



# **Consumer Involvement Pack**

## **How to get involved in health and medical research**

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# 1. What is consumer involvement?

Consumer and community involvement is where patients, carers, and other people who use health care services, actively work with researchers and research organisations to help shape decisions about health research priorities, policy and practice.

This information pack focuses on consumer and community involvement in clinical research. Clinical research is the study of health and illness in people. Clinical trials are one type of clinical research and give health professionals evidence of what treatments work best. Every year, many thousands of Australians take part in clinical trials and other types of clinical study and the findings from these studies allow consumers and health professionals to make better decisions about treatments, care, and services.

“When it comes to our health, I cannot understate the importance of the statement ... nothing about us without us” (Consumer)

When consumers and the community get involved in clinical research, they work alongside researchers to help make decisions about what research gets done, how research gets done and how the results are shared and used in practice. Consumer involvement is not the same as taking part in research. It's not, for example, about being the person who takes a new drug in a clinical trial. It's about consumers and researchers working together to design and run studies.

By getting involved in research, you can help make research more relevant and useful to both consumers and the community. You can stop money being wasted on research that doesn't actually help people. By working with researchers or research organisations, you will improve research and therefore make a difference in the way health care is provided in the future.

“Research has always seemed to be a mystery, only carried out by very clever people. What I know now, is that it's a very normal process and everyone should have a say in what goes on, because research affects our lives. The information that comes out from research impacts on me, so for me to have a say in it, is a necessary process.” (Consumer)

“We have a vested interest to ensure good quality studies will produce results that will ultimately improve standards of care and therefore improved patient outcomes”. (Consumer)

“We can challenge researchers to think outside their box. We can ask what we might think is an obvious question, but they might never have thought of it before. Research is all about asking questions, and we can helpfully challenge researchers by asking them questions.” (Consumer)

## 2. What can I contribute to research?

Your own lived experience, or the care of others, is of great value to researchers. Many researchers are healthcare professionals and will know a lot about treatment and services. They may also have textbook knowledge about your condition, but unless they have also lived through it, there may be gaps in their understanding. By contributing your experience and your views, you provide valuable expertise that would otherwise be missing.

“Clinical trials exist for the benefit of patients. We represent their interests, therefore, our contributions are inestimable.” (Consumer)

If you get involved in research, you will not be expected to have technical knowledge of how research works. You will be supported to undertake your role, for example, by being given training on the research process and background information on the project you are involved with. The important knowledge you already have – your experience of living with an illness or disability or, using services or looking after someone else. This knowledge is what’s unique about your contribution to the research team.

“You’re the most experienced person on what’s happened to you and that experience can really help research. You don’t need to try to speak on behalf of all patients, just give your opinion based on what you know.” (Consumer)

“We ensure that research is appropriate and aligned with the wishes and priorities of those at the centre of the research.” (Consumer)

“At first, it was intimidating sitting in a room full of eminent doctors. I wondered whether I could contribute anything. But they started asking me questions like ... ‘do you think patients will want to do this?’ or, ‘what do you think from a patient’s perspective?’. I knew then that my being there was useful.” (Consumer)

“Don’t, for one minute, think you need to have a science background to be a consumer representative. If you are asked to review documents that will be given to patients taking part in a study, the whole point is, if you don’t understand the technical language used, nor will they ... that’s incredibly useful feedback!” (Consumer)





## Dan's story of involvement

Retired Manager. Former Chair Australasian Gastrointestinal Trials Group (AGITG) – Consumer Advisory Panel (CAP). Currently Director AGITG.

### What was your motivation for getting involved in research?

Having spent most of my working life in primary and secondary industry I was fully aware of the benefits in research – when looking at medical research few of us would be here today but for research over the years. We lost a daughter to metastatic breast cancer and in 2005 I was diagnosed with rectal cancer. Following successful surgery and chemotherapy, I later had the opportunity to join the AGITG CAP when it formed in 2008 – I jumped at the opportunity to make a contribution.

### What studies have you been involved in?

The AGITG opens some 3–4 new collaborative trials each year and each of these trials requires endorsement from the CAP – so during my time on the CAP, we would have been involved in some 30 or so trials. In one of the early trials, I was an investigator - I have been an associate investigator on several others.

### How did you feel when you first got involved?

The inaugural 10-member CAP involved colorectal cancer patients/survivors and it was great to exchange our lived experiences both with fellow CAP members, AGITG staff and Directors. As a CAP member, I certainly felt part of a team that wished to contribute to Gastrointestinal (GI) cancer research and clearly understood that the AGITG looked forward to and valued the input which consumers could make.

### How is it now you have been involved for a few years?

I have now been involved with this research group for over ten years. I have witnessed our trials (along with many others) improve patient outcomes and quality of life. I have found that the knowledge gaps which we seek to resolve via research are usually common between both researchers and consumers. Many new treatments

and drugs have become available – indeed the treatment regime I received back in 2005 has been significantly changed through research.

### Has anything surprised you about being involved in research?

I am amazed at the passion which researchers continually display in seeking to find ways and means and drugs and treatments which will improve the quality of life and outcomes for patients. The amount of time which many researchers volunteer pro-bono to propose research hypotheses and develop research applications is something which the general population does not appreciate or understand. In 2015 the AGITG, which comprises over 1,300 members, primarily clinicians, introduced an Annual Award for Excellence in AGITG Research – as the proud recipient of this inaugural award it exhibited to me the benefits which consumers can and do bring to clinical research.

### What would you say to people who are new to getting involved?

Do not be afraid or daunted. Most researchers and research organisations I know welcome consumers into their team or project as the consumer invariably brings some lived unique experiences as well as a non-clinical set of eyes. There is plenty of mentoring and training available and through asking questions and with the experience of time your input and contribution will improve.

### 3. Have I got the right experience to be involved?

There are many different types of research looking at hundreds of different topics. Researchers are likely to want to hear the views of a range of people from a variety of backgrounds. This means your experience might be more relevant for some projects than for others. It's about finding the projects that need input from people like you and roles that match your interests and experience.

For example:

- Researchers working on a new insulin pump for pregnant women with diabetes wanted to work with diabetic women who had recently had children.
- Researchers looking at the impact of hospital staffing levels on care wanted to involve anyone with a recent experience of hospital services. They wanted to hear the views of people who had been inpatients or outpatients or had received emergency care, as well as people who had been caring for a relative or friend in hospital.
- Researchers developing a new screening test for lung cancer wanted to involve community members (not patients), who were smokers and ex-smokers, to contribute their views on the research.
- Researchers working on a project to improve the health of people living in damp housing wanted to involve people from a local community where there were lots of problems with damp housing. These people weren't patients, but they had experience that was relevant to the research.

“Don't be disappointed if you put yourself forward for a role but are not chosen. It may be because the researcher has already found someone with a similar background to you. They might need to find someone with a different background or culture to get as wide a range of feedback and opinion as possible”. (Researcher)

You don't have to have any kind of qualification to be involved in research. But you may have skills from other parts of your life that will be valuable to researchers, from working, volunteering or family life. The combination of these skills and your knowledge and experience, might make you the ideal person for an involvement role. For example, in a research project involving women with ovarian cancer, one of the women drew on her skills in organising events to help plan a final workshop for patients. She wasn't just a volunteer providing an extra pair of hands on the team. She used her experience as a patient as well as her organisational skills to help plan the workshop. She ensured it was easy for women with ovarian cancer to attend, and that the workshop would cover what other patients would most want to hear about.

## 4. What difference will I make?

You can make a difference at any and every stage of research. Your contribution will help shape the thinking behind the research and the planning and delivery of the project. You have a powerful voice that can also influence others beyond the research team, including the people who take part in the research and the people who use the results. Sometimes it's the contributions from consumers that determines whether a project gets funded, whether it runs successfully and whether the results change practice.

The following are some of the different ways you could help researchers, as well as examples of how consumers and carers have made a difference in previous research projects.

### You could help research by:

#### Giving researchers new ideas for research

A carer working with researchers on a project about support for carers identified a group of 'hidden' carers that the researchers had not known about. The researchers had only been thinking about carers of people with a disability, or people with mental health problems. The carer involved had looked after her husband when he had heart disease but hadn't identified herself as a carer at the time. Sharing her experience led to a new project to look at support services for this group.

#### Making sure researchers work on the most important questions

While working on a project with a group of women who had experienced domestic abuse, researchers discussed a number of ideas about what to research next. The women said research on how GPs could better identify, and support children affected by domestic violence was a high priority for them. This influenced the researchers' decision about which project to work on next.

#### Helping to write a funding bid

Researchers wanted to work on a project to assess the evidence as to whether people who have different blood pressure measurements in each arm are at greater risk of heart disease or stroke than people whose blood pressure is the same in both arms. They involved consumers in writing their application for funding. The feedback from them made the application easier to understand by improving the way it was written, and helped the researchers to more clearly describe the group of people who would be affected.

#### Helping funders to decide which projects are worth funding

A group of people with Multiple Sclerosis (MS) reviewed an application for funding for a trial of a new exercise program for people with MS. They rejected the application because the program was targeted at people with mild MS. The patients explained that people with mild MS can usually go to a gym. It's the people with severe MS, who may be in a wheelchair, who find it difficult to know how best to exercise and where to go. They suggested that it would be better to fund research that focused the people who are more severely affected.

#### Making sure research focuses on the most important outcomes

In a study to improve the care of premature babies, the researchers assumed that parents would be worried about how long their child had to stay in a specialised unit far from home. However, the parents explained they were more worried about delays to their child returning to a local hospital because of lack of transport or an available bed. So, as well as measuring the length of stay in specialised care, the researchers also measured these delays in transfer, to see if their research identified ways to reduce them.

### **Inspiring and motivating researchers**

Researchers who meet consumers for the first time, often say they are surprised to realise that their research means so much to other people. This gives them the motivation and enthusiasm to keep going, whenever the going gets tough. Working with consumers reminds them that their work really matters to the people they most want to help.

### **Helping to design projects that make it easy to take part**

A research project based in a city centre, expected people with bowel cancer to attend clinic appointments at 8.30 in the morning. The consumers involved in the project commented that this would be difficult and expensive because people would be likely to get stuck in traffic. They suggested scheduling the appointments later in the day.

### **Identifying how best to support people who take part in research**

A research project looking at the side-effects of the drugs used to treat Parkinson's disease, needed patients to come to the clinic for tests after not taking their medicine in the morning. The consumers involved in the project explained that this would make it very difficult for some people to get up and get out of the house. The researchers, therefore, provided a professional carer to help the participants attend the clinic appointments while off their drugs.

### **Helping to collect the data and working with researchers to make sense of the results**

In a project assessing the problem of drug use in prisons, the researchers invited an ex-offender to work on their team. He helped to recruit prison inmates to take part in focus groups. He helped run the groups and to make sense of the findings. He identified issues that the researchers might otherwise have missed.

### **Making sure that any written materials are clear, easy to understand AND includes the most important information**

A group of consumers with mental health problems reviewed a brochure that a researcher had written to explain what would happen to the people taking part in her study. The study involved taking scans of the brains of people with experience of psychosis. The consumers made suggestions about how to improve the wording and the layout to make it easier to read and understand. The leaflet explained that music would be played through headphones while people were in the scanner. One person in the group with experience of psychosis said that if he was experiencing paranoia at the time, he would need to know exactly what piece of music would be played, in order for him to feel safe.

### **Helping to share the results with people who want to use them**

A consumer who was involved in a research project about secondary breast cancer, helped to present the results at a conference. Having the consumer speak seemed to 'electrify the audience'. It can be extremely powerful to hear directly from the people who will be affected by the research. They have a perspective that researchers don't always hear, and they can give a realistic view on whether the results are genuinely useful.





## Nicole's story of involvement

Patient Partner Centre for Kidney Research, Co-Chair Consumer Advisory Board BEAT-CKD. Member SONG-GN and SONG-TX life participation working groups. Patient Partner KHA-Cari guidelines group.

### How did you become involved in health research?

I saw an expression of interest for Kidney Disease patients to be involved in a Consumer Advisory Board for BEAT-CKD. I applied in April of 2018 and that is how my adventure began.

### What was your motivation for getting involved in research?

As a rural physiotherapist/patient I wanted to be able to represent those of us in Rural Australia and to learn more about our disease and be able to share that knowledge with others from the bush.

### What studies have you been involved in?

Mobile exercise App to improve fatigue in patients on dialysis: an adaptive trial (M-FIT), SONG-GN study to will improve the validity, transparency, usability, and contribution of research relevant to patients with glomerulonephritis and lastly SONG Transplant-Life participation.

### How did you feel when you first got involved?

It was quite overwhelming as I did not know anyone.

### How is it now you have been involved for a few years?

I love it, so much so that I have commenced a PhD in my chosen area this year

### Has anything surprised you about being involved in research?

How many projects that the research teams have on the go at one time and how hard it is to apply for funding – so many hoops to jump through.

### What has been your greatest achievement?

Presenting at the International Society of Nephrology's Global health policy Forum in Melbourne in 2019. To be included in this amazing forum and to have an opportunity to share the patient voice regarding what's important to us was just amazing.

### What would you say to people who are new to getting involved?

Do it, work out what you are interested in and have a go!

## 5. What will I be expected to do?

This will depend on a number of things. The following are common areas where consumers are asked to share their thoughts:

- the researchers' ideas and plans for their research
- the information that has been written to publicise the project, or to inform people taking part, or to share the final results.

You might do this in any number of ways, for example by:

- attending meetings with researchers
- joining a consumer group run within a research organisation and working with them to give your views on different projects
- joining a group to advise on a specific project
- becoming a member of a research team
- commenting on written documents sent to you by post or email.

Some meetings may be in person. Some may be held over the phone or online. You will often be able to work in a way that suits you best, choosing roles that match your interests, experience and skills. You can do as much or as little as you want and can always say 'no' if what's being asked of you feels too much.

*"It's important not to do more than you want to. Being involved can be tiring, and you might have an emotional reaction to the discussions. You need to set your limits, especially if you are managing a health condition or have other demands on your time." (Consumer)*

Over time, you may want to take your involvement further. You might want to get involved in actually doing the research and helping researchers to make sense of the findings.

You might want to get involved in:

- training and recruiting new researchers
- presenting research results at conferences and workshops
- writing articles for patient newsletters and social media
- contributing to articles written by researchers.

You can go as far as you want in developing your skills and experience in consumer involvement, working on small or large projects, for only a few weeks or over a few years. There could be a range of opportunities that are open to you.

## 6. What can I expect of the people who involve me in their work?

When you work with researchers or research organisations on an ongoing basis, you should expect:

- clear information about any involvement role – what your responsibilities will be and what's expected of you
- a fair and open process of recruitment
- a good working relationship with the people who involve you, based on mutual trust and respect
- regular feedback on how your involvement has made a difference
- access to a range of training and support to enable you to have your say
- payment for any expenses you have as a result of your involvement and clear information about how to claim your expenses
- practical support to make your involvement possible (e.g., booking accessible venues for meetings, providing paperwork in large font, easy parking, paying for childcare and parking fees)
- a point of contact who can provide information and support on request
- involvement in evaluating how well the process has worked, and the impact of the work you have done.

“One thing that was important was that everyone knew each other's goals – what the research team expected from me, and what I was hoping to get from being involved in the project. The researchers were really good at feeding back how I had helped them. I think this kept me motivated. They were also not afraid to give feedback to us on aspects that were not working so well, which we were happy about because it helped the group make ‘the involvement process’ better.” (Consumer)

Sometimes researchers will offer a payment as a thank-you for your time and contributions to their project. This is likely to be an honorarium fee rather than a salary. The amount will depend on the role and type of research.



## Melinda's story of involvement

**Founder, Miracle Babies Foundation. Honorary Research Associate, University of Sydney, Medical School. Inaugural Chair, Perinatal Society of Australia & New Zealand's (PSANZ) Consumer Advisory Panel (CAP).**

### How did you become involved in health research?

As the Founder of Miracle Babies Foundation, I met Professor William Tarnow-Mordi who wanted to explore partnering in research. Research wasn't the main reason for starting the Foundation, therefore I didn't really understand the need for parents to be involved with trials. William conveyed how important research was for babies outcomes and how in the neonatal space, uptake into trials was exceptionally low. This means that sometimes it took way too long for results to be obtained and put into practice meaning that babies lives and outcomes were at risk.

### What was your motivation for getting involved in research?

I wanted to continue to help families of premature and sick babies in any way I could. I know that the success of the Miracle Babies Foundation and its family programs is because of the collaboration between health staff and families. It didn't take long to realise that we could also help families journey and outcome by assisting and being that parent voice in research.

### How did you feel when you first got involved?

I was probably a little unsure of my role and what I could contribute and if I had anything of value to offer. It was also a little daunting to be sitting at the table with such highly qualified and well-established health professionals and researchers. I was really fortunate that they understood this, and I felt an instant willingness and openness to work together.

### How is it now you have been involved for a few years?

Now it feels extremely comfortable. The welcomeness and receptiveness of parents in research continues to grow and we hope to develop and nurture the community for more consumer advocates to enter the space and have an equally meaningful impact.

### Has anything surprised you about being involved in research?

Surprise might not be the right word, but I think, to be honest I have never been more in awe of people in my life. At conferences or research meetings, I often find myself with goosebumps thinking that all of these professionals are working for mothers like me, for families like mine. I wish every parent of a preterm or sick baby across the country was able to sit in my shoes and be privy to not only the amazing work in research taking place but in those people behind the scenes – the doctors, professors, researchers – and their un-waiving dedication and passion to make our families and our babies outcomes better. I never had any idea as a patient the hard work going on trying to better health so that my son's futures were guaranteed.

### What has been your greatest achievement?

Being the first parent to be invited onto a neonatal trial as an Associate Investigator in 2012 and then as a Chief Investigator in 2019, and also winning the inaugural Australian Clinical Trials Alliance (ACTA) Consumer Involvement Award for assisting in receiving a waiver of consent for the WHEAT Trial. I think these have been pivotal moments and all have led to demonstrating what can be achieved through researcher/consumer collaboration.

### What would you say to people who are new to getting involved?

I would say if you are really passionate about using your personal experience to make a genuine difference to the experience of others and their health outcomes, you've come to the right place. The ultimate goal is that research simply becomes part of routine clinical care, and where patients entering the hospitals are asking if there is any research they can be involved in. The only way to achieve that is through working together.

## 7. What advice can you give me for when I first get involved?

This section provides further details of what is likely to be expected of you and what you can expect, when you first:

- go to meetings with researchers
- comment on a research proposal
- comment on information written for patients (e.g., help writing plain language summaries)
- join a group of patients, carers, and members of the public.

The precise details may vary from project to project, and the researchers or staff will work with you to make clear what your role is and what they expect from you.

### Going to meetings with researchers

When you go to a meeting with researchers, they will be expecting you to contribute your views to the group discussion. You may be sent papers to read in advance and given a list of the topics that will be discussed (the agenda). Doing this for the first time may feel daunting for some people, especially if the research environment is new.

It can be helpful to bear in mind that:

- researchers are people too and may be just as nervous about meeting you and getting everything right
- everyone in the room will want to hear what you've got to say – your views have value
- you can draw on your experience and that of other people you know – but you are not expected to speak on behalf of all patients, overall you are bringing the consumer perspective to the discussion
- it's helpful to ask questions – sometimes the simplest and most obvious question is exactly what needs to be asked
- you might not understand what's being said, especially if people are using jargon – take the opportunity to ask what it means, as you'll be helping other people in the room too
- you might have more freedom to say what you think than other people and that can be very powerful – you can open up discussions that might not have happened before
- there will be people there whose job it is to support you and enable you to have your say, including other patients, carers, members of the public, staff and whoever is chairing the meeting.

“Consumer representatives are often described as the ‘critical friend’ of the research team. This is exactly right. You get to challenge researchers by asking them to justify why they want to do something. Sometimes there is a good reason, but sometimes there is not. The change may make it easier for the study to be completed successfully.” (Consumer)



## Commenting on research proposals

When you are asked to comment on a research proposal, you are very likely to be given support and guidance as to what's needed from you. The researchers may have specific questions they want to ask you, or they may ask for general comments. They will want to know whether the research is important from your point of view and whether it is looking at the outcomes that matter most to people like you.

Sometimes you might be asked to look at a research proposal by a potential funder, such as a charity or government funding body, to help make decisions about whether the research should be funded. In this case, your feedback might help the funder rather than the researcher.

Sometimes, you might be asked whether you think a proposal is ethically acceptable. In this case, your feedback might help the researchers to improve their plans, or might be used to inform an ethics committee, which decides whether the research can go ahead.

This task includes drawing on your experience to think about:

- whether taking part will cause people any distress or harm, and how this could be avoided or reduced to an acceptable level
- whether the practical arrangements for participants could be improved to make it easier to take part
- whether the people taking part might need additional support or care to manage the demands of taking part.

## Commenting on information written for consumers and the community

You may be asked to comment on information that has been written for consumers and the community, such as:

- information about research that's underway to let people know the research is happening
- posters, letters, and articles being used to advertise the research project to people who might want to take part
- participant information sheets – these explain what taking part in a research project will mean for the participants, so they can decide whether they want to do it
- articles, reports and press releases that are used to share the results with patients and the public
- plain-language summary of the research.

Your task will be to comment on whether the information:

- contains all the details that people need to understand the research
- contains all the details that potential participants need to decide whether they want to take part
- is written clearly and simply in a way that is easy to understand
- is laid out in a format that is clear and easy to read
- is produced in a format that is accessible to the target audience (e.g., in large font, if the target audience is likely to have visual problems).

## Joining a group

Many research organisations are now setting up consumer advisory groups to support them across a wide range of research projects, as well as helping them to develop their own policy and practice in involvement. Some groups are topic-specific and involve people who all have experience with the same condition. Others involve people with experience of different conditions. Each organisation will run its group slightly differently. Before you join a group, you will be given information on the way that the group works and about other relevant local organisations and networks.

Joining a group may not appeal to everyone, but the advantages are:

- being able to learn from members of the group with more experience of involvement
- receiving support from your peers
- being supported and trained by staff
- having someone to contact when you need help.

“After my first meeting with my group, I remember thinking, ‘I so want to do THAT again, it was such a laugh!’ They got all the work done and it was such a lovely environment and I walked away feeling uplifted. I didn’t think I would feel like that at all.” (Consumer)

## 8. Why do researchers want to involve consumers in their research?

When researchers apply for grants from funders like the National Health & Medical Research Centre (NHMRC), they must include information about how they have involved consumers and the community in developing their proposal, as well as how they plan to involve them in carrying out their research. There is now good evidence that involving consumers may improve the quality of research studies. As such, it is not surprising that researchers are very interested in involving consumers in their studies.

Many researchers understand the added value of involvement. They want to listen and learn from their conversations with consumer and community representatives. So, they want to hear what you have to say and will often make changes to their ideas and plans as a result.

“It was a surprise to me that we would be valued as equals – every academic I have worked with has been so down to earth.” (Consumer)

“Being involved changes how you think about researchers. We put them on a pedestal, but when you sit down with them with a cup of tea, they are just like you or I, and they are very willing to listen to you.” (Consumer)

However, there may still be a small number of researchers who don't yet understand the value of consumer involvement. When working with them, it may feel like they are simply 'ticking a box'. If they are open to your ideas, you may be able to change their views about what involvement could achieve, and work with them to increase your influence. If you feel you are not being heard, you could speak to the person who leads on involvement, a member of staff or another researcher. You always have the option to politely decline to be involved any further and to explain your reasons why.

“We all know we should be engaging consumers, but how to do it effectively to avoid it being just tokenism can be hard. As researchers, we also need to be trained”. (Researcher)



# Anne's story of involvement

Consumer Advocate. Manager, Community Engagement,  
Telethon Kids Institute.

## What is your role?

I have been privileged for the past 25–30 years to work alongside clinicians, researchers and consumers to raise awareness of the value of involving consumers and community members in health services and research and support the implementation of these roles in such areas.

## How did you first get involved in research?

My youngest daughter was born with spina bifida and we had to learn to cope with a new life based around disability, hospitals and engaging with many different doctors. During that time, I became increasingly interested in patient advocacy and how research informed healthcare.

In 1994 I was very fortunate to have a role to establish the first 'Parent Advocate' position at WA's Princess Margaret Hospital for Children. This role advocated for the engagement of families in decisions around service delivery. Working in this role gave me an opportunity to meet many families just like mine – people who wanted to use their experiences to improve health services. I still see some of those brave parents who spoke up at a time when the patient 'voice' was not always valued and am reminded why I still work in this area.

A decade later, I had a fantastic opportunity to work for Telethon Kids Institute and The University of Western Australia's School of Population and Global Health as the Consumer Advocate, which was a one-of-a-kind role in Australia.

## What sort of projects have you done?

During my 15 years in the role as the Consumer Advocate, I established a consumer and community involvement program that is now delivered across Western Australia. I'm proud to say it is recognised nationally and internationally as a good practice model. A major achievement of this initiative was the development of training workshops on implementing consumer and community involvement in research. This was an extremely nervous time for me, as I hadn't done anything like this before, but my passion for consumer involvement

and my ability to think on my feet stood me in good stead. I have now facilitated 130 workshops across Australia with researchers, clinicians and consumers.

At Telethon Kids I have worked on numerous projects with researchers and consumers. One outstanding example was working with researchers and consumers in the Fetal Alcohol Spectrum Disorder (FASD) team to develop resources around raising awareness among health professionals in the identification and care for patients with FASD. In addition, we facilitated community events to hear about issues regarding information available on alcohol consumption during pregnancy, established national community reference groups and undertook a project to identify the 'top ten' priorities for future research from both community members and service providers. This work has been extremely rewarding on a personal level, but it has also played a role in ensuring the community is integral to all research conducted in this area.

## How do you feel now compared to when you started?

I feel as passionate about consumer involvement in healthcare and research now as I did when I first started.

## What's your greatest achievement?

In 2015 I was appointed to the Order of Australia for 'Significant service to community health through consumer advocacy roles and strategic policy research and development'. This was a very humbling honour and fantastic to be recognised in such a way for doing work that I love and am really passionate about.

## Any messages to people new to involvement?

Do it, what have you got to lose? Your experiences of living with or caring for someone with a condition are truly invaluable. Being involved can be great fun and provide friendships that last a lifetime.

## 9. What training and support might I be offered?

### Training for people who get involved

Before you get involved in a research project, or when you join a group, you may be offered training involvement and about research. The aim will be to help you understand the research world a bit better so that you can understand when and how your contributions add value. Depending on your background and experience, you may find some forms of training more helpful than others. Everyone will have different things they want to learn.

As with anything else in life, you will learn how to 'do involvement' in a number of ways. You'll read about it and you'll learn from others with more experience than you. But you'll probably learn the most from actually doing it – 'learning on the job'. Don't be concerned if everything isn't perfect at the start. Your skills, understanding, and confidence will greatly increase over time.

"I came into it with mental health issues and I was quite scared at the beginning, but I've grown and become an extremely confident person and that's amazing. As you can become more confident, you're more able to challenge. Start gently and you will grow, and your contributions will get better. You have to find your feet at first, but it doesn't take long." (Consumer)

### Support for people who get involved

There should always be at least one person whose job it is to support consumers to be involved. They will support you in the way that meets your needs, perhaps giving you extra support at the beginning, and helping you develop your confidence over time. They will aim to meet your practical needs, your emotional needs and your learning and support needs.

"One of our projects wanted to involve a woman with gout – I didn't even know women got gout, but they do, and we found one. She would never have put herself forward, but we encouraged her and gave her a lot of support at the start. One of us went to the meetings with her, but she doesn't need us now! Sometimes people can do a lot more than they realise but might need a bit of extra support at the beginning." (Consumer)

"Sometimes I've been near to tears when somebody says something. It can just touch a nerve, so you've always got to be sure there is somebody there who will make sure you're alright. That's what I found with the staff team here. They make sure there is no obstacle for me. They always make everything simple and easy for me. All these things make a difference." (Consumer)



## 10. How will I benefit from being involved?

People who have been involved in research say that the experience has been more rewarding and more fun than they expected. It has given them a renewed sense of purpose, from being able to use their experience and knowledge to improve research, and help make the future better for others.

“If I can help just one person so they don’t have to go through the pain that I went through, then my time being involved in research is worthwhile. Coming here, you’re thinking of the people who come after you, and how you can improve things for them.” (Consumer)

It has given people new knowledge, from learning about how research works, what researchers are really like, and hearing about the latest research on different conditions. Some people use the knowledge and skills they gain through involvement to better prepare for their interactions with health professionals.

“Now when I see my doctor, I am much more confident to ask him about the latest research into my condition. I feel much more in control of my condition. (Consumer)

Involvement allows people to develop new skills and provides opportunities to use their existing skills. People end up doing things they would never have imagined doing before. They sometimes go back to doing things their health had stopped them doing. Sometimes developing and reusing these skills helps people to find work or go back to work.

Many people enjoy the sense of feeling valued by researchers. People who have lost jobs because of their health, often say they lost confidence in their abilities, but getting involved helped to remind them of what they can do, helping them to feel useful again. As they gain confidence over time, people improve the quality of their contributions and get involved in more varied and extensive ways.

Talking about their condition with researchers sometimes provides people with a different way to cope. They value being able to talk to someone who is genuinely interested in their condition and making good use of what might have been a bad experience.

“Being involved gave me a better handle on my fibromyalgia, rather than going to therapy or talking to a sympathetic friend. I don’t always want a pat on the shoulder or for someone to feel sorry for me. With research, you get to talk about it in a very different way, which helps you get your mind around it and gives your experience a value, and you a value, that you don’t get anywhere else.” (Consumer)

People who join groups or work with other consumers often say they make many new friends over the years, people who provide a much-valued source of support.

“I wasn’t aware how exciting involvement would be. It has opened up a new world that I had no idea existed and I’ve met loads and loads of different people. That’s a massive bonus.” (Consumer)

# 11. Why do people get involved in research?

People who get involved in research have different reasons for wanting to do it. For most people, it's about making a difference, wanting to ensure that future care will be better for the people who come after them. Some people have had difficult experiences and appreciate being able to do something positive with that experience. Others have had very good experiences, and see their involvement as an opportunity to 'give something back'.

"I still have my condition, but my experiences and other people's experiences can help to change things. I know what we do makes a difference, maybe not to my health, but to someone else's, to future generations. To be able to be part of that journey, by being involved, is an amazing thing to do." (Consumer)

If you have a particular concern, or a specific change you want to see, involvement in research may not be the best way for you to influence others, unless the research is very specifically about your issue. There may be other ways to help improve services, for example, by working directly with healthcare organisations to improve the way care is delivered.

Getting involved in research is about helping to test out ideas of what makes care better, rather than focusing on what went wrong. Finding effective ways to share the most significant parts of your story, is important to help researchers understand what matters most to consumers.

## 12. Where can I find out more?

If you would like to get involved in research, there are likely to be a number of opportunities that might suit you. The challenge lies in finding them, as they are advertised in different places by a variety of organisations.

Some of the places you could look and organisations you could contact include:

- Consumers Health Forum (<https://www.chf.org.au>)
- Local Consumer Groups (e.g., WA Consumer and Community Health Research Network or Health Consumers NSW)
- Health Issues Centre (<http://www.healthissuescentre.org.au/health-services/consumer-engagement-guide/recruiting-consumers/>)
- Research4Me (<https://research4.me>)
- Local Healthcare organisations (e.g., hospitals and GP practices). Ask staff if they know of any involvement opportunities in your area
- Universities working on health research
- If you are a patient or carer, any medical charities supporting people with your health condition
- Newspapers – local and national.