

# ADVANCING HEALTH CHARITIES

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# Advancing health charities

- Balancing diverse stakeholder interests
- Raising funds in a competitive environment and the cost of working together
- Issues with federal structures
- Finding our voice in a noisy political landscape

# BALANCING DIVERSE STAKEHOLDER INTERESTS

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Purpose, core business, accountability

# The diverse stakeholders

- Patients/consumers
- Clinicians
- Researchers
- Pharmaceuticals
- Donors and supporters
- Members (Federation; ?)
- Government
- Colleague organisations
- Alliance partners
- Other

# Cystic Fibrosis Foundation (US)

## Focus areas

- Service provider
- Advocacy
- Fundraiser
- Drug discovery and development
- Commercial activities
- Venture capitalist

## Fundraising

- Funds raised from public (41% or \$126m public; no govt funds)
- Commercial activities (57% or \$174m)
- Royalty payment from drug development (\$150m royalty kalydeco)
- Venture capitalist (\$175m in kalydeco)

# Perspectives on CF US partnership with pharmaceuticals

Margaret Hamburg,  
Commissioner, US FDA

“This unique and mutually beneficial partnership...great model for what companies and patient groups can achieve if they collaborate on drug development.”

Tim Kendall, Director of Research,  
Royal College of Psychiatrists

“Drug companies will try to do anything to align their interest with those of the patients. They do things at every level of the health service and we know they do it with patient groups...a multi-pronged approach to persuade patients that their drug is the one.”

## Questions – balancing diverse stakeholder interests

1. Is there a conflict of interest for a charity engaging in drug development and subsequently receiving royalties?
2. Is the charity's voice compromised as a result?
3. Who is influencing who?
4. Who are the real beneficiaries?
5. Is it confusing to the market? Consumers?
6. Are there competing interests between health consumers, pharmaceutical partners and health professionals? Can common interests prevail?
7. What about partnerships with or funding from government? Do the same problems exist?

# RAISING FUNDS IN A COMPETITIVE ENVIRONMENT & COST OF WORKING TOGETHER

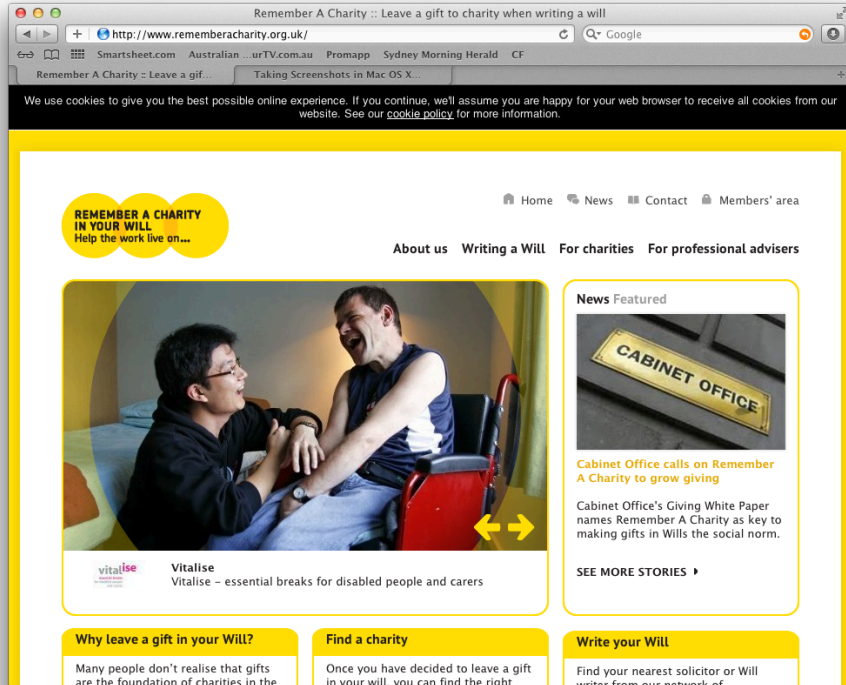
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Sustainability, collaboration or dilution



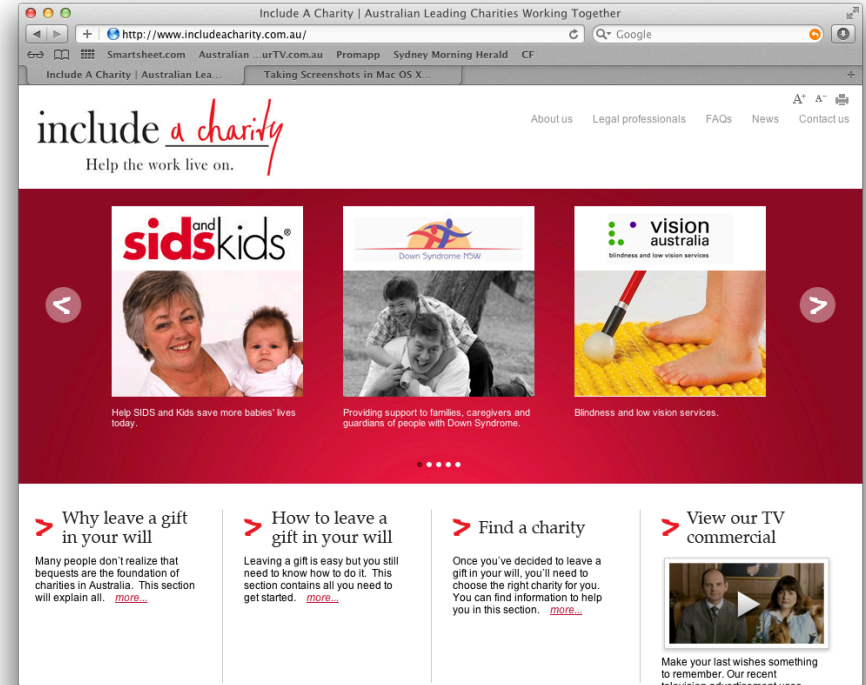
# Working together

## Remember a charity (UK)



The screenshot shows the homepage of Remember A Charity. The browser address bar displays 'http://www.remembercharity.org.uk/'. A cookie consent banner is visible at the top. The main navigation includes 'Home', 'News', 'Contact', and 'Members' area'. A secondary navigation bar lists 'About us', 'Writing a Will', 'For charities', and 'For professional advisers'. The hero section features a large image of a man in a wheelchair talking to another man, with the text 'REMEMBER A CHARITY IN YOUR WILL Help the work live on...'. Below this is a 'Vitalise' section with the tagline 'Vitalise - essential breaks for disabled people and carers'. A 'News Featured' section highlights a 'Cabinet Office calls on Remember A Charity to grow giving' article, mentioning the 'Giving White Paper'. At the bottom, there are three yellow call-to-action boxes: 'Why leave a gift in your Will?', 'Find a charity', and 'Write your Will'.

## Include a charity (Australia)



The screenshot shows the homepage of Include A Charity. The browser address bar displays 'http://www.includea.org.au/'. The main navigation includes 'About us', 'Legal professionals', 'FAQs', 'News', and 'Contact us'. The hero section features the logo 'include a charity' with the tagline 'Help the work live on.' Below this is a carousel of three charity images: 'sids and kids' (Help SIDS and Kids save more babies' lives today), 'Down Syndrome NSW' (Providing support to families, caregivers and guardians of people with Down Syndrome), and 'vision australia' (Blindness and low vision services). The main content area is divided into four columns: 'Why leave a gift in your will', 'How to leave a gift in your will', 'Find a charity', and 'View our TV commercial'. Each column contains a brief description and a 'more...' link. The 'View our TV commercial' column includes a video player thumbnail and the text 'Make your last wishes something to remember. Our recent television advertisement uses...'.

# Profit earning ventures

- “such projects account for only a small share of funding in most nonprofit domains, and few of the ventures make money.”

## Reasons cited for low returns

- Unwarranted optimism
- Potential financial returns often exaggerated
- Challenges of running a successful business are routinely discounted
- They can distract nonprofits from their core social business
- Confusion between revenue and profit

## Personal connection a motivator

“When health charities’ communications strategies for legacy funding and for responding to legacy donations are examined, a striking feature is the **immediacy and personalization of the gift**, either **through the donor’s links to specific local health institutions, or to the particular health conditions they (or their families) have experienced**. Much research has established that **personal links are an important motivation behind giving...**”

## Questions – raising funds in a competitive environment

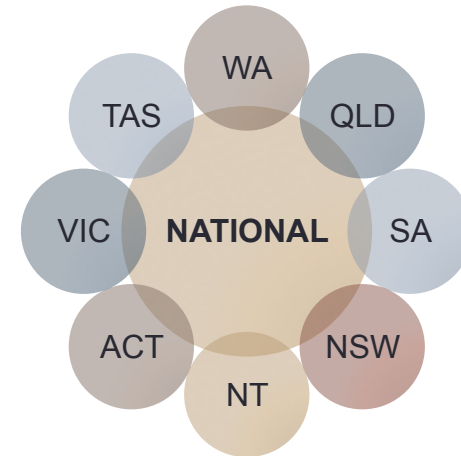
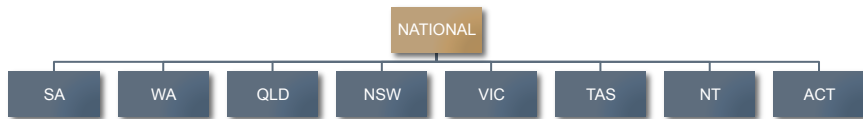
1. Does working together (common giving platforms) reduce, dilute or enhance individual charities? What about EDH?
2. Is there an opportunity cost of working together in this way?
3. Do profit earning ventures advance health charities? Why? Why not?
4. Does entering a charity partnership advance the health charity? Why? Why not?
5. ? If personal connection is a motivator, should health charities solicit donations from their members/clients/consumers/patients and their families?

# ISSUES WITH FEDERAL STRUCTURES

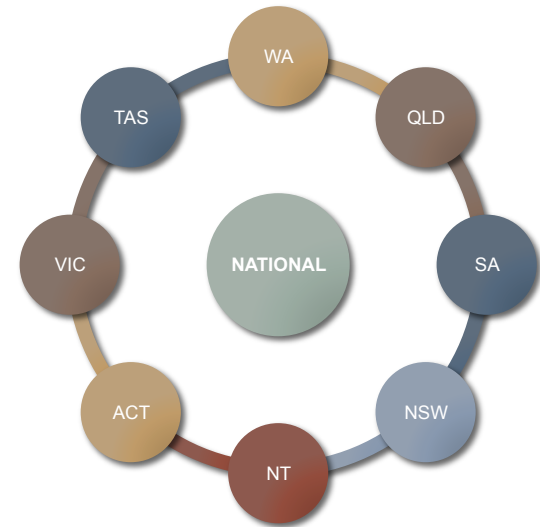
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Can they work or change?

# Federal structures



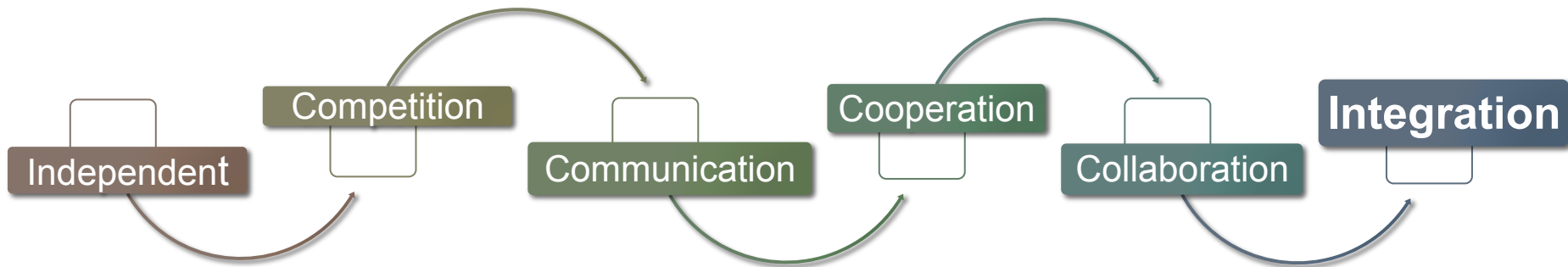
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# Challenges for federations

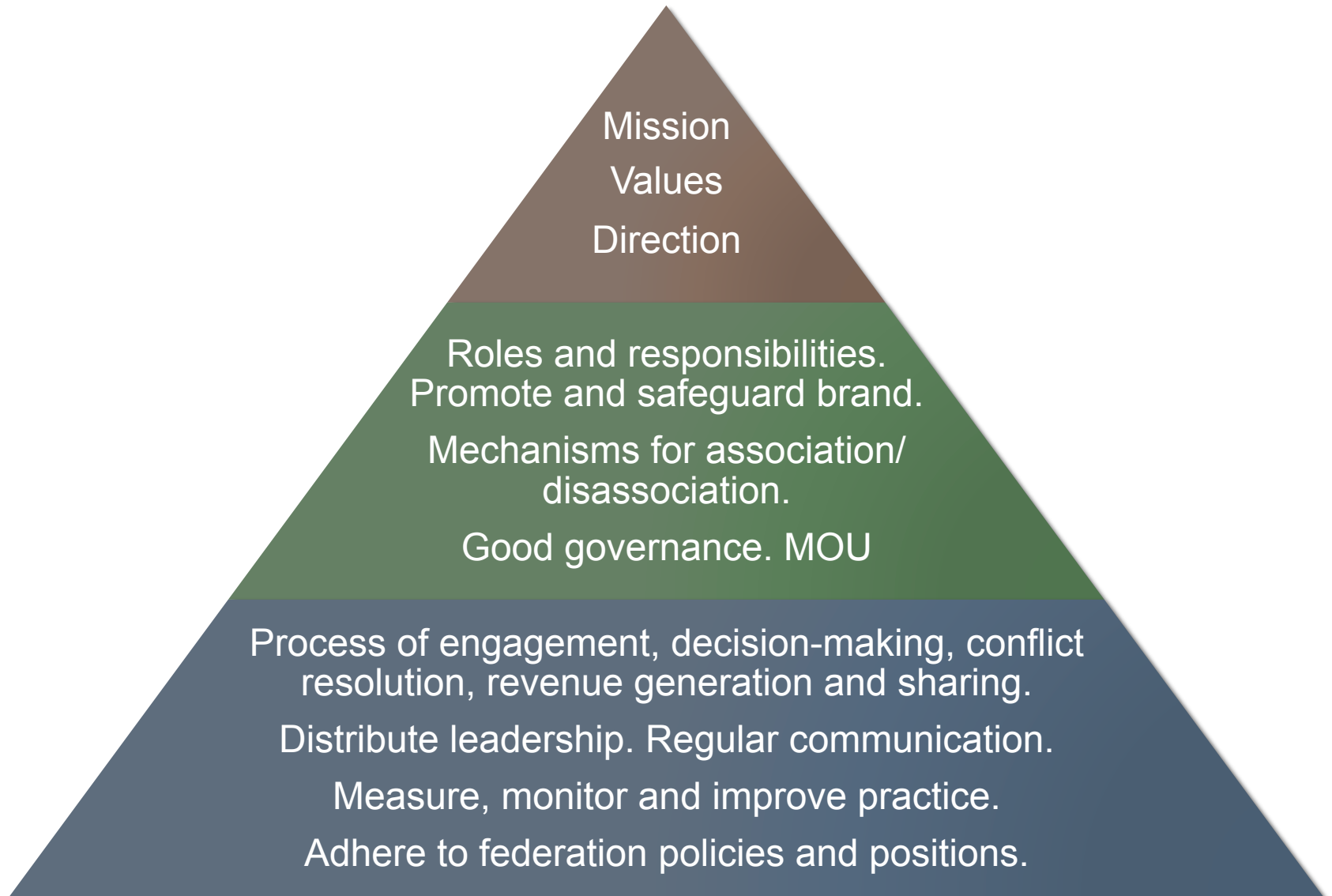
- Leadership
- Authority
- Change management
- Decision making
- Duplication
- Expensive
- Joint fundraising mechanisms and distribution of profit
- ?

# Relationship continuum





# FEDERATION SUCCESS FACTORS



## Questions – issues with federal structures

1. Is there an ideal structure for a health charity?
2. Does it really make a difference?
3. If a new structural model is preferred, what are the steps to change?

# FINDING YOUR VOICE IN A NOISY POLITICAL LANDSCAPE

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Advocacy, alliances

# Advocacy for new CF treatment



## Alexandrena Parker

My name is Alexandrena Parker, I am 23 years old, I have Cystic Fibrosis and I have been on Kalydeco for almost 1 year. Before Kalydeco I was extremely underweight, my lung function was low 60% and rapidly dropping, I was constantly lethargic due to the fact I was unable to sleep properly due to gastric reflux, I suffered from depression due to my ill health, I could only work casually due to the unpredictable nature of my health and I was constantly in and out of hospital on a monthly basis. Since starting on Kalydeco my lung function is now 80% and increasing every day. I have gained 8kg, I have more energy than ever before, I have finished my teaching degree and am now employed part time lecturing photography, and I run a successful freelance photographic business and travel interstate frequently working 80 plus hours per week. I am able to keep up with social activities with my friends and family and I have a positive outlook on my life and future again. Kalydeco is the best thing that ever happened to me.

## Scott, Leila and Flynn Piefke

Thinking of how to describe what Kalydeco means to us – my mind just spins, how can we put a life saving drug into words? Twenty months ago our world came crashing down when our gorgeous son Flynn was diagnosed with cystic fibrosis. After reading and hearing all of the miracles Kalydeco has done and is doing for other families then learning Flynn's gene type, G551d, we feel like the most fortunate family in the world – better than winning lotto!

It feels like our prayers and dreams have been answered, finally we see light at the end of the tunnel. Kalydeco will mean the WORLD to us! Kalydeco will allow Flynn to live a long healthy happy life (just like he deserves) and not allow Cystic Fibrosis to stand in his way.



## Kate French

Targeted gene therapies for cystic fibrosis would greatly improve the quality of life for cystic fibrosis sufferers such as me. Although Kalydeco would not be applicable for my gene mutation, it is an amazing and important step forward in treating cystic fibrosis. While my cystic fibrosis is well controlled at the moment and does not affect my life as significantly as it affects others, it means that in the future sufferers will have the same opportunities to enjoy life as I have had. I believe that all cystic fibrosis sufferers should be given the best chance to enjoy a normal and fulfilling life and this can be helped through such treatments as Kalydeco. Better treatments would mean less time off from my studies from illness, hopefully less daily medications, less worry about what the future will hold and more confidence in creating long-term plans and goals for myself.

## Questions – finding your voice

1. How can a health charity achieve “cut through” in advocating for a new treatment? Program?

# Mapping charity characteristics against charity focus

Charity focus	Charity characteristics					
	Lobbyist	Corporate/ govt. partnership	Legacies	Charity partner	Profit earning	Your charity
<b>Core business</b>	Determined	Determined	Focused	Focused	Distracted	
<b>Stakeholders</b>	Conflict of interest	Influenced		Competitors	Conflict of interest	
<b>Fundraising</b>	Interest groups	Corporate/ govt	Public donation	As agreed	Commercial	
<b>Voice</b>	Critical	Confusing		Critical, diluted		
<b>Alliances</b>	Critical	Convenience		Critical	Business partnership	

# Conclusion

- Strong health charities transparently balance stakeholder interests with their commitment to their core business
- Financially sound health charities will have a balanced portfolio of fundraising activities and give significant attention to nurturing donors from a single donation to a bequest and ensure any commercial activities are a logical expression of core business and organisational values
- Efficient and effective health charities have an organisational structure which serves the mission, enables core business, avoids duplication of role and responsibility and facilitates efficiency
- Influential health charities have clarified their message, identified their audience/s, and articulate the benefits of engaging with them as a consumer or supporter