

# Consumer engagement & involvement

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[www.clinicaltrialsalliance.org.au](http://www.clinicaltrialsalliance.org.au)

ACTA gratefully acknowledges operational funding from the Australian Government's Medical Research Future Fund

# Acknowledgement of country

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I'd like to acknowledge that we are on the traditional Country of the Kaurna people of the Adelaide Plains and wish to pay my respects to their Elders past, present and emerging and for their generosity and wisdom.

# Definitions

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**Consumer** - people who directly or indirectly make use of health service (i.e. patients, potential patients, carers)

**Consumer representative** - a member of a committee, steering group or similar who voices the consumer perspective

**Community** - a group of people sharing a common interest but not necessarily a common geographic location

**Stakeholders** - an individual or group who has a key interest in the service or project

# Labels



# What

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Researchers, clinicians and consumers working together to:

- Make decisions about research priorities, policy and practice
- Advocate for the translation of research results to improve health outcomes

# What's the difference

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## Participation

Being a subject in a research project

## Involvement

Consumers and community members working in partnerships with researchers, clinicians and other stakeholders to shape decisions about research

## Engagement

Respectful conversations and activities between a research organisation and the community

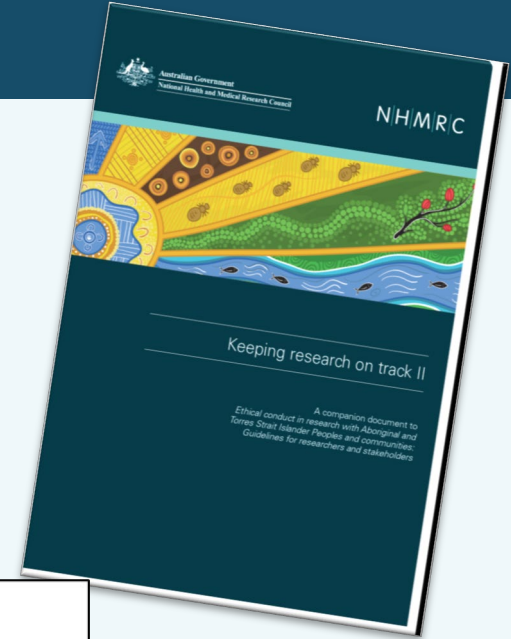
# And what it's not about ....

- Researchers raising awareness of their research – interviews, speaking at service clubs...
- The participants (subjects) taking part in research
- A recruiting tool
- An opportunity to 'tick the box'
- Fundraising or public relations



# WHY? - Key reasons for involvement

1. Funding bodies require some form of involvement
2. Consumer and community involvement helps to enhance or improve the quality of research
3. Accreditation requirements
4. Human Research Ethics Committee requirements
5. Involvement can help to empower people





# Who

Consumers  
(Patients and families or  
carers)

Community members

Members of the public



# Tips for getting started – planning is crucial!

Take the time to consider the following:

- What do you want to achieve?
- What level and stages will you involve consumers and community members?
- How will you find community members?
- What methods will be you use?
- What resources will you need?
- Identify any potential barriers.

# Levels of Involvement



# Platform Trials & Consumer Involvement

Included consumers in early discussions – ensure that the questions being asked are useful to community and the outcomes used

Held workshops prior to submission of grant application

Allowed lived experience to be included from the beginning

Recruited members for 3 reference groups  
young people with CF 13 – 25  
people with CF >25 and  
Parents, Partners & carers

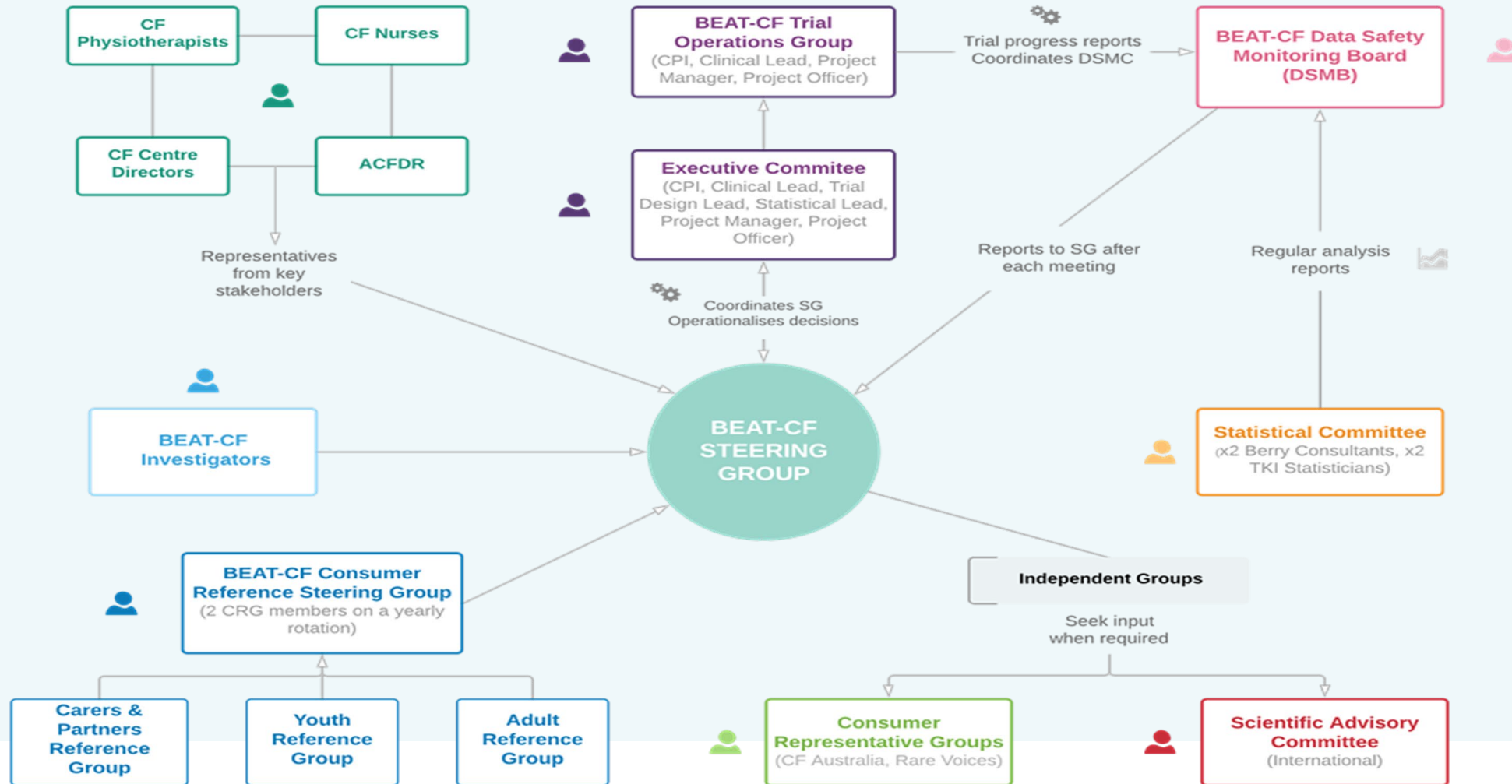


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To tackle such a complex issue, we have invited people from different areas of healthcare to come together to help improve our understanding of exacerbations. This is what is represented in our logo for BEAT CF. The different sides of the cube represent different aspects of healthcare, coming together to support the platform.



# Embedding community



# What do consumers value about platform trials?

Everyone can be involved – different to ‘regular’ trials which often have narrow inclusion criteria

They want to use their lived experience to support and help ensure that the questions are useful and answers used

Being able to participate in more than 1 question (through multiple domains)

Knowing that Platform Trials allow multiple questions to be asked at the same time.



# Why do consumers want to be involved?

Can provide extra/missing domains

Outcomes that mean something to the participant/community

Input to protocols due to lived experience – Antibiotic domains in BEAT CF

Support for new consent processes e.g. e-consent

Help ensure public/participant documentation makes 'sense' and is clear.





Translation of results - clear and easy to understand. Challenge on language

Access to networks

Input to protocols due to lived experience – Antibiotic domains in BEAT CF

Support for new consent processes e.g. e-consent

Like the possibility of perpetual platform

# Strategies

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Include involvement in the budget as a priority not as an afterthought or in a piecemeal way

Salaried investigator – consumer advisor with links to networks and support the reference groups as a priority. Not tacked onto someone else's role

Including consumers in the decision making at Steering Group level

## Participation on DSMC

- Can ask questions – what does this mean for participants? Clarification
- How and when to relay information/trial decisions to the community to support understanding

# Opportunity

There is a real opportunity to ask better questions, increase participation

Working with consumers and the community will support your grant outcomes

Better community understanding of research allows greater support from funders.

No one will fund work that does not have community buy in

Get in early and you gain the advantage

# Thank you

## Consumer Steering Committee & Reference Group members

Sophie Longton, Kate Spaapen, Pia Sappl, Melanie McKean, Jane O'Brien, Cynthia Watterson, Caz Boyd, Amanda Bearcroft, Tylah Clark, Ellie Duncan, Daniel Maree, Marc Phegley-Giura, Karen Cooper, Melissa Gibson, Donna Emery, Sarah Potts, Reanna Grey, Katherine Robins, Rebecca Dell, Holly Robins, Allanah Starr, Peter Maree, Sophie Robinson, Elissa Kadar, Wendy Endebrock-Brown, Davina Pasmanik, Emily Stride

Prof. Tom Snelling, Tracey Meares, Julie Marsh and my colleagues in the Adaptive Health Intelligence group  
Anne McKenzie

Belinda Frank and Karen Forde from the Community Engagement program at Telethon Kids Institute