



Government of **Western Australia**  
Child and Adolescent Health Service



# CAHS Research Education Program Research Skills Seminar

## Consumer and Community Involvement in Research

**16 June 2023**



Presented by

**Belinda Frank**

Involvement Coordinator



**CAHS Research Education Program Research Skills Seminar Series**

✉ [ResearchEducationProgram@health.wa.gov.au](mailto:ResearchEducationProgram@health.wa.gov.au)

🌐 [cahs.health.wa.gov.au/ResearchEducationProgram](https://cahs.health.wa.gov.au/ResearchEducationProgram)



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Child and Adolescent Health Service, Department of Research

Department of Health, Government of Western Australia

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# Consumer and Community Involvement in Research

## PRESENTATION SLIDES





Government of Western Australia  
Department of Health



Perth  
Children's  
Hospital

# CAHS Research Education Program

## 2023 Research Skills Seminar Series

# Consumer and Community Involvement in Research

*Presented by* 16<sup>th</sup> June 2023



**Belinda Frank**  
Telethon Kids Institute  
Community Engagement Manager




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Perth  
Children's  
Hospital  
Foundation

1




## Acknowledgement of country

I would like to acknowledge the  
traditional custodians of the land,  
the Noongar Whadjuk people,  
and pay my respects to their elders,  
past, present and future.




2




## CAHS Research Education Program


### Research Skills Seminar Series

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact.


- 

#### Over 20 topics across the research process

  - 1h overview
  - Handouts are provided
- 

#### Recorded and uploaded
- 


#### Feedback

  - Back of handout
  - Emailed link
- 

#### Please hold questions to the end

  - Use provided microphone

3



## Introduction to consumer and community involvement in health research

Proudly supported by the people of Western Australia through Channel 7's Telethon

**Belinda Frank**  
June 2023

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## What's being covered today

- Involving the community (what, why, who, where, when & how)



- Tips for getting started
- Stages and levels of involvement
- Good practice examples

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## Definitions being used today

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

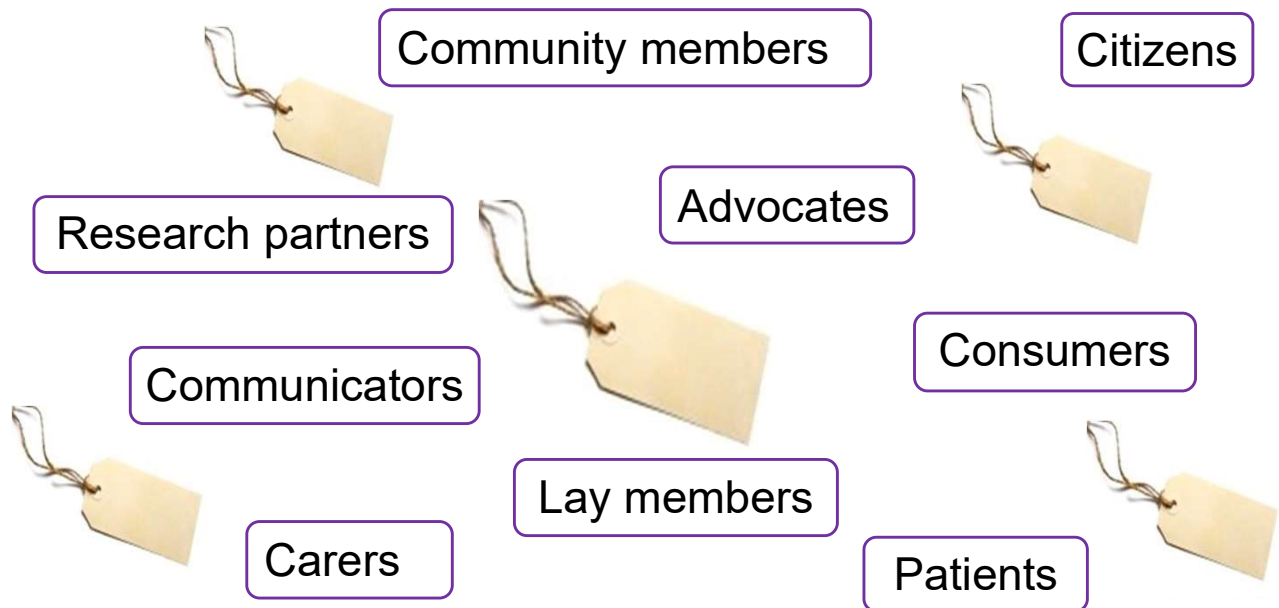
**Consumer representative** - a member of a committee, steering group or similar who voices the consumer perspective

**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

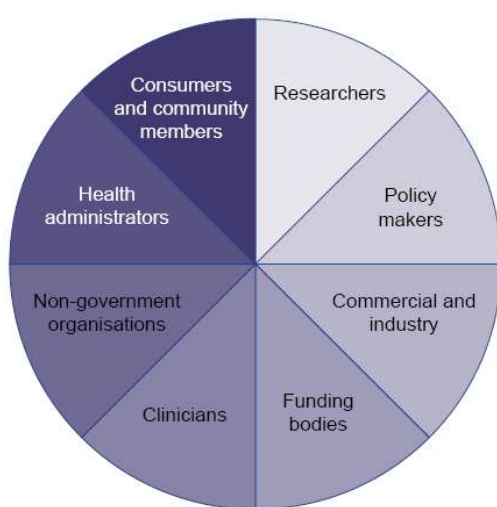
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## Labels...

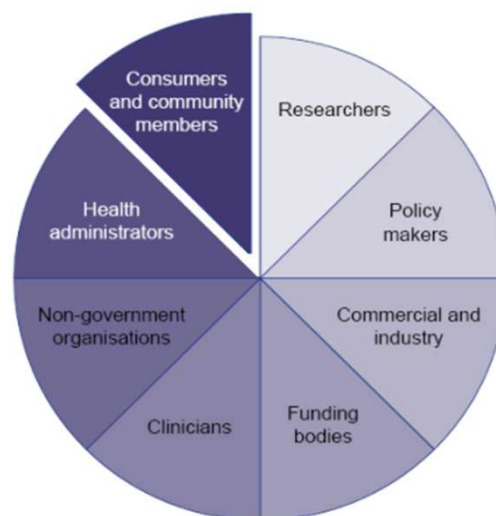


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## Stakeholders



Complete stakeholder wheel



Incomplete stakeholder wheel

8



## What

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



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## What's the difference

### Participation

- Participating 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



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

- Researchers raising awareness of their research
- The participants (subjects) taking part in research
- A recruiting tool
- An opportunity to 'tick the box'
- Fundraising or public relations



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11

**Why**



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## 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



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## Who

- Consumers  
(Patients and families or carers)
- Community members
- Members of the public



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How



17



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## 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.



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<https://www.telethonkids.org.au/be-involved/help-shape-our-research/>

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## Stages of involvement



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## Levels of involvement



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## Important points to consider

- Be clear about the stage and level of involvement you are seeking
- Use a framework or tools to help everyone consider the appropriate stage and level of consumer and community involvement
- Support consumers and/or community members to make informed decisions about becoming involved

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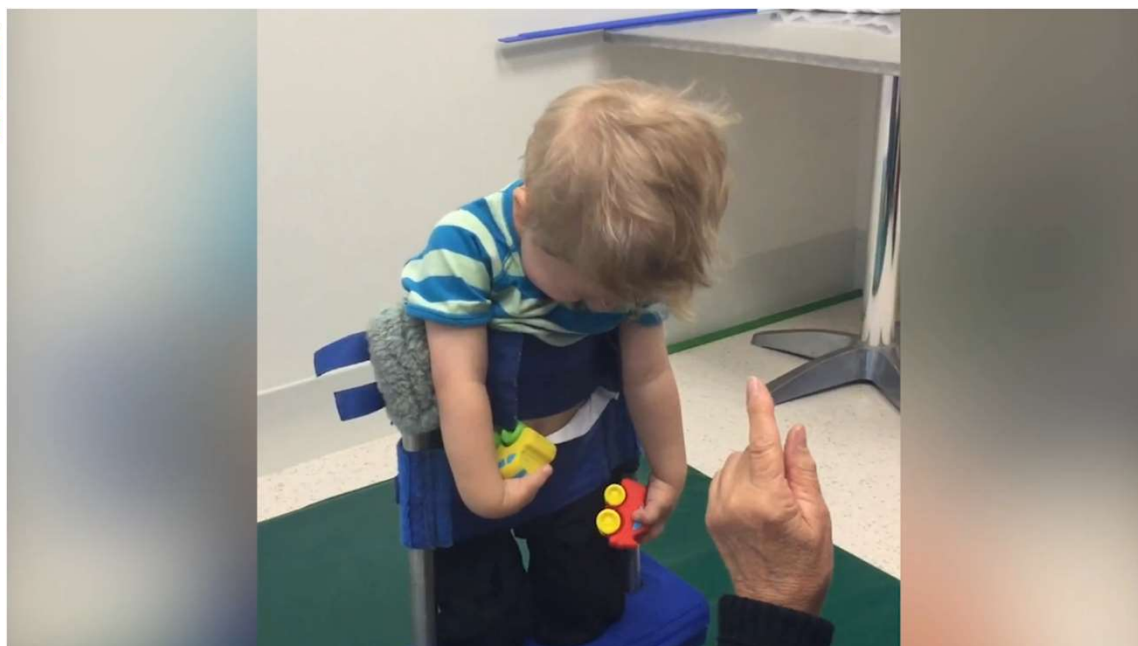
## Involvement methods

Currently there are hundreds of people involved in decision-making activities in research across the state - these include consumers:

- Reviewing grant applications, commenting on documents and helping to write plain language summaries
- Attending community forums, events and training
- Serving as community members, research buddies, members of reference groups, steering groups or advisory councils



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## Good practice examples of consumer and community involvement

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## Diabetes research

**RIO TINTO CHILDREN'S DIABETES CENTRE**  
A JDRF Global Centre of Excellence

The Rio Tinto Children's Diabetes Centre aims to improve the lives of children and young people living with type 1 diabetes by bringing together research, education, clinical care and the T1D community.

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## Cystic Fibrosis Research

BEAT CF trial is evaluating a range of treatments and eliminating those found to be inferior, making way for more effective available alternatives.

Three national community advisory groups:

- Adults
- Youth
- Parents/partners and carers

The advisory groups have provided input into the trial since its ideation.



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## Koolungar Moorditj Healthy Skin Project

Project aims:

- To understand more about the skin health of urban-living Aboriginal koolungar in WA.
- To embed an evidence-based dermatology research-service program.
- And to develop and evaluate culturally appropriate moorditj healthy skin educational resources.








**Guiding principles:** *respect, reciprocity, capacity building and community involvement.*

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## Final tips on getting started

Planning for involvement – it is important to ensure you have the following in place before you begin involvement activities:

-  Senior level support and sign off
-  Budget
-  Time
-  Training needs of researchers and community members
-  Administration support and a named person with responsibility for involvement activities

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## Resources



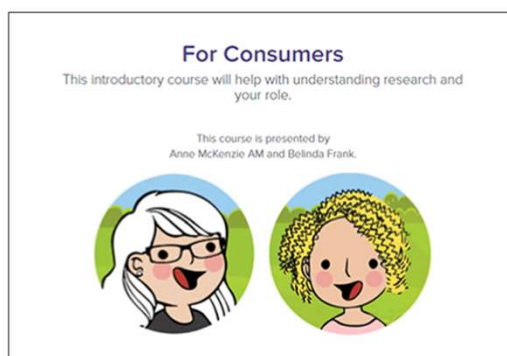
<https://www.telethonkids.org.au/be-involved/help-shape-our-research/>

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# Free online consumer training module

## Consumer and community involvement training



<https://bit.ly/TKITraining>

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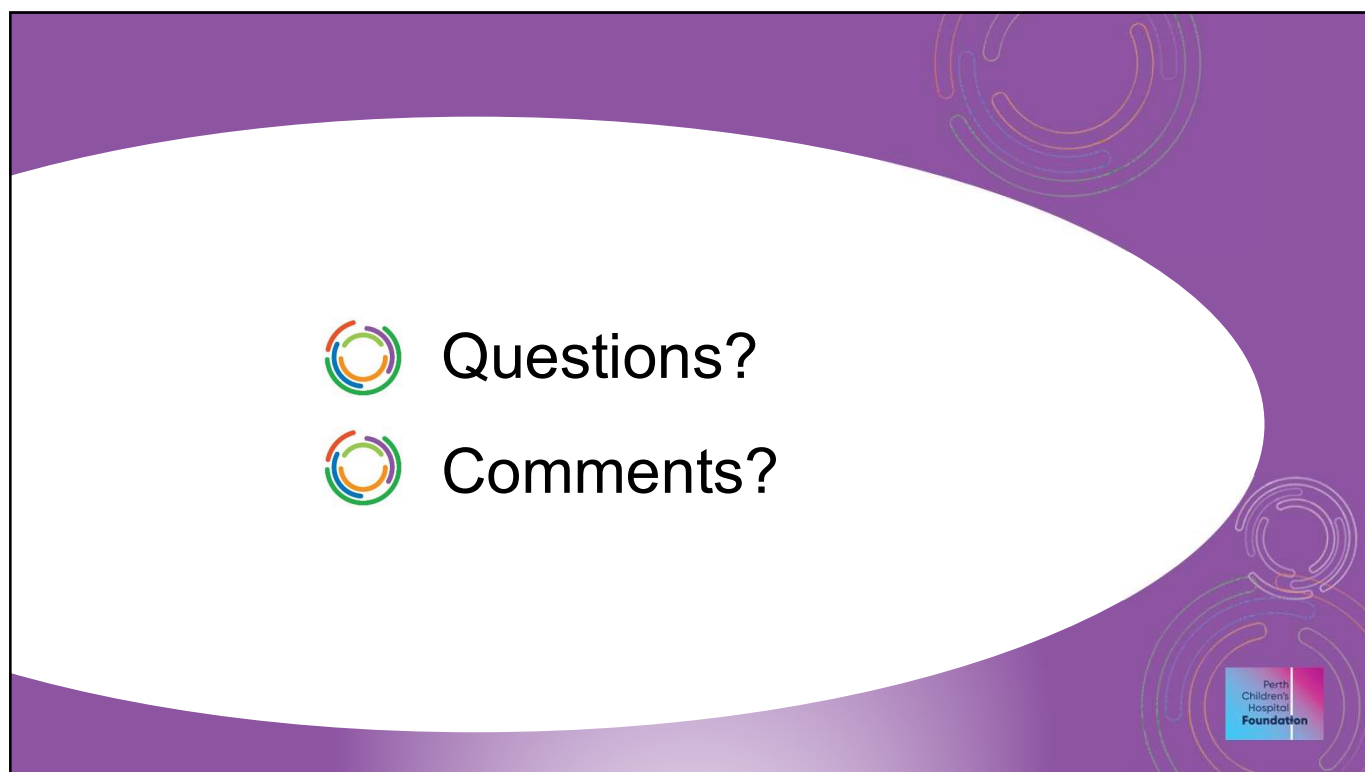
# Thank you

[Engagement@telethonkids.org.au](mailto:Engagement@telethonkids.org.au)

Thankyou to Australian Clinical Trials Alliance for use of the videos contained in the presentation.

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## Upcoming Research Skills Seminars

- 23 June**     **Project Management**  
                   Melanie Wright, East Metropolitan Health Service
- 30 June**     **Sample Size Calculations**  
                   Michael Dymock, Telethon Kids Institute

Register → [researcheducationprogram.eventbrite.com.au](https://researcheducationprogram.eventbrite.com.au)

### We love feedback

A survey is included in the back of your handout, or complete online  
<https://tinyurl.com/ConsumerCommunityInvolvement>

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# Consumer and Community Involvement in Research

## RESOURCE NOTES





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## 2. State resources

### 2.1. Telethon Kids Institute

<https://www.telethonkids.org.au/be-involved/help-shape-our-research/>

#### 2.1.1. Barriers Report

McKenzie A., Bulsara C., Haines H., Hanley B., Alpers K. Barriers to community involvement in health and medical research: Researchers perspectives on consumer and community involvement in research: a qualitative study. 2016. ISBN 978-0-9872783-5-7

#### 2.1.2. Purple Book

McKenzie A, Hanley R. Planning for Consumer and Community Participation in Health and Medical Research: A Practical Guide for Health and Medical Researchers. Perth: The University of Western Australia and the Telethon Kids Institute 2014. ISBN 978-0-9872783-3-3

#### 2.1.3. Fact Sheets

McKenzie, A., Haines, H. Consumer and Community Involvement Fact Sheet Series, 2011, Perth; The University of Western Australia and the Telethon Institute for Child Health Research. ISBN 978-0-9872783-2-6

#### 2.1.4. Green Book

McKenzie, A., Hanley, B. Consumer and Community Involvement in Health and Medical Research, A practical guide for health and medical research organisations 2007, Perth; The University of Western Australia and the Telethon Institute for Child Health Research. February 2012, Second Print, ISBN 978-0-9872783-0-2

#### 2.1.5. Program Report

McKenzie A, Alpers K. Consumer and Community Participation Program: Report on Activities 1998-2014. Perth: The University of Western Australia and the Telethon Kids Institute 2015. ISBN 978-0-9872783-4-0

### 2.2. The Consumer and Community Involvement Program

<https://cciprogram.org/>

### 2.3. The Health Consumers' Council of WA (HCC)

<http://www.hconc.org.au>



## 3. National resources

### 3.1. **Cancer Australia**

<https://canceraustralia.gov.au/>

### 3.2. **Health Issues Centre**

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

### 3.3. **Consumers' Health Forum of Australia**

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

### 3.4. **The National Health and Medical Research Council**

<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

### 3.5. **National Health and Medical Research Council.**

*Expectations and Value - Framework for Effective Consumer and Community Engagement in Research.pdf*

<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

(scroll to 'Download' section)

### 3.6. **NHMRC Consumer Involvement Guidelines**

<https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>

### 3.7. **Australian Clinical Trials Alliance Consumer Involvement and Engagement**

<https://involvementtoolkit.clinicaltrialsalliance.org.au/>

## 4. International resources

### 4.1. **Health and Care Research Wales**

<http://www.healthandcareresearchwales.org>

### 4.2. **National Institute for Health Research**

<https://www.nihr.ac.uk/>

### 4.3. **Canadian Institutes for Health Research**

<https://cihr-irsc.gc.ca/e/193.html>

### 4.4. **Patient-Centered Outcomes Research Institute**

<https://www.pcori.org/>



## 5. Barriers

- McKenzie A., Bulsara C., Haines H., Hanley B., Alpers K. 2016. Barriers to community involvement in health and medical research: Researchers perspectives on consumer and community involvement in research: a qualitative study. ISBN 978-0-9872783-5-7
- Thompson J, Barber R, Ward P, Cooper C, Armitage C, Jones G. 2009. Health researchers' attitudes towards public involvement in health research. Health Expectations

## 6. Writing in plain language

- TwoCan Associates. 2008. Getting it right for service users and carers, getting it right for researchers: How to decide whether to help researchers find people to take part in research. UK  
<http://www.twocanassociates.co.uk/wp-content/uploads/2017/05/WellcomeGuideFINAL.pdf>
- How to write reports in plain English. New Mills: Plain English Campaign  
[www.plainenglish.co.uk](http://www.plainenglish.co.uk)
- The National Institute for Health Research website dedicated to supporting each research study it funds has a clear and concise plain English summary.  
<https://www.nihr.ac.uk/documents/plain-english-summaries/27363>





# CAHS Research Education Program

## Research Skills Seminar Series 2023

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact

# Project Management

23rd June 2023

12.30-1.30pm

Efficient and effective project management techniques are essential to move your research project from initiation to execution, through to success.

This seminar provides insights to improve internal communications, foster team alignment, facilitate risk management and improve workflows for smooth processes and engaged stakeholders.

### Perth Children's Hospital Auditorium

Level 5, 15 Hospital Ave Nedlands

Accessible via pink or yellow lifts

- OR -

Access online via Teams or Avaya

- OR -

Watch live  
from a hosted video-conferencing site

- Bunbury Hospital
- Fiona Stanley Hospital
- Lions Eye Institute



### Meet the presenter

**Melanie Wright**  
Director Research  
South Metropolitan Health Service

*Excellent health care, every time*

Care ■ Integrity ■ Respect ■ Excellence ■ Teamwork



Mel has 39 years of healthcare experience and for the past 6 years has led strategic transformation of the research environment in SMHS, achieving significant cultural change, to one where researchers are supported, enabled and empowered to conduct high quality local, state and international research projects.

Mel is passionate about project management, research and involving consumers with lived experience in every aspect of healthcare as equal and active partners. Mel has over 10 years of healthcare project management experience and she is also passionate about teaching, coaching and mentoring staff to achieve their very best.

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## CAHS Research Education Program

### 2023 REDCap Workshop Series

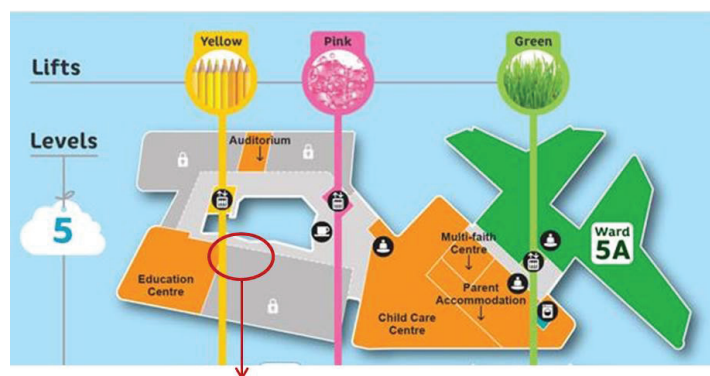
#### REDCap Workshop 6: Advanced REDCap

27th June 2023 • 1.00 - 3.30pm • PCH, TKI Level 5 Seminar Room

This workshop explores a more in-depth look at advanced features in REDCap and how to design and distribute a survey through REDCap.

Enrolment in this workshop requires previous attendance at one of our preliminary sessions (Basic OR Intermediate) or be able to demonstrate that you are already administering projects within REDCap.

Can you comfortably create a matrix of fields, use branching logic, piping and calculated fields? If you answer No to any of the above, please register for an Intermediate Workshop.



#### Location of the TKI Seminar Room

Accessible via yellow or pink lifts

#### About the Presenter

**Dr Jane Mugure Githae**  
REP Research Fellow



Mugure joins us from Kenya where she practiced as a General Surgeon & Honorary Lecturer in General Surgery. She has experience in clinical research, clinical audits and medical education. She is keen to simplify the process of integrating day-to-day clinical work with research.



<https://20230627RedcapAdvanced.eventbrite.com.au>

**Register** via Eventbrite

**View** our online REDCap resources

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Places are strictly limited and offered on a first-come, first-serve basis. If you are unable to attend a workshop for which you have registered, please contact Research Education Program support via email to cancel your booking and/or be placed in another workshop or on the waitlist.

Laptops are available if required

#### Contact Us



(08) 6456 0514



[researcheducationprogram@health.wa.gov.au](mailto:researcheducationprogram@health.wa.gov.au)



[cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program](https://cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program)



# CAHS Research Education Program

## Research Skills Seminar Series 2023

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact

# Sample Size Calculations

30th June 2023

12.30-1.30pm

This seminar provides an overview of how to perform sample size calculations for different research study designs and demonstrates how to use free "PS" software.

It also covers issues specific to clinical trials and assists researchers to identify situations where the best course of action is to consult a statistician.



### Meet the presenter



**Michael Dymock**

**Biostatistician - Telethon Kids Institute**

### Perth Children's Hospital Auditorium

Level 5, 15 Hospital Ave Nedlands  
Accessible via pink or yellow lifts

- OR -

Access online via Teams or Avaya

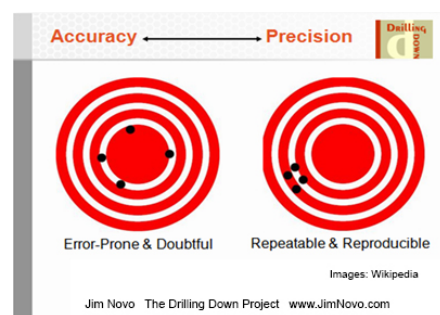
- OR -

Watch live  
from a hosted video-conferencing site

- Bunbury Hospital
- Fiona Stanley Hospital
- Lions Eye Institute
- Royal Perth Hospital

In 2018 Michael received a first-class Honours degree in Computational Statistics at UWA, where he was later employed as a consultant statistician with the Centre for Applied Statistics.

His current research interests include Bayesian adaptive trial designs, computational statistics and vaccine safety surveillance.



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## CAHS Research Education Program

# Research Skills Seminar Series

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact.

## 2023 Seminar Schedule

Interactive in pdf format  
Last updated 14/6/23

	DATE	TOPIC	PRESENTER	ENROL	WATCH
1	3 Mar	Research Fundamentals	Dr Kenneth Lee, UWA	-	<a href="#">2023</a>
2	17 Mar	Introductory Biostatistics	Michael Dymock, TKI	-	<a href="#">2023</a>
3	28 Apr	Scientific Writing	A/Prof Tony Kemp, UWA	-	<a href="#">2023</a>
4	5 May	REDCap for Data Capture and Management	Dr Jane Mugure Githae, CAHS	-	<a href="#">2023</a>
5	12 May	Using Social Media in Research	Dr Kenneth Lee, UWA	-	<a href="#">2023</a>
6	19 May	Getting the Most out of Research Supervision	A/Prof Sunalene Devadason, UWA/CAHS	-	<a href="#">2022</a>
7	26 May	Research Impact	Dr Tamika Heiden, Vic	-	<a href="#">2023</a>
8	2 Jun	Survey Design & Techniques	Dr Jane Mugure Githae, CAHS	-	<a href="#">2023</a>
9	9 Jun	Conducting Systematic Reviews	Prof Sonya Girdler, Curtin Uni	-	<a href="#">2023</a>
10	16 Jun	Consumer & Community Involvement in Research	Belinda Frank, TKI	<a href="#">REGISTER</a>	<a href="#">2022</a>
11	23 Jun	Project Management	Melanie Wright, SMHS	<a href="#">REGISTER</a>	<a href="#">2022</a>
12	30 Jun	Sample Size Calculations	Michael Dymock, TKI	<a href="#">REGISTER</a>	<a href="#">2022</a>
13	21 Jul	Introduction to Good Clinical Practice	Alexandra Robertson, CAHS	<a href="#">REGISTER</a>	<a href="#">2021</a>
14	28 Jul	Data Collection and Management	DoH Data Library, tbc	<a href="#">REGISTER</a>	<a href="#">2022</a>
15	4 Aug	Rapid Critical Appraisal of Scientific Literature	Dr Natalie Strobel, ECU	<a href="#">REGISTER</a>	<a href="#">2022</a>
16	18 Aug	Media and Communications in Research	tbc	<a href="#">REGISTER</a>	<a href="#">2022</a>
17	25 Aug	Oral Presentation of Research Results	Dr Jane Mugure Githae, CAHS	<a href="#">REGISTER</a>	<a href="#">2022</a>
18	1 Sep	Involving Aboriginal Communities in Research	Cheryl Bridge, Mara West and Mel Robinson – TKI and CAHS	<a href="#">REGISTER</a>	<a href="#">2022</a>
19	8 Sep	Knowledge Translation	A/Prof Fenella Gill, Curtin Uni/CAHS	<a href="#">REGISTER</a>	<a href="#">2021</a>
20	13 Oct	Research Governance	Natalie Giles, CAHS	REGISTER	<a href="#">2022</a>
21	20 Oct	Grant Applications and Finding Funding	Dr Tegan McNab, TKI	REGISTER	<a href="#">2022</a>
22	27 Oct	Statistical Tips for Interpreting Scientific Claims	Michael Dymock, TKI	REGISTER	<a href="#">2022</a>
23	17 Nov	Ethics Processes for Clinical Research in WA	Natalie Giles, CAHS	REGISTER	<a href="#">2020</a>
24	24 Nov	Qualitative Research Methods	Dr Shirley McGough, Curtin Uni	REGISTER	<a href="#">2022</a>
25	1 Dec	Innovation and Commercialisation	Dr Helga Mikkelsen, Brandon BioCatalyst + Ashley Schoof	REGISTER	<a href="#">2022</a>

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[cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program](https://cahs.health.wa.gov.au/Research/For-researchers/Research-Education-Program)





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# Child Health Research Symposium

Celebrating Innovation, Collaboration and Translation

[cahs.health.wa.gov.au/Child-Health-Research-Symposium](https://cahs.health.wa.gov.au/Child-Health-Research-Symposium)



8 - 10 November 2023



Perth Children's Hospital Auditorium  
and Telethon Kids Institute Manda

PLUS

breakfast sessions and poster evening event

Incorporating the CAHS Nursing and CAMHS Symposiums

Neonatology | Community Health | Mental Health | Perth Children's Hospital







## CAHS Research Education Program

### Research Skills Seminar Series

A free, open-access resource designed to upskill busy clinical staff and students and improve research quality and impact.

## Consumer and Community Involvement in Research

Thank you for your interest in this seminar

Please complete this 1-minute evaluation.

Your feedback will help guide future presentations and educational activities.

#### How did you attend the seminar?

- ☐ Live seminar at Perth Children's Hospital
- ☐ Hosted video-conference on-site (e.g. FSH, Lions Eye, RPH etc.)
- ☐ Online via Avaya or Teams
- ☐ Viewed online recording

#### Please rate your agreement with the following statements:

	N/A	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
The aims and objectives were clear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The session was well structured	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Presentation style retained my interest	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The speaker communicated clearly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The material extended my knowledge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The additional resources were helpful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### What were the best aspects of the seminar?

#### What changes or improvements would you suggest?

#### How did you hear about the seminar?

(you can select multiple answer)

- ☐ Email invitation from Research Education Program
- ☐ CAHS Newsletters e.g. The Headlines, The View, CAHS Research Newsletter
- ☐ "Health Happenings" E-News
- ☐ Healthpoint Intranet Upcoming Events
- ☐ Collegiate lounge screen or other posted promotional material
- ☐ Telethon Kids Institute screen or other posted promotional material
- ☐ Telethon Kids Institute Newsletter
- ☐ Other

Thank you!





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**CAHS Research Education Program Research Skills Seminar Series**

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