



# Autism CRC 2017 Research Academy

## FINAL REPORT

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[autismcrc.com.au](http://autismcrc.com.au)

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## **About the Cooperative Research Centre for Living with Autism (Autism CRC)**

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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# 1. Background

The mission of the Autism CRC is to motivate, facilitate and translate collaborative autism research across the life-span, underpinned by inclusive practices. To support inclusive practices, the Autism CRC developed a number of resources including the Autism CRC Statement on Inclusive Practices and a series of Inclusive Research Practices Guides and Checklists. Understanding that implementation of these practices needs to be supported through capacity building, the Autism CRC Research Academy was instituted.

The Autism CRC Research Academy was established in 2015 and currently comprises 28 Autistic adults and 19 autism researchers. The members of the Academy have been trained through this Autism CRC initiative in inclusive research, specifically peer research (also termed 'co-production'). This involves researchers and Autistic people working together as 'peers' to ensure what is being researched and how it is being researched, is both appropriate for and relevant to people on the spectrum and their communities. For a literature review of peer research refer to the 'Autism CRC Research Academy: Final Report' for 2015, available at [autismcrc.com.au](http://autismcrc.com.au).

The 2017 graduates of the Research Academy were upskilled in peer research through a range of activities, based on learnings and feedback given by the 2015 graduates. This document outlines these activities, and provides an evaluation.

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## 2. Objective and Governance

To meet the objective of enabling autism research underpinned by inclusive practices, it was determined that members of the Research Academy needed to:

- Learn the specific skills needed to be a peer researcher;
- Develop an understanding of the benefits of peer research;
- Learn about effective peer research; and,
- Network with potential peer researchers from around Australia.

The facilitation and delivery of content and activities that met this aim was governed by a project team (authors of this report) comprising: three Autistic adults, a parent of an Autistic adult, and a project coordinator based at Autism CRC head office. Three project team members delivered the 2015 Academy, and the others were Academy Alumni.

A Project Advisory Group - consisting four 2015 Alumni and two autism researchers - was established to provide specific advice to the Project Team, where required.

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## 3. Participants and Delivery

### 3.1 Participants

Participants in the 2017 Research Academy were seven autism researchers, and 14 Autistic adults. Expressions of interest were received from 11 researchers and 28 Autistic adults. The selection committee (n=5) were majority Autistic and applications were evaluated independently with regard to expressed desire and capacity for peer research engagement.

### 3.2 Delivery Methods

The methods used to upskill the participants was based on feedback from the 2015 Academy members. This established the requirement for:

- enhancing researchers' knowledge of autism and lived-experience;
- enabling more time for researchers and autistic participants to network and practice skills;
- providing research process and practice content in a written format, that could be worked through at their own pace; and,
- the workshop for Autistic participants to be shorter than five days, focusing on interactive activities and/or discussion.

Accordingly, **autism researchers** were required to:

1. Engage with prescribed readings and videos that promoted understanding of neurodiversity and the lived-experience, and submit written reflections. These materials were chosen by Academy 2015 Alumni.
2. Read the Autism CRC Inclusive Guides and Checklists and other peer research literature, and submit written work. This required the detailing of how they could promote meaningful engagement with people on the spectrum and/or their family members and carers, in each of stage of their research.
3. Attend the Researching Autism Together Workshop, from June 24-25 (termed 1-day workshop).



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**Autistic participants** were required to:

1. Complete Modules that related to research practices and processes. These Modules were written by members of the 2015 Academy Project Team, with the 'autism friendliness' assessed by two 2015 Academy Alumni. The modules were:

- Introduction to Autism CRC and Inclusive Research
- Introduction to Ethics
- Introduction to Quantitative Research
- Introduction to Qualitative Research
- Introduction to Mixed Methods Research
- Introduction to Participatory Methodologies
- Introduction to Dissemination of Research
- Optional Module: Introduction to Evidence Based Practice

Modules were presented through a purpose built e-learning platform. This also incorporated discussion boards to enable dialogue regarding content, and interactions with other participants.

2. Attend the Researching Autism Together Workshop, from June 23 to June 26, 2017 (termed 3-day workshop).

### 3.3 Workshop delivery

The topics delivered at the workshop, as shown in Table 1, were those related to processes and protocols for research and peer research engagement. Consistent with feedback from the 2015 Academy, and as also shown on Table 1, the format for delivery included discussion, role play and small group activities. However, the majority of topics included a portion of didactic teaching in order to: provide orientation to topic; familiarisation of theory; and, reduce social fatigue through provision of a non-interactive component in each session.

Table 1. Workshop topics, allocations, format and session attendees

Topic	Time allocation (minutes)	Format of Delivery	Attendees
<b>Creating 'Autism Friendly' Ice-breakers</b>	60	Didactic & Discussion	Autistic Participants
<b>Meeting Etiquette &amp; Expectations</b>	60	Didactic & Role Play	Autistic Participants
<b>Providing Input/ Feedback at Meetings</b>	60	Didactic & Role Play	Autistic Participants
<b>Research Designs</b>	60	Didactic & Discussion	Autistic Participants
<b>Ethics</b>	60	Didactic & Role Play	Autistic Participants
<b>Power Relationships &amp; Engaging in Small Talk</b>	60	Didactic & Discussion	Autistic Participants
<b>Engaging in Peer Research</b>	60	Didactic & Discussion	Autistic Participants
<b>Making Peer Research Work</b>	60	Didactic & Panel Discussion	Autism Researchers Autistic Participants
<b>Research Translation</b>	60	Didactic	Autism Researchers Autistic Participants
<b>Hands-on Workshopping</b>	180	Small group activities and presentations	Autism Researchers Autistic Participants
<b>Workshop Evaluation</b>	60	Focus Group	Autism Researchers Autistic Participants

Following successful delivery and the results of the evaluation in 2015, the supportive processes and practices, criteria for venue selection, and preparation for participants remained unchanged. Details of these can be found in the 'Autism CRC Research Academy: Final Report', which is available for download from [autismcrc.com.au](http://autismcrc.com.au).

## 4. Evaluation

### 4.1 Participants

Participants in the evaluation were Autistic adults (n=14) who attended the workshop for 3-days, and autism researchers (n=5) who attended the workshop for 1-day.

### 4.2 Method

The method for evaluation for participants was a fit-for-purpose survey, developed for the 2015 Academy workshop. In addition, the opinions and perspectives of Autistic participants were elicited through a focus group. The focus group was conducted as the last session of the workshop, and utilised a semi-structured protocol.

### 4.3 Results

Analysis of quantitative data, as shown in table 2, indicated high approval ratings for the workshop ( $\bar{x}$  = 3.75) and the online components ( $\bar{x}$  = 3.42 for Autistic participants,  $\bar{x}$  = 3.75 for autism researchers). As also shown in table 2, the quality and value of assessment tasks for researchers was highly valued ( $\bar{x}$  = 3.75), with all participants indicating they would recommend the workshop to others.

**Table 2.** Mean scores for workshop and online modules rating and endorsement

	3-day workshop n = 12	1-day workshop n = 5
Overall workshop rating *	$\bar{x}$ = 3.75 range = 3-4	$\bar{x}$ = 3.75 range = 3-4
Overall online modules/resources rating *	$\bar{x}$ = 3.42 range = 3-4	$\bar{x}$ = 3.75 range = 3-4
Quality and value of assessment tasks *		$\bar{x}$ = 3.5 range = 3-4
Recommend the workshop to others **	$\bar{x}$ = 1	$\bar{x}$ = 1

\* rating scale: 1=poor, 2=okay, 3=good, 4=excellent

\*\* rating scale: 1= yes, 2= no

The data also indicated: an increase in competence to engage in peer research and related elements; and for researchers, increased likelihood to engage in peer research. Excluding cases which identified as ‘very competent or likely’ prior to Academy engagement, casewise comparison indicated 100% participants as more competent and likely to engage in peer research, as shown on Table 3. It should be noted, however, that only a small number of participants completed these questions. As also shown in Table 3, the majority of Autistic adults indicated increased competence to undertake all aspects of peer research.

**Table 3.** Percentage of participants indicating increase in competence or likelihood to engage in peer research

	3-day workshop	1-day workshop
<b>Competence to:</b>		
- Engage in peer research	100% (n=2)	100% (n=3)
- Be a part of a research team meeting	100% (n=2)	–
- Give your opinion on research design and meaning of findings	78% (n=9)	–
- Give your opinion on research techniques	78% (n=9)	–
- Give input to research projects	78% (n=9)	–
- Become an advisory group member	8% (n=9)	–
<b>Likelihood to engage in peer research:</b>	–	100% (n=2)

Qualitative data supported positive ratings elicited through survey. In relation to *methods and processes* it was additionally highlighted that:

- module content was informative and helpful in preparing for the workshop;
- information booklets with preparatory information (including: photos of people they would meet, the venue; menus; what to expect; what to bring and wear etc.) was valuable to reducing anxiety;
- responsiveness to needs and desires enabled people to be their ‘true-selves’;
- it was appreciated that most sessions were run by autistic presenters but through co-presenting, peer research was continually demonstrated.

With regard to *format* it was indicated that:

- having time as a group before autism researchers attended the workshop allowed the group to bond with ‘their tribe’;
- the time with the researchers was not long enough to enable effective networking.

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## 5. Conclusions and Recommendations

The evaluation data indicated highly successful and appropriate delivery in-line with the objectives of the Academy project. Reflections of the project team and a number of graduates suggest additional benefits of Academy delivery as enabling people to 'find their tribe' - indicating this as significant to empowerment and community inclusion, and potentially more heightened for those newly diagnosed or self-identified. This indicates the inclusion of empowerment as a key outcome and objective for future Research Academy delivery and other initiatives.

Post-delivery, a number of Autistic participants have engaged with autism researchers on research projects and initiatives. This has happened both independently of the CRC, and with the CRC as a segue of introduction - matching the research interests of Autistic members of the Academy. Further, a number of Autistic graduates from 2017 are co-producing guidelines and checklists to facilitate the inclusion of people on the spectrum in workshops, functions and conferences. This is due for publication in mid-2018.

While the above indicates the successful translation of theory to practice, avenues for engagement in peer research, continued skill development and ongoing support is required. Further, there remains an imperative to evaluate peer research in action to identify barriers and facilitators of peer research.



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