



# Engaging Young People and Families in Research Workshop

Saturday 15<sup>th</sup> October 2016, 9.30 am – 4.30 pm

Mercure Hotel Sydney, 818 - 820 George Street, Sydney NSW 2000

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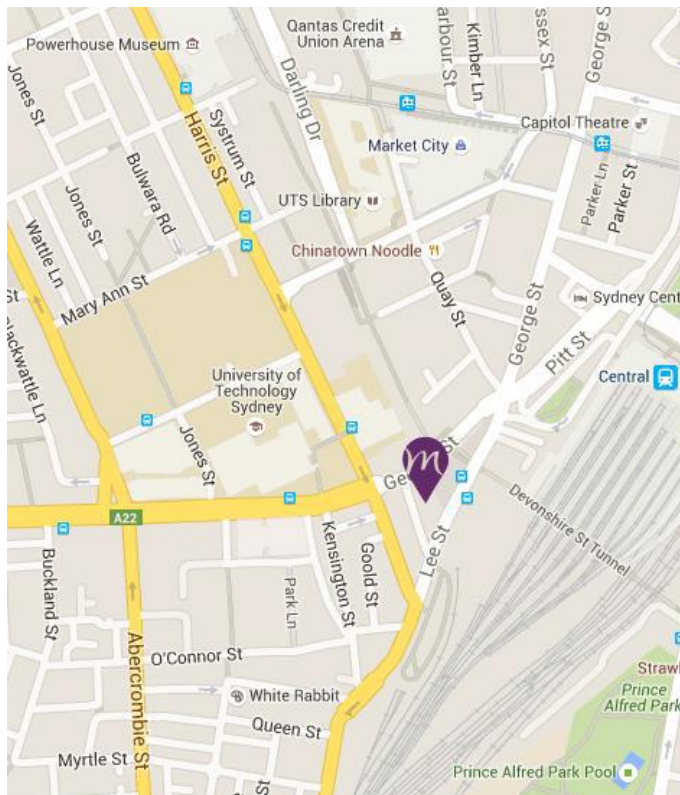
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## Workshop details

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- Time:** 9.30 am – 4.30 pm
- Date:** Saturday 15th October 2016
- Venue:** Mercure Hotel Sydney, 818 - 820 George Street, Sydney NSW 2000
- Cost:** Free registration (inclusive of catering)
- Parking:** Available on site, entrance via Little Regent St, Chippendale NSW 2008



### Contacts

- Pamela Lopez-Vargas 0412 235 393 [pamela@thekaleidoscopeproject.com.au](mailto:pamela@thekaleidoscopeproject.com.au)
- Allison Tong 0414 276 883 [allison.tong@sydney.edu.au](mailto:allison.tong@sydney.edu.au)

# Overview

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## Outline

This national workshop brings together young people, families, communities, and health professionals to learn and discuss how to engage young people with chronic conditions and their families in research. This workshop is part of a larger project known as The Kaleidoscope Project (TKP), which aims to engage a range of stakeholder in research priority setting for childhood chronic disease. At this workshop, you will hear from Sally Crowe who is a world-recognised expert in patient engagement, a member of the British Medical Journal's Patient Panel and former Co-Chair of the UK-based James Lind Alliance (JLA), which facilitates research priority setting partnerships globally. This workshop is hosted by BT4K, an initiative funded by the NSW Health (Office of Health and Medical Research), aimed to increase the number, relevance and quality of clinical trials in young people.

## Meeting objectives

The goals of the workshop are:

- To learn about engaging young people and families in research
- To understand the different approaches used in Australia and overseas to engage young people and their families in research activities
- To develop and discuss research priorities in childhood chronic disease
- To begin to identify common issues of high importance shared among young people with chronic disease and their families, that should be used to inform a common agenda for trials in Australia

## Participants

This workshop will bring together people who have an interest in childhood chronic diseases, including:

- children and young people (11 to 18 years of age) with a chronic condition
- parents/caregivers (of children and young people aged 0 to 18 years with a chronic condition)
- patient advocates or representatives from patient organisations
- researchers
- clinicians (doctors, nurses, allied health professionals)
- industry
- policy makers

All attendees will have the opportunity to be a named contributor on publications arising from this workshop.

# Program

Time	Session
9:30 am	Registration and coffee
10:00 am	<b>Welcome and setting the scene</b> Prof Jonathan Craig, <i>The University of Sydney, The Children's Hospital at Westmead</i>
10:10 am	<b>Opening remarks</b> Dr Antonio (Tony) Penna – <i>Director of the Office for Health and Medical Research, NSW Health</i>
10:15 am	<b>Icebreaker</b> Sally Crowe, <i>Director Crowe Associates Ltd</i>
10.30 am	<b>Session 1: ENGAGING YOUNG PEOPLE AND FAMILIES IN RESEARCH - why it matters</b> Chair: Prof Jonathan Craig  <b>Making health research relevant and useful - what have we learnt from setting research priorities with people who live with chronic conditions?</b> Sally Crowe, <i>Director Crowe Associates Ltd</i>  <b>An Australian perspective</b> Anne McKenzie, <i>Consumer Manager, Consumer and Community Participation Program, The University of Western Australia</i>
11:00 am	Morning tea
11.30 am	<b>Session 2: VIEWS FROM ORGANISATIONS THAT REPRESENT YOUNG PEOPLE WITH CHRONIC CONDITIONS AND THEIR FAMILIES</b> Chair: Sally Crowe  <b>Presenters:</b> <ul style="list-style-type: none"> <li>• Nettie Burke – <i>CEO, Cystic Fibrosis Australia</i></li> <li>• Laura Griffin – <i>Network Manager (Consumer Engagement), Sydney Children's Hospitals Network</i></li> <li>• Chandana Guha – <i>Parent, Transplant Australia</i></li> <li>• Jessica Keath – <i>Research Manager, Children's Cancer Institute</i></li> <li>• Anthony Brown – <i>Executive Director, Health Consumers NSW</i></li> </ul>
12.15 pm	<b>GROUP DISCUSSION – How do we make sure that young people's and their families' views and experiences influence research priorities?</b> Chair: Sally Crowe
1:00 pm	Lunch
1.45 pm	<b>Session 3: THE KALEIDOSCOPE PROJECT- SUMMARY OF PROGRESS</b> Dr Pamela Lopez-Vargas, <i>Project Coordinator, The Children's Hospital at Westmead</i>
2.00 pm	<b>Session 4: GENERATING QUESTIONS: CHILDHOOD CHRONIC DISEASE WHAT MATTERS TO YOU?</b> Facilitators: Jonathan Craig, Angela Ju, Angeliq ue Ralph, Allison Tong, Anita van Zwieten, Laura James and Pamela Lopez-Vargas  <b>Breakout group discussions – generating and voting on questions</b>
3:00 pm	Afternoon tea
3:30 pm	<b>Session 5: SHARING AND SUMMARISING PRIORITY RESEARCH QUESTIONS</b> Whole group discussion Facilitator: Sally Crowe
4:15 pm	<b>Summary of the workshop</b> Prof Jonathan Craig
4.30 pm	<b>Close</b>

## Speaker and Chair biographies

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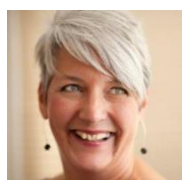
**Dr Anthony Brown** has been working as our full-time Executive Director since April 2014. He is passionate about consumer and carer engagement and was a member of the Steering Committee which helped establish HCNSW in 2012. He has worked for the Men's Health Information and Resource Centre at the University of Western Sydney and the Council for the Ageing before joining us. His vision for HCNSW is to make sure that health providers really listen to and show respect to health consumers, their families and carers



**Nettie Burke, CEO, Cystic Fibrosis Australia.** As the Chief Executive Officer of Cystic Fibrosis Australia, Nettie Burke brings experience and expertise shaped in senior management roles in both the corporate and the not-for-profit sectors in the UK and Australia. In previous roles Nettie has developed strategic plans that addressed business development, client engagement and brand strategies for the future. These strategies attracted partnerships with the community, corporate sector and government, involved program restructures and development and established business review and reporting procedures designed to deliver financial sustainability and business growth.



**Professor Jonathan Craig** is a Paediatric Nephrologist at the Children's Hospital at Westmead and holds a personal Chair in Clinical Epidemiology in the School of Public Health at the University of Sydney. His research is focused on improving the evidence-base underpinning the prevention and treatment of kidney disease in children and adults. He has sought to achieve this by facilitating the development of a clean and comprehensive register of all randomized controlled trials in kidney disease, systematically evaluating and synthesising these trials into systematic reviews, and then integrating these systematic reviews into evidence-based guidelines. He has also conducted a variety of large scale clinical and population health research projects. Examples include studies designed to prevent the development of kidney disease in Aboriginal children, to prevent urinary tract infection in children, and more effective detection and treatment of people with kidney disease and cancer.



**Sally Crowe** is an experienced facilitator of patient and public involvement in health and social care research and services development. She co-chaired the James Lind Alliance (JLA), a national coalition tackling treatment uncertainties in health care, from 2007 – 2013 and is currently supporting a JLA Priority Setting Partnership in Early Osteoarthritis of Hip and Knee. She supports the International Pelvic Pain Partnership, a group of patient organisations striving for better treatments and more relevant research in chronic pelvic pain. Sally is public representative on the NIHR Systematic Review Programme Board, and the Medical Research Council Ethics Regulation and Public Involvement Committee. She is a member of the British Medical Journal's Patient Panel and on the Editorial Board of BioMed Central's new Research Involvement and Engagement Journal.



**Laura Griffin** is the Network Manager Consumer Engagement at Sydney Children's Hospitals Network (SCHN). She has a background in psychology and health service management. Laura's passion is for person-centred health care, focusing on the relationships between people. Laura manages a team of four at SCHN, and the team has a proactive and reactive focus on the patient experience through complaints management, carer support, and consumer engagement.



**Chandana Guha** Chandana is well acquainted with the transplantation world. Her daughter was diagnosed with a renal condition at the age of two and went on the transplantation list at the age of 11. The effects of chronic renal disease and the impacts of a difficult post-transplant experience left her daughter feeling lost and unsupported. Chandana and her daughter experienced firsthand the need for patients to be assisted in a number of critical areas while recovering from the surgery and also in the long term. Her experience with transplantation helped Chandana provide valuable information and support to patients and their families who were struggling like her to come to terms with life after transplant. At Transplant Australia she has found the opportunity to draw from her experience and support recipients in several critical areas through the Quality of Life Program. This program aims to support recipients and their families through their journey by promoting an environment that encourages and sustains their long term health and wellbeing.



**Jessica Keath** is a Research Manager with over eight years' experience. In her current role as Research Manager at the Children's Cancer Institute, she is responsible for Consumer Engagement and in 2015 she employed a Consumer Engagement Coordinator for the first time at the Institute, who has been a champion of two way consumer engagement. Jessica has successfully supported researchers in developing relationships with consumers and Children's Cancer Institute researchers consistently receive funding from Cancer Australia and Cancer Council NSW. Previously Jessica was a Grants Officer at UNSW Australia and a Drama Tutor at NIDA. Jessica has a Bachelor of Arts and Sciences from the University of Melbourne (European Studies & Biochemistry) as well as a Diploma in Performing Arts from Actors' Centre Australia. Outside of work she has written theatre and restaurant reviews for Guardian Australia and Timeout and has volunteered as a presenter and producer at Radio 2SER.



**Dr Pamela Lopez-Vargas** is the Project Manager for The Kaleidoscope Project. She completed her PhD in 2015 on the educational needs of patients with chronic kidney disease. Pamela has worked at The Centre for Kidney Research since 2003 on a variety of research projects involving adults and children. She has expertise in guideline implementation, systematic reviews and qualitative research. Her research interests include patient education, priority setting partnerships and implementation science.



**Anne McKenzie** is the Consumer Advocate/Manager for the Consumer and Community Participation Program at The University of Western Australia, School of Population Health and the Telethon Kids Institute since 2004. She now leads and manages the joint Consumer and Community Involvement Program at both organisations. Her role is to support and facilitate active consumer and community involvement in the research. Anne is also a senior consumer representative for Consumers Health Forum of Australia and former Chair of the Health Consumers Council of WA and she serves on key national and state committees. In 2015 Anne was appointed to the Order of Australia Medal for service in the area of health consumer advocacy and research.



**Dr Antonio Penna** is a paediatrician and medical administrator. He specialised in paediatric pharmacology and undertook clinical research for over a decade before he moved into administration. Tony was a medical administrator at Westmead Hospital and Royal North Shore Hospital before taking on the position of Chief Executive of the Children's Hospital at Westmead for 5 years. In August 2013 he was appointed as Director of the Office for Health and Medical Research in the NSW Ministry of Health.



## Attendee List

The participants include patients, parents/caregivers, healthcare providers, researchers and policy makers.  
**NB\***Indicates participants who were not able to attend the workshop.

All participants will have the opportunity to provide feedback on the workshop report/publication.

First name	Last name	Affiliation
<b>Parents/Caregivers</b>		
Adam	Bowyer	
*Barrie	Littlefield	Cure Brain Cancer Foundation - Head of Engagement
Carolina	Valerio	The Children's Hospital at Westmead
Caron	Kambi	
Chandana	Guha	Transplant Australia
*Chelli	Edri	
Chris	Walker	Parenteral Nutrition Down Under Inc.
Dane	Kambi	
*Fiona	Lynch	The Children's Hospital at Westmead
Fred	Elharris	
Georgia	Pagano	
Jen	Stumbles	The Children's Hospital at Westmead
*Jennifer	Brankin	The Children's Hospital at Westmead
Josephine	Gile	
*Justine	Roberts	
Karen	Wong	
Kylie	Black	
*Lesley	Bowen	
Melissa	Bowyer	
*Milena	McDonald	The Children's Hospital at Westmead
Mustapha	Harris	
Peggy	Lin	The Children's Hospital at Westmead
Penny	Jones	Sydney Children's Hospital
Peter	McGann	
Pietro	Pagano	
Rema	Elhassan	
Sophie	Cole	
Suzy	Haddad	
Zoe	Fernance	The Children's Hospital at Westmead
<b>Representatives from consumer organisations</b>		
Anne	McKenzie	Consumer and Community Health Research Network. The University of Western Australia School of Population Health
Anthony	Brown	Health Consumers NSW
Jayne	Blake	HeartKids Australia
Jessica	Keath	Children's Cancer Institute
Juliet	Chandler	Arthritis & Osteoporosis NSW
Laura	Griffin	Sydney Children's Hospitals Network
Lizzy	Harnett	Association for the Wellbeing of Children in Healthcare (AWCH)
Maria	Lorenzo Fernandez	Little Wellness Program
Megan	Jackson	Australian Research Alliance for Children and Youth, University of Canberra
Michelle	Haskard	Australasian Society of Clinical Immunology and Allergy (ASCIA)
*Mike	Wilson	Juvenile Diabetes Research Foundation Australia
Nettie	Burke	Cystic Fibrosis Centres across Australia
Robert	Gardos	Polycystic Kidney Disease Foundation of Australia
Sally	Crowe	Crowe Associates Ltd
Siobhan	Brophy	National Asthma Council Australia

First name	Last name	Affiliation
<b>Health professionals</b>		
Adam	Jaffe	Sydney Children's Hospitals Network - Randwick & University of NSW
Alison	Bowers	Queensland University of Technology
Allison	Tong	The University of Sydney
*Amit	Arora	The University of Sydney
Angela	Ju	The University of Sydney
Angelique	Ralph	The University of Sydney
*Angie	Morrow	The Children's Hospital at Westmead, The University of Sydney
Anita	van Zwieten	The University of Sydney
Antonio	Penna	NSW Health – Office for Health and Medical Research
Benjamin	Wyse	Macquarie University
Camilla	Scanlan	The University of Sydney
Carolyn	Rogers	The GOLD Service (Genetics of Learning Disability)
Chris	Cowell	Sydney Children's Hospitals Network
*Deborah	Gubler	The Children's Hospital at Westmead, Paediatric Palliative Care (Fellow)
*Elizabeth	Stewart	University of Sydney, The Sydney Children's Hospitals Network
Grace	Spencer	The University of Sydney
Harriet	Hiscock	Centre for Community Child Health, Murdoch Children's Research Institute, Royal Children's Hospital
Harrison	Odgers	The University of Sydney
Helen	Puusepp-Benazzouz	The Children's Hospital at Westmead
Husna	Razee	University of New South Wales
Jackie	Boyle	NSW Genetics of Learning Disability Service, Hunter Genetics
*Jacqueline	Tudball	The Children's Hospital at Westmead, University of Technology Sydney
Jan	Belcher	John Hunter Children's Hospital
Jenny	Couper	Women's and Children's Hospital , South Australia
Jonathan	Craig	The University of Sydney
Justyna	Ozimek-Kulik	Sydney Children's Hospitals Network
Karen	Bau	The Children's Hospital at Westmead
Karine	Manera	The University of Sydney
*Katherine	McCorkindale	Queanbeyan Hospital and Community Health Centre
*Kristine	Lobley	The Children's Hospital at Westmead
Laura	James	University of Sydney, Children's Hospital at Westmead
Laurel	Mimmo	University of NSW; Sydney Children's Hospital, Randwick
Leanne	Hallowell	Australian Catholic University
Margaret	Wallen	Cerebral Palsy Alliance
Michael	Bowden	Sydney Children's Hospitals Network
Natasha	Nassar	Menzies Centre for Health Policy, University of Sydney
Pamela	Lopez-Vargas	The Children's Hospital at Westmead
Petra	Karlsson	Cerebral Palsy Alliance, The University of Sydney, Australia
*Rebecca	Ivers	The George Institute for Global Health, University of Sydney
Ross	Pinkerton	Lady Cilento Children's Hospital
Samantha	Carlson	The Children's Hospital at Westmead, National Centre for Immunisation Research and Surveillance, University of Sydney
Sharron	Hall	Hunter Medical Research Institute
Sukanya	De	The Children's Hospital at Westmead
Suzanne	Sheppard-Law	Sydney Children's Hospitals Network and University of Technology, Sydney
Yana	Wilson	Cerebral Palsy Alliance, University of Sydney, Garvan

