, national fundraising campaign, working in collaboration with other CF organisations to research and develop the concept and campaign.</li> </ul>	KDL	2019-2020
Develop a Marketing Plan for each 'offer' to <b>attract and retain customers</b> . These plans describe the offer, target audience, value proposition, pricing plan, and promotional campaign.	KDL	2017-2020
Explore opportunities to partner with Telethon Kids Institute on a ' <b>Care Today, Cure Tomorrow</b> ' fundraising joint venture.	KDL/NMB	2017-2018
Conduct a <b>customer survey</b> to evaluate and monitor customer value (aligned with a biennial review of the strategic plan).	KDL	2018, 2020
Explore opportunities to conduct the customer survey in partnership with the Federation.	NMB	2018

<sup>4</sup> Not-for-profits that operate with a *Profit for Purpose* culture are driven to be self-sustaining. They aim to reduce reliance on government funding by maximising profits from diversified revenue streams. Examples of organisations that operate with a *Profit for Purpose* culture include MSWA (offering telemarketing services and lottery management services) and Surf Lifesaving Australia (selling first aid training courses to the general public).

## Our aspirations

CFWA provides access to personalised care, services, treatment and information to improve quality of life for people affected by CF. We maximise use of limited resources to provide the highest level of care for our members and demonstrated value for funding bodies.

Actions	Who	When
Stay in touch with <b>members' needs</b> through informal feedback channels (such as home visits, phone calls, emails, Facebook comments, etc) and formal feedback channels (such as surveys, focus groups, etc) and ensure feedback is provided to the appropriate people for their consideration and response.	KDL/KP	On-going
Continue to provide <b>valued support services</b> to meet members' needs, such as physiotherapy, counselling, cleaning and education, and provide access to new services in response to emerging and changing needs.	KP	On-going
Form a <b>CF Adult Taskforce</b> to better understand and respond to the needs of adults with CF. Explore opportunities to partner with CF Foundation USA's CF Adult Taskforce and the Federation.	KP	May 2018
Form a <b>CF Regions Taskforce</b> to stay in touch with and represent the needs of people in regional WA. Adopt digital innovations (teleconferences, telehealth, etc) and collaborate with organisations that share an interest in improving access to services in regional areas (such as Telethon and other health service providers).	KP	May 2018
Improve access to <b>mental health services</b> by reviewing and securing mental health funding, educating health service providers about CF and the specific needs of people affected by CF, providing members with a list of CF trained mental health service providers, and exploring opportunities to collaborate with mental health organisations (such as headspace and beyondblue) and other chronic disease groups.	KP/NMB	Dec 2018
Review <b>subsidies</b> annually as part of the budget / business plan. Conduct gap analysis (supply vs demand over the year), determine how best to allocate and stretch available resources, and advocate on behalf of members for new, improved or extended subsidies to address outstanding needs.	KP	Aug 2018 Aug 2019 Aug 2020
Develop an <b>Outpatient Hospital Parking Strategy</b> in collaboration with major hospitals (SCGH, PCH and FSH) to meet members' needs.	KP/NMB	May 2018
<b>Improve access to education</b> resources and support (such as tutoring) to assist students with CF to catch up with their peers during or following a period of poor health.	KP	2018-2019
Evaluate <b>partnership opportunities</b> to deliver and extend support services (such as mental health services, cleaning, personal training, masseuse, tutoring, etc). Consider social enterprise agreements to support fundraising efforts.	KP/NMB	On-going
<b>Secure funding.</b> Renew critical contracts (e.g. Department of Health 3 + 1 + 1 contract).	NMB/RR/KP	July 2018 July 2019 July 2020
Strengthen regard for CFWA by <b>acquitting grants</b> in a timely and effective manner and demonstrating excellent value for money (e.g. Telethon and Lotterywest).	RR	As due



Actions	Who	When
Conduct a <b>member survey</b> to evaluate member value (aligned with a biennial review of the strategic plan). Explore opportunities to conduct this study in partnership with the Federation.	NMB/KP	2018, 2020
Host the <b>2019 Australasian CF Conference</b>	NMB	2019

### Our aspirations

We are valued and respected as the voice of the CF community in Western Australia. Key partners, including the State Government of Western Australia, Perth Children's Hospital and Sir Charles Gairdner Hospital, are open to collaborating with CFWA to understand and address local and state priorities.

We work closely with the Federation and CFA to effectively address national advocacy priorities. New drugs are being listed in line with global standards.

Actions	Who	When
Review and encourage adoption of the <b>Advocacy Development Protocol</b> among the Federation. This protocol is based on the triage system whereby CFWA identifies members' priorities and advocates on behalf of members to address local and state level priorities (across Western Australia) and collaborates with the Federation to address national priorities.	NMB	Oct 2017
Support CFA to be a strong and effective advocate to address <b>national priorities</b> on behalf of the Federation, working towards new drugs being approved in line with global standards.	NMB	On-going
Be a strong and effective advocate for <b>local and state priorities</b> . Build and strengthen relations with key partners in Western Australia (such as the State Government, hospitals, clinics, schools, employers, etc) to foster open communication, mutual understanding and improved decision making.	NMB/KP	On-going
<b>Monitor local, state and national advocacy priorities</b> through an annual survey with a valid, representative and robust sample of members. Invite the Federation to collaborate on this project to strengthen the voice of the CF community, nationally and locally.	NMB	July 2018 July 2019 July 2020

### Our aspirations

CFWA supports researchers to develop and deliver clinical benefits to people living with CF. Outcomes based research demonstrates a tangible link to lives unaffected by CF, and progress towards it.

Actions	Who	When
<b>Support critical CF research</b> projects for children and adults by contributing to the ACFRT and funding five PhD top up scholarships (2 x top up scholarships for adult-based research and 3 x top up scholarships for child-based research)	NMB	2018-2020
Collaborate with Telethon Kids Institute to support <b><i>Little Lungs, Big Futures (LLBF)</i></b> and determine the most effective management and fundraising models to support LLBF.	NMB/FS	2018
<b>Promote adult CF research</b> being conducted at the Institute for Respiratory Health or other credible research institute through the ACFRT process.	NMB/AB	2018
<b>Inform members</b> of critical CF research projects for children and adults, that are being conducted locally, nationally and internationally (e.g. drug development pipeline <i>CF Lives Matters</i> , <i>Red Magazine</i> and through events such as an <i>Evening with CF Scientists</i> ).	NMB/AB	On-going

## Our aspirations

Children and adults who are affected by CF feel understood and supported in their local community. There is growing awareness and understanding about CF among health professionals and in schools, the workplace, sporting clubs, and the general community.

Actions	Who	When
Increase awareness and understanding of CF in <b>high need areas</b> (i.e. members' schools, workplaces, sporting groups, etc.). Collaborate with members to develop a database of target organisations.	KP/KDL	On-going
Advocate for CF to be included in the <b>teaching curriculum</b> for doctors, nurses, physiotherapists, psychologists, other allied health professionals, teachers, and other relevant professions to improve awareness and understanding of CF.	NMB	2020
Collaborate with the Federation, in particular CFQ who is developing a <b>National PR Strategy</b> , to improve awareness and understanding of CF across the general community.	NMB/KDL	2018
Collaborate with funding partners (such as DoH, Telethon and Lotterywest) to <b>write and share stories about CF</b> , the challenges people with CF face, and how funding is helping to improve quality of life for people with CF.	NMB/KDL/KP	On-going
<b>Measure prompted awareness</b> of CF in the general community. Consider opportunities to collaborate with the Federation, Department of Health, and other chronic disease groups.	KDL	2018

## Our aspirations

CFWA is a strong, well respected and trusted brand. We use communication channels effectively to ensure the CF community (including members, volunteers, partners, and others) are informed about what they need to know, when they need to know it.

Actions	Who	When
Review <b>CFWA's brand and IP strategy</b> .	KDL/NMB	Oct 2017
In collaboration with the Federation review national brand architecture and develop a <b>CF Brand Strategy</b> to strengthen and protect the "CF" brand and "CF Rose" logo.	NMB/AB/KDL	2018
Develop a <b>Third Party Endorsement Policy</b> to agree on an approach for promoting or endorsing third party innovations that target people affected by CF – i.e. smart apps, electronic games, communication platforms (websites, blogs, social media sites, etc) and other innovations.	NMB/KDL	Dec 2017
Develop and implement a <b>Communications Plan</b> that covers key strategic messages, target audience, channel, timing plan, responsibilities and KPIs. This plan will cover social media, Red Magazine, CFWA website, e-news, SMS alerts, signage, advertising, etc. Ensure the timing plan is reviewed and agreed with individuals who will contribute information (i.e. clinicians, allied professionals, researchers, business partners, etc).	KDL	Aug 2017 Annually thereafter as part of the budget process
Develop and maintain a <b>Customer Relationship Management (CRM)</b> database that enables key stakeholders (including customers, donors, sponsors, members and others) to customise and manage their preferences and increase their engagement with CFWA.	KDL/RR	2018, on-going
Develop and maintain an effective <b>website</b> .	KDL	Dec 2017, on-going

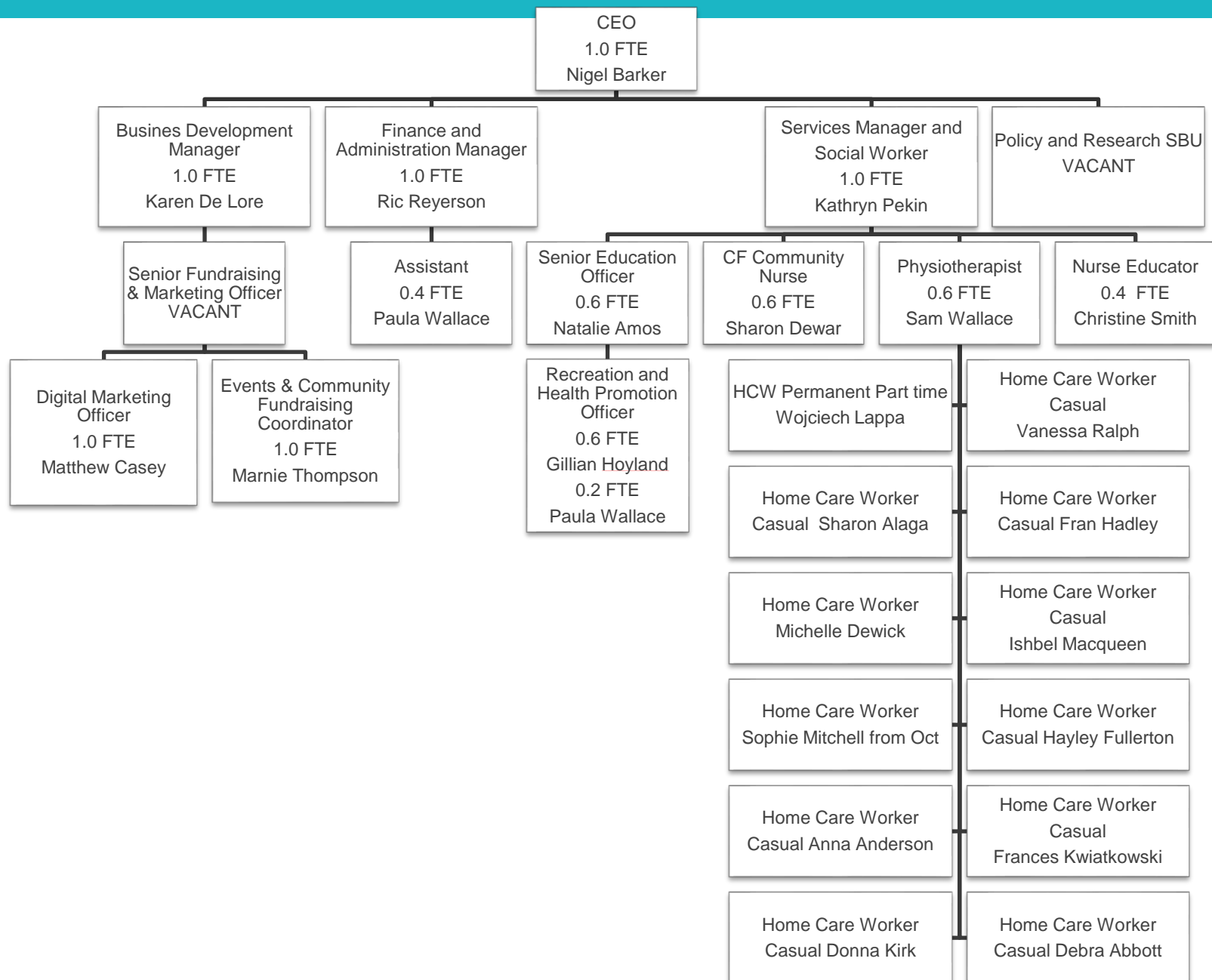
## Our aspirations

CFWA is managing organisational growth effectively with well-matched resources, policies and systems. We enjoy strong financial and cultural health with 12 months operating reserves, sound growth projections and high engagement among board members, staff and volunteers.

CFWA has strong and positive relationships with key stakeholders, in particular, with other members of the Federation. We respect and leverage each other's strengths, benefitting from synergies and economies of scale to accelerate achievement of our vision: 'Lives Unaffected by CF'.

Actions	Who	When
Align CFWA's Constitution with the Associations Incorporation Act 2015 and this Strategic Plan.	NMB	Jun 2019
In collaboration with CFWA's members and key stakeholders, review the way the Federation works and adopt a position on the preferred model moving forward.	Board, NMB	Jun 2018
In collaboration with the Federation, review and agree on <b>CFA's</b> role and funding model, and support CFA to fulfil its constitutional requirements.	CFWA President / NMB	Jun 2018
Develop a <b>key stakeholder management strategy</b> – mapping key partners (including CFA and the State and Territory associations), identifying internal champions for each key partner, and establishing shared goals.	NMB/KDL/KP	Dec 2017
Review the <b>HR strategy</b> (covering JDFs, staff and volunteer recruitment and retention, training and development, etc), to ensure alignment with the Strategic Plan.	NMB/KDL/KP/RR	Dec 2017
Conduct an <b>employee and volunteer engagement survey</b> (aligned with the biennial review of the strategic plan). Explore opportunities to conduct this survey in collaboration with the Federation and other not for profit organisations to access national benchmarks.	NMB	2018, 2020
Develop a <b>pro bono resourcing strategy</b> to address professional skill gaps.	NMB	Jun 2018
Adopt a strong commercial focus. Develop <b>annual budgets</b> to support the Strategic Plan and review progress against financial KPIs on a monthly basis.	NMB/RR	Annually as part of the budgeting process
Develop a <b>digital business strategy</b> to support business improvement initiatives across all strategic priorities, and review annually.	KDL/RR/NMB	2018 Review annually
Conduct an annual OHS assessment to ensure CFWA continues to meet <b>occupational health and safety standards</b> .	RR/KP/KDL/NMB	Annually (Apr)
Conduct an annual <b>risk assessment</b> .	NMB/RR/Board	Annually (Apr)

## 6 Resourcing the Plan





## 7 Evaluating Success

CFWA's success will be evaluated against the following key performance indicators (KPIs):

KPIs	2017 Benchmark	2020 Target
Member Quality of Life Rating (% thriving)	42	Moving closer to Australian general public rating = 62
Total revenue (grants + contracts + fundraising + other revenue)	\$2.1m	\$2.7m
Fundraising revenue (donations + events + other fundraising)	\$0.8m	\$1.3m
Diversity of income (fundraising expressed as % of total revenue)	38%	48%
Profit for purpose multiplier (return on every \$ spent on fundraising)	x3.3	x5
Annual contribution to CF research (Incl. LLBF)	\$350k	\$1m
CFWA Member Value (Value Index Score)	79	80+
Meeting member needs in key areas (Performance Index Score):		
• Home care treatment and assistance	81	80+
• Advocacy and lobbying	77	80+
• Supporting and funding researchers	79	80+
• Raising awareness and understanding of CF in schools/community	79	80+
Net Promoter Score (NPS)		
• Employee NPS (recommend CFWA as a place to work)	71	70+
• Volunteer NPS (recommend CFWA as a place to volunteer)	63	60+
• Customer NPS (recommend CFWA as a charity to support) <sup>5</sup>	NA	27+
Awareness of CF in the general community (% prompted recall)	NA	Increasing
12 months of cash reserves (% of target achieved)	45%	55%
Production days lost through injury and sickness absence (days)	10	<10

<sup>5</sup> Average NPS for Australian Charities is 27