



# Engaging Young People and Families in Research - Workshop

Workshop: Saturday 15<sup>th</sup> October 2016



Better Treatments 4 Kids  
IMPROVING HEALTH OUTCOMES  
FOR NSW CHILDREN & FAMILIES



THE UNIVERSITY OF  
SYDNEY

kids  
research Institute  
the children's hospital at Westmead



# Engaging Consumers in Research and Advocacy

Nettie Burke, CEO, Cystic Fibrosis Australia



# Consumer Engagement is Vital

- Improve communication and provide a flow of valuable information to the community, the media and government
- Establish an intelligent and respectful two-way communication
  - a dialogue - and capture feedback
- Educate key stakeholders and supporters about cystic fibrosis issues
- Establish a devoted, well informed team of consumer advocates who...
  - have an active voice in their communities
  - can support national advocacy principals

# Consumers Have Power

- Consumers share a passion for the cause including its guiding principles, values and priorities
- Consumers are valuable members of the debate and have strong connections to a variety of target audiences and stakeholders
- Consumers can share their inspirational and unique stories and add substance to advocacy and insights to research
- Consumers can share a vision, key messages, strategies, advocacy targets and objectives
- The consumer voice will become a powerful chorus as the CF cohort joins to achieve more engagement, better services, more government funds and a better quality of life

# Consumers and Research

- Gain an understanding of the motivations of the community
- Reveal needs, wants, perceptions, attitudes and fears
- Understand what needs have not been met – Government, Medical and Community
- Get accurate and consensus feedback through group discussions
- Initiate a dialogue with consumers to ensure we meet the needs of our community.

# Consumers and Advocacy

## **Individual Advocacy**

### **One On One Relationship of Support**

Providing support, guidance, a voice and an agenda for a family member or person in need.

## **Systemic Advocacy**

### **The Voice of Many, Not the Opinion of One or Two**

*“Partnering with Consumers ... planning, design, delivery, measurement and evaluation of systems and services and their own care, to the extent that they choose.”*

**National Safety and Quality Health Service Standards**

# Consumers and Advocacy

**The role of an advocate is not for everyone.**

**An advocate is the voice of many, not the opinion of one or two.**

***CF CAN* (Consumer Advocacy Network) is the voice of many and we have great impact and can make great change.**

## **ACTIVITY:**

Government meetings

TGA submissions

Government Consumer Comments portals

PBAC hearings and stakeholder meetings

Media stories and interviews

Presentations at events and fundraisers

Sounding board for consumer organisations

Panelists – Consumer Reps

# Consumers and Advocacy

## OUTCOMES

- Speak to the powerful **for the powerless**
- Bring key **decision-makers** to the table
- Agreed advocacy **strategies** and actions for a common goals
- Build **relationships** to inform and shape public opinion
- Adapt, change focus and manipulate messaging to **drive agenda**
- Protect the community and associates from **reputation damage**
- Deliver clear, coherent, credible and consistent **communications**
- Work to **persuade and motivate** changes in behavior
- Encourage more consumers to become advocates

# In closing, a new beginning

Traditionally patients and consumers were the subject of medical investigations.

Today patients and consumers are now partners in their care.

In the future patients and consumers will be the agenda setters and the drivers of their own care.

These set the outlook for...

**Exciting and Empowering Times.**