AutismCRC

Autism CRC Research Academy

FINAL REPORT

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THE UNIVERSITY OF QUEENSLAND
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AutismCRC
Research Academy

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Autism CRC Research Academy

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Note on terminology: It is acknowledged that members of the autism community have varied views about appropriate terminology, however, consistent with Autism CRC style guide and discussions with our Academy members, the terms , ‘on the autism spectrum’ and ‘on the spectrum’ will be used in this report.

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 with autism.

autismcrc.com.au

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1. Background

The Autism CRC was established in 2013, our ambitious goal is to transform the lives of people on the autism spectrum across the lifespan. As the Autism CRC evolved, it became clear to us that we had dual responsibilities regarding the promotion of autism research in Australia. Firstly, having received the single largest Commonwealth investment of funding into autism research in Australia's history, we needed to invest wisely in projects that met the needs of children and their families and adults on the spectrum, to reach our agreed Commonwealth milestones/ deliverables. Secondly, and equally importantly, we had an opportunity to change the way in which autism research was conducted in Australia. There was a risk that more autism research funding could just lead to more of the same, in terms of how research was conducted and we wanted to change that. We had a vision that Autism CRC would engage extensively with the autistic and autism communities. Further, that this engagement would ensure that our research projects would meet the needs of these communities and that the findings would be more readily translated into practice.

As part of this plan, we developed an Autism CRC Statement on Inclusive Research Practices to guide our work. This statement outlines nine principles regarding research being informed by those on the autism spectrum, that the research would be meaningful, that those on the spectrum would play a central role, that co-production opportunities would be provided, research would have real world benefits, use research designs that are appropriate for the questions being asked and engagement of end-user perspectives, and that the strengths of those on the spectrum would be acknowledged.

Subsequently a process for inclusive research practices was developed and a series of Inclusive Research Practice Guides and Checklists were also created to help researchers to be more inclusive at all stages of commissioning, undertaking research and disseminating, evaluating and utilising findings. These Guides and Checklists were co-produced by researchers and adults on the spectrum and were launched in December 2014. See www.autismcrc.com.au

On further reflection, we recognised that while the Statement and Inclusive Research Practice Guides provided the 'how to', they needed to be embodied and used and this would require significant capacity building among the research and autistic communities. In essence, the challenge was to bring to life the ink on the page and ensure the principles and ideas embedded in the Guides were understood and implemented. To this end, the concept of developing an Autism CRC Research Academy took form with the aim of upskilling both adults on the spectrum and existing scholars to be able to work together as peer researchers who could undertake the tasks of co-production.

Sylvia Rodger

Professor Sylvia Rodger AM.
Director of Research and Education

2. Literature Review

Peer research, also termed research co-production, involves researchers and end-users working together as 'peers' to ensure that what is being researched and how it is being researched is relevant to, and appropriate for, those on the spectrum and their communities. Traditionally, people on the spectrum have been 'subjects' of research studies and excluded from direct research involvement and autism-policy development (Raymaker & Nicolaidis, 2014). Peer research, however, recognises and equally values the skills of researchers and the expertise that people on the autism spectrum have gained through their lived experience, and engages people on the spectrum at every stage of the research process - from identification of research questions, data collection and analysis, through to dissemination and knowledge translation (Cargo & Mercer, 2008). Research methodologies that engender co-production and peer research include participatory research, participatory action research and community based participatory research (AASPIRE, 2015; Jivraj, Sacrey, Newton, Nicolas & Zwaugenbaum, 2014).

Co-production has historical roots in civil rights and social care in America (Realpe & Wallace, 2010) and has been applied in various research contexts and with various groups including: intellectual and developmental disability (McDonald & Raymaker, 2013; Puyalto, Pallisera, Fullana & Vila, 2015); health care (McColl-Kennedy, Vargo, Dagger, Sweeny, & van Kasteren, 2012; Stantiszewska, Brett, Mockford, & Barber, 2011); 'disabled' children and young people (Bailey, Boddy, Briscoe & Morris, 2014; Kirby, 2004); and those on the autism spectrum (Nicolaidis et al., 2013).

A review of the literature indicates a number of potential benefits of research co-production, including increases to the quality, relevance and appropriateness of research, as well as research implementation and translation. Co-production as facilitative of quality research has been indicated by a number of authors (Bailey et al., 2004; Kirby, 2004; Puyalto et al., 2015; Stantiszewska et al., 2011). McDonald (2013) highlighted that quality is improved through better designed studies, more trustworthy conclusions and access to larger samples. Similarly, Nicolaidis et al. (2013) indicated that access to larger samples was facilitated by the generation of accessible data collection instruments through co-production.

Co-production has been identified as having the potential to generating more relevant and appropriate research that facilitates effective response to the needs of people on the spectrum by Bailey et al. (2004), Cargo and Mercer (2008) Stantiszewska et al. (2011) and others. Pellicano, Dinsmore and Charman (2014) indicate that through co-production, research can more accurately respond to the needs of the autistic community. Pellicano et al. (2014) also suggest that co-production is supportive of research implementation and translation. They indicate that it enhances the likelihood of implementation as research findings and interventions are accessible, useful and sustainable. Cargo and Mercer (2008) highlight that co-produced research is more likely to result in wider dissemination and translation of the research.

The evidence suggests that co-production also has a number of benefits for peer researchers on the spectrum. Bailey et al. (2004), Kirby (2004) and Pellicano et al. (2014) indicate end-user involvement in co-production increases empowerment, personal development and self-esteem for individuals and autistic communities. Despite the benefits heralded in the literature, there is a dearth of research that has evaluated peer research endeavours from the perspectives of adults on the spectrum, researchers and others, nor determined whether the many benefits proffered have been realised.

However, while there are a number of potential benefits associated with co-production and peer research, recent research has indicated implicit resistance by researchers to engage in co-production with people on the spectrum, and has highlighted the need to increase the ‘research literacy’ of members of the autism community (Pellicano et al., 2014). To that end, the Research Academy was developed to build an appreciation and capacity for co-production within both the autism and research communities.

3. Research Design

3.1 OBJECTIVES AND METHOD

The objective of the Autism CRC's Research Academy was to start to build the capacity for co-production within the autistic and research communities in Australia.

To meet this objective, the Researching Autism Together Workshop was delivered in October 2015 to adults on the spectrum (n=14) and autism researchers (n=14). The specific objectives of the workshop were for participants 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;
- network with potential peer researchers from around Australia; and,
- gain membership into the Research Academy

3.2 ETHICAL CLEARANCE

Ethical clearance for researching the workshop delivery and long-term engagement in co-production was obtained from The University of Queensland's Behavioural and Social Sciences Ethical Review Committee (approval number 2015000771).

4. Development and Recruitment

4.1 DEVELOPMENT

The Research Academy was developed by a national project team (project report authors) which included an adult on the spectrum and a parent of an adult on the spectrum. Seven project team meetings were held both face-to-face and using online modalities over the year. The project team identified holding a one week national workshop as the most appropriate way to meet the objective of capacity building within the research and autism communities for research co-production.

A national Project Advisory Group was established to provide consultation to the project team with regard to workshop recruitment, venue, structure, content, delivery and evaluation. The group met with project team members three times using online and virtual meeting modalities. The group comprised four people on the spectrum and two people experienced in co-production methodologies, such as action and participatory research, and workshop delivery. Further consultation was sought by the project team with an autism education expert with regard to content delivery, and the need for flexibility versus content consistency and structure.

Key decisions made regarding the development of the Research Academy were as follows.

- Face-to-face workshop delivery to allow for peer learning and flexibility in content delivery based on the needs of participants. Further, a workshop was thought to enhance networking with other potential peer researchers.
- Adults on the spectrum to attend the workshop for 5-days to ensure knowledge of the research process was maximised and thereby facilitating future co-production.
- Researchers to develop an appreciation for, and skills to undertake, co-production through:
    (a) completing readings (approximately 4-5 hours) including the Autism CRC's Inclusive Research Practices Guides and Checklists for Autism Research as well as other literature relating to terminology preferred by the autistic community and co-production;
    (b) submitting an assessment task (approximately 1200 words) relating to how, in their current or previous research, they could promote meaningful engagement with people on the spectrum and/or their relatives in each of stage of the research process (commissioning, undertaking and dissemination). The assessment task was graded as pass or fail by members of the project team (n=2) with an opportunity provided for resubmission; and,
    (c) attending the workshop for 1-day alongside adults on the spectrum attending for 5-days to allow networking with potential peer researchers and to develop further understanding of the importance of and processes associated with co-production.

- For adults on the spectrum residing in Australia and attending the 5-day workshop, the Autism CRC funded the cost of travel, accommodation, lunch and refreshments.
- Locate a venue with consideration given to the sensory needs of adults on the spectrum and that had a conference room, accommodation and a restaurant to enable (a) quick regress to accommodation should participants feel overwhelmed or need a break, and (b) participant needs be met at one site.

4.2 RECRUITMENT

Information flyers, frequently asked questions and expressions of interest forms (see Appendix A) were developed and assessed for 'autism friendliness' by the Project Advisory Group. Distribution was undertaken through Autism CRC media and networks (including essential and other participants), advocacy agencies, support groups and service provider agencies.

Expressions of interest were received from 18 adults on the spectrum and 22 researchers. Applications were assessed by the project team and in order to be inclusive, further information or clarification was asked of respondents where required (n=3). Positions were offered and accepted by 14 adults on the spectrum for the 5-day workshop (with 1 international attendee self-funding), and 17 researchers for the 1-day workshop. Attrition (9.68%, n=3) was reduced by offering second round workshop placements where an invitation was accepted but the person could not attend.

5. Workshop Delivery

5.1 TOPICS

The topics covered during the 5-day workshop, time allocations and format for delivery are summarised in Table 1. The topics covered during the 1-day workshop attended by both people on the spectrum and autism researchers are indicated by bold-face type. The content was delivered in 60 minute sessions, allowing for a minimum 10 minute break between sessions.

The majority of sessions were delivered or facilitated by the project team members to aid familiarity and consistency. Guest presentations on the topic of co-presenting were provided by a non-verbal adult on the spectrum using augmentative alternative communication and two researchers. Guest presentations on co-writing were delivered by an adult on the spectrum, a researcher on the spectrum and an autism researcher; and the topic of advisory groups were delivered by a person on the spectrum, two researchers on the spectrum and an autism researcher.

Table 1. Summary of workshop content and time allocation

Topic	Time allocation (minutes)	Format of Delivery
Co-production/ Peer Research	180	Didactic & Discussion
Attending Meetings	60	Didactic & Discussion
Research Team Meetings- Etiquette and Expectations	60	Role Play & Discussion
Ethics	60	Didactic & Discussion
Solving an Ethical Dilemma	60	Role Play & Discussion
Research Design and Methods: Qualitative, Quantitative and Mixed-Methods	180	Didactic & Small Group Activity
Co-presenting	60	Guest Presentations
Providing Input to Researchers	60	Didactic & Discussion
Dissemination	60	Didactic and Discussion
Participatory Methodologies	**60**	**Didactic & Small Group Activity**
Managing Risk	**60**	**Didactic and Discussion**
Hands on Workshopping- Giving and Receiving Feedback	**60**	**Small Group Activity**
Making it Work: Advisory Groups, Co-presenting and Co-writing	**180**	**Guest Presentations & Discussion**
Workshop Evaluation	60	Discussion

5.2 FORMAT

The format for content delivery included didactic methods, role plays, small group activities, guest presentations, and discussion.

- Role play. The first role play was performed by the project team to illustrate specifics of a role play and avoid 'putting people on the spot'. Participation in the second role play was voluntary with details provided in advance.
- Group activities. Small group activities were used to provide participants with the opportunity to apply the material presented e.g. coding data.
- Didactic. This format was used for topics with a large amount of content, however, was delivered in a flexible format which allowed for content changes based on participant needs and in which questions could be asked at any stage. All didactic sessions (with the exception of a 15 minute session) were led by members of the project team to increase comfort through personal familiarity.
- Guest presentations. Presentations were delivered by three people on the spectrum, three autism researchers on the spectrum and four autism researchers. Guest speakers were used to deliver first hand experience of aspects of co-production, co-presenting and co-writing.
- Discussion. Although an element through all sessions, discussion as a specific format for content delivery was used to provide opportunity for participants to ask questions, verbalise their understanding, opinions, and apply theory in practice.

5.3 SUPPORTIVE PROCESSES AND PRACTICES

To support content delivery to adults on the spectrum, a number of facilitative processes and practices were undertaken prior to the workshop, during the week and daily during workshop delivery.

Prior to the workshop:

- Surveying participants to ascertain their current level of knowledge (see Appendix B) to ensure optimal engagement and learning during delivery;
- Providing all PowerPoint slides, activities and information on role plays to participants for download three weeks in advance of the workshop and providing these in printed format at the workshop;
- Using consistent icons/symbols in PowerPoint slides to highlight when questions and comments were sought during sessions; and,
- Having participants chose the most accessible format for PowerPoint slides and handouts (font size, font colour and background colour) prior to developing these.

During the week:

- Enhancing engagement in session content by allowing optional attendance of sessions when participants needed a break;
- Accommodating participants preferred mode for learning, e.g. sitting, standing at tables, lying on beanbags;
- Using a consistent real world research example throughout content delivery, including for delivery of ethics and research method content;
- Having a "questions and comments" box to provide opportunity for participants to write questions and provide remarks anonymously;

- Utlising a ‘parking lot’ whereby if participants wished to discuss topics beyond the parameters of the session, these were recorded in the ‘parking lot’ for exploration at a later point in time;
- Providing participants with a visual dictionary of research terms which they could add to throughout the workshop (see Appendix C for current version of co-produced dictionary);
- Having sensory items available to participants who find this facilitative of concentration; and,
- Having a non-teaching afternoon at the midway point through the 5-days to reduce fatigue.

Daily:

- Project team maintaining flexibility to alter content based on the needs of participants;
- Empowering participants to adjust air-conditioning and lighting configuration to suit their needs;
- Having an introductory and conclusion session each day led by the same project team member for the purpose of daily consistency and addressing questions and comments and ‘parking lot’; and,
- Utlising communication dots on nametags to increase comfort- red meaning I would prefer to be left alone, yellow meaning I am happy for a quick chat and green meaning I am happy to engage in conversation. These were used by project team members as well as participants.

6. Workshop Planning

6.1 VENUE CONSIDERATIONS

Adults on the spectrum and members of the project team evaluated the appropriateness of multiple venues. Considerations for an appropriate venue were:

- Having accommodation and function room within the one venue to enable participants to quickly and safely regress to their rooms if needed;
- Having a function room of such size to facilitate both the 1-day and 5-day attendees, and enable 5-day participants to move freely and utilize tables and chairs, beanbags or standing tables;
- Adjustable and quiet air-conditioning systems;
- Non-fluorescent lighting and not highly patterned or brightly coloured carpets;
- Quiet rooms - both accommodation and function room;
- Close proximity to multiple eating establishments to cater for varying dietary requirements and budgets;
- Close proximity to a supermarket to enable in-house catering; and,
- Toilets with paper towel, or allow for the provision of paper towel, so loud hand dryer machines did not need to be used.

6.2 PREPARATION FOR 5-DAY PARTICIPANTS

To reduce potential anxiety related to workshop attendance, specific activities were carried out and information was provided to participants in advance of the workshop. These related to travel, venue, social interactions and dietary requirements.

Travel

- Participants were given the mobile phone number of the Project Officer for support during travel.
- Where people were traveling to the venue via car, support was offered by the Project Officer to help with route planning.

For participants travelling to the venue by plane:

- A guide to the Brisbane airport was developed and given to participants in advance of flying. This identified instructions for, and photos of: boarding; disembarking; check-in; baggage claim; exiting and navigating the airport; and, locating the taxi rank.
- Where multiple people where located in the same state, participants and members of the project team were booked on the same flights. For departure to Brisbane a specific location at the airport was identified to provide people with the option to check-in together. For departure to home states, participants travelled in taxis together to enable support through check-in and navigating the airport.
- Flight bookings were made by the Project Officer and participants were given instructions on how to change their seat allocation and meal requirements according to their needs.

Venue
To aid environmental familiarity and reduce fatigue, participants staying at the hotel were accommodated the night prior to workshop commencement. Further, to reduce potential anxiety, participants were provided in advance with an information booklet which detailed:

- Emergency contact numbers- ambulance, police, local hospital, poisons information centre and project team member staying at the hotel;
- Important contact numbers- hotel lobby, local doctor, local dentist and project officer;
- Emergency procedures if smoke or flames are seen, if the fire alarm is sounded and if the lift stops working. These were accompanied by photographs;
- Emergency evacuation maps for the floor of the function room and, for those staying at the venue, the floor of their hotel room;
- A guide for what to bring and what to wear;
- Instructions for connecting to the internet at the hotel, for those staying at the venue;
- Photos of the Autism CRC head office which was visited by participants; and,
- A map of the local area showing food outlets and supermarkets, and opening hours of popular places to eat.

Additionally, in advance of the workshop, participants were provided with a list of facilities in their rooms and videos showing the hotel rooms, the function room and lobby, the restaurant and outside of the venue.

Social interactions
Cognisant of the potential anxiety related to social interactions, a number of processes were undertaken. First, familiarity with other participants and the project team was enhanced through a closed Facebook group which included photos and videos uploaded by the participants and project team members. Second, through explanation that communication dots (indicating desired level of social interaction at any given time) would be used. In addition, included in the participant information booklet provided in advance were:

- Photos and biographies of the autism researchers attending the 1-day workshop;
- Photos of the project team and functions manager of the venue; and,
- Photos of Autism CRC staff members they would meet during the site visit.

Dietary requirements
Catering menus were provided in advance to participants to enable them to assess suitability. Where participants had allergies, specific sensitivities and/or dietary requirements, the project officer liaised with the venues chef to gain further information and make accommodations.

Expectations
Conveyed to participants in written format were expectations regarding flexibility in attending workshop sessions, necessity to store and manage own personal medication and what to wear during the workshop.

6.3 RISK MINIMISATION

A risk assessment was undertaken by the project team, identifying potential risks and mitigation strategies. In addition, participants disclosed their personal, medical and dietary needs, potential triggers and what calms or relaxes them if stressed. This information, along with participant's emergency contacts and general practitioner, was held confidentially by members of the project team throughout the duration of the workshop.

To further minimise risk, participants were able to phone one member of the project team staying at the hotel throughout the workshop week. Additionally, the building evacuation procedure, using a recording of the fire alarm, was described and practiced during the first workshop session on the first day

7. Evaluation

7.1 PARTICIPANTS

Participants in evaluation included adults on the spectrum (n=14) who attended the workshop for 5-days, autism researchers (n=13) who attended the workshop for 1-day.

7.2 INSTRUMENTS

Quantitative evaluation of the 1-day and 5-day workshop was in the form of surveys developed by the project team. Both surveys asked respondents to rate the workshop overall (1=poor, 2=okay, 3=good, 4=excellent) and whether they would recommend the workshop to other people (1=yes, 2=no).

The survey for adults on the spectrum also asked them to indicate what topics (n=10) they understood better because of the workshop, and competence to engage in various peer research activities before and after the workshop (1=not at all competent, 2=not very competent, 3=fairly competent, 4=very competent). The peer research activities listed were:

- to be involved in peer research;
- to be part of a research team meeting;
- to give researchers your opinion on research design and meaning of findings;
- to give researchers your opinion on research techniques, e.g. survey or focus group questions;
- to give input to research projects;
- to become an advisory group member;
- to co-present research findings; and,
- to co-write a report on research findings.

In addition to overall workshop rating and endorsement, the survey for researchers asked respondents to rate their competence and likeliness to engage in peer research both before and after the workshop (1=not all all, 2=not very, 3=fairly, 4=very). Participants were also asked to rate the merit and quality of the sessions (n=4) and merit and relevance of the pre-readings (1=very poor, 2= poor, 3=good, 4=excellent). Two open ended questions relating to perceived barriers to engaging in peer research and workshop improvements were also included.

Qualitative evaluation of the workshop was undertaken with adults on the spectrum using focus group method. The focus group adopted a semi-structured protocol (see Appendix F) with questions focusing on: workshop content and methods; format; venue; and outcomes.

7.3 FINDINGS

Survey data collected with 1-day (autism researchers, n=13) and 5-day (adults on the spectrum, n=14) workshop attendees showed high approval ratings. As highlighted in Table 2, all participants rated the workshop as ‘good’ and ‘excellent’ (aggregated $\bar{x}$= 3.70), and all participants would recommend the workshop to others.

Table 2. Mean scores for workshop rating and endorsement

	5-day workshop n = 14	1-day workshop n = 13
Overall workshop rating *	$\bar{x}$= 3.79 range= 3-4	$\bar{x}$= 3.62 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*

Analysis of data also indicated an increase in *competence* to engage in peer research and, for researchers, *likeliness* to engage in peer research. Casewise comparison, excluding cases which identified as ‘very competent’ prior to the workshop, indicated 80% of the researchers as more likely to engage in peer research, and 85% of adults on the spectrum and 92% of researchers as more competent to engage in peer research, as shown in Table 3. As also shown in Table 3, the majority of adults on the spectrum indicated increased competence to undertake all aspects of peer research.

Table 3. Percentage of participants indicating increase in competence or likeliness to engage in peer research after attending the workshop

	5-day workshop n = 14	1-day workshop n = 13
Likeliness of engaging in peer research	80%	-
Competence to:		
Engage in peer research	85%	92%
Be part of a research team meeting	64%	-
Give your opinion on research design and Meaning of findings	83%	-
Give your opinion on research techniques	100%	-
Give input to research projects	90%	-
Become an advisory group member	100%	-
Co-present research findings	93%	-
Co-write a report on research findings	69%	-

Additional data collected with researchers indicated the merit of the 1-day workshops sessions in terms of future peer research, quality of the presentations, and merit and relevance of pre-readings as ‘good’ or ‘excellent’, as shown in Table 4.

Table 4. Mean scores for 1-day sessions merit and quality, and pre-readings merit and relevance

	n= 13 $\bar{x}$
Participatory methodology	
Merit of the session	3.58
Quality of presentation	3.65
Managing risk	
Merit of the session	3.92
Quality of presentation	3.77
Small group activity	
Merit of the session	3.77
Guest presentations on advisory groups, co-presenting & co-writing	
Merit of the session	3.77
Quality of presentation	3.70
Pre-readings	
Merit	3.38
Relevance	3.46

rating scale: 1= very poor, 2= poor, 3= good, 4= excellent

Analysis of qualitative data collected with adults on the spectrum emphasised a highly successful workshop which exceeded their expectations. It was identified that throughout the workshop their lived experience was "truly valued" and their needs were considered and catered for. With regard to workshop *content and methods* it was identified that:

- The content was pitched at the right level;
- Less content would have allowed for more group interaction, which was preferred;
- Supportive processes, such as the question and comments box, enabled people to voice their opinion and ask questions; and,
- Having the project team perform the first role play alleviated anxiety around their involvement in role play activities.

With regard to *format*, it was identified that:

- Longer breaks were required for some participants to maintain energy levels;
- Engagement in the group may have been lessened for those who lived locally so were not staying at the hotel; and,
- Having only 1-day with researchers was not enough time to enable interaction and engagement.

8. Implications for Future Practice

Evaluation data as well as reflections and feedback from the Project Advisory Group and the project team highlighted a number of implications for future practice. These relate to content, methods and processes, preparation, and format.

Content, methods and processes

- Future workshops should provide less content to allow more group interaction and discussion, or allocate time to enable expression without impinging on content delivery;
- For the purpose of emotional support, enable participants to ‘vent’ to appropriate people if they wish to- such as by providing blue dots for participants to place on their nametag if they are willing to have others ‘vent’ to them.

To enable networking between researchers and people on the spectrum that is facilitative of peer research:

- More than one contact day is necessary;
- Researchers to complete readings about autism culture prior to attending to provide them with an understanding of the alienation felt by the autistic community so that (a) they can appropriately enter the ‘autistic space’ and (b) aid them in more effective peer-research;
- In addition to providing photos and bios of autism researchers, provide participants on the spectrum with some personal information on the researchers– potentially a video clip. Additionally, provide researchers with bios of those on the spectrum;
- Prepare researchers for supportive processes used at the workshop, e.g. stickers to indicate desired level of communication, and encourage them to use this system;
- Debrief researchers on the terminology used by the attendees on the spectrum to describe autism and the autism community;
- Ensure the function room is set appropriately to enable open sharing and discussion- not in lecture style;
- Consider activities that are facilitative of building trust and rapport, rather than ‘question and answer’ style.

Preparation

- Prepare participants on the spectrum for what it is like being in a space which in which others on the spectrum are the majority (termed ‘autistic space’). For example, that they can expect open sharing of personal experiences and thoughts.
- Participants on the spectrum need to be informed of the potential ‘emotional cost’ of attending, in terms of emotional, physical and social loads.
- Provide participants on the spectrum with an understanding of potential isolation and exhaustion they may experience on returning home after workshop completion. Also, to help them prepare for this likelihood during the workshop.

Format

- Consider format of workshop delivery in terms of enabling content delivery required for effective peer research, potential participant fatigue and the power of ‘autistic space’. Potential formats include combinations of face-to-face workshop, virtual meetings and online modules.
- Provide participants with opportunities for peer research immediately after workshop delivery to maintain momentum and engagement.

9. Conclusions and Current Projects

As a result of the Researching Autism Together Workshop, 14 adults on the spectrum and 12 autism researchers graduated as the inaugural members of the Research Academy. Post-workshop co-production activities with Research Academy members on the spectrum have included the finalisation of the Visual Dictionary of Research Terms (see Appendix C), development of Inclusive Research Practices Guides 8 and 9 (see Appendix E), analysis of the Priorities for Autism Research survey data and an Open Letter to Researchers (see Appendix D). While these projects are internal to Autism CRC, a number of Academy members have engaged with researchers in peer-research. Data collection to assess the extent of co-production by Academy members will be ongoing.

The Researching Autism Together Workshop was the first step towards building capacity for co-production within the autistic and research communities. There remains the necessity to continue to support the Research Academy members through engagement in co-production. Such support might further include upskilling and supporting the inaugural Academy members, consulting with researchers as to how co-production could be enhanced in their research, and networking adults on the spectrum with projects that accord with their research interests and capacity for engagement. For co-production to be realised in more autism research, there remains a necessity to continue to monitor the uptake of co-production undertaken by Academy members, formally evaluate co-production, and graduate new members of the Research Academy.

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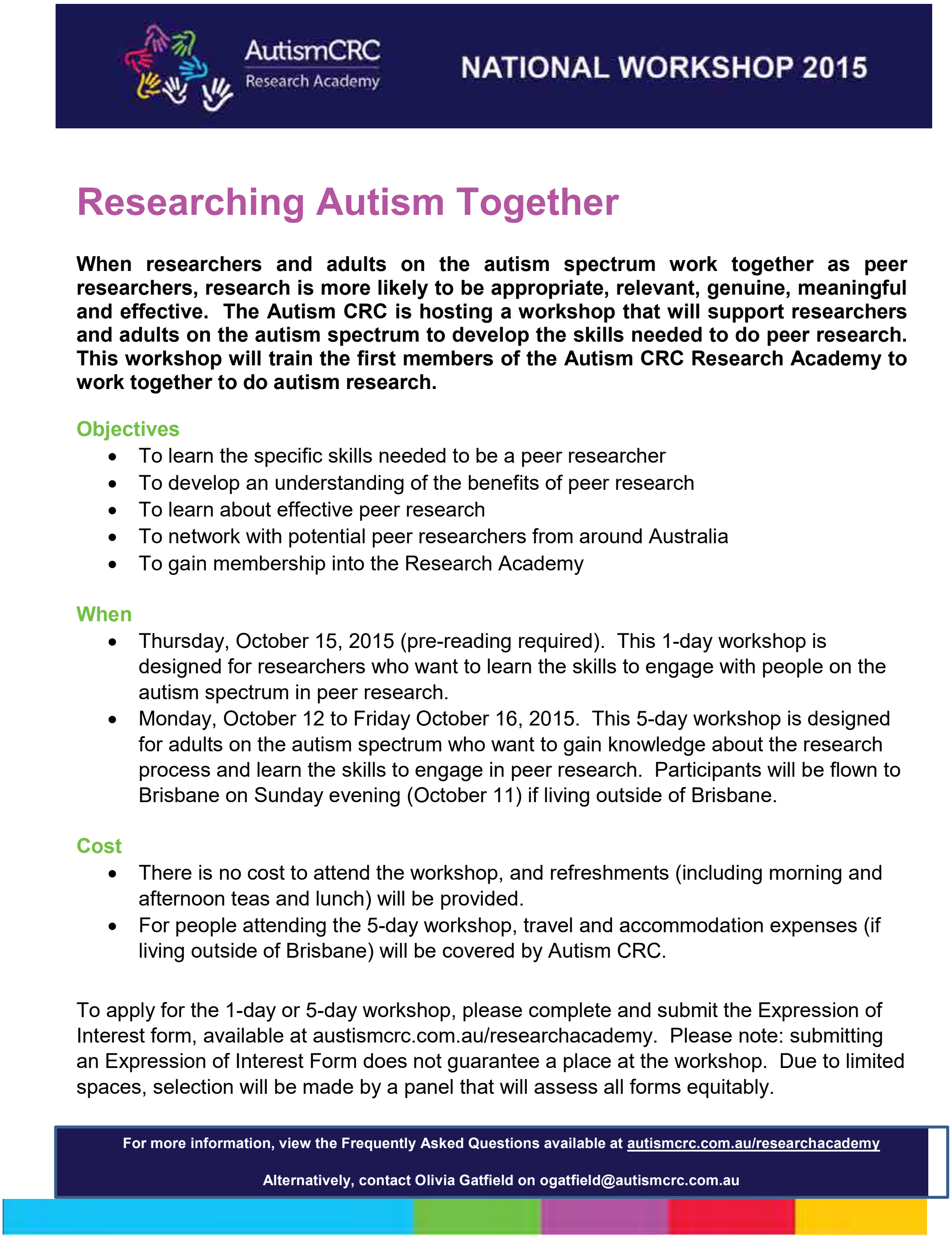
Appendices

APPENDIX A: INFORMATION FLYERS, FREQUENTLY ASKED QUESTIONS AND EXPRESSIONS OF INTEREST FORMS



AutismCRC
Research Academy

NATIONAL WORKSHOP 2015

Researching Autism Together

When researchers and adults on the autism spectrum work together as peer researchers, research is more likely to be appropriate, relevant, genuine, meaningful and effective. The Autism CRC is hosting a workshop that will support researchers and adults on the autism spectrum to develop the skills needed to do peer research. This workshop will train the first members of the Autism CRC Research Academy to work together to do autism research.

Objectives

- To learn the specific skills needed to be a peer researcher
- To develop an understanding of the benefits of peer research
- To learn about effective peer research
- To network with potential peer researchers from around Australia
- To gain membership into the Research Academy

When

- Thursday, October 15, 2015 (pre-reading required). This 1-day workshop is designed for researchers who want to learn the skills to engage with people on the autism spectrum in peer research.
- Monday, October 12 to Friday October 16, 2015. This 5-day workshop is designed for adults on the autism spectrum who want to gain knowledge about the research process and learn the skills to engage in peer research. Participants will be flown to Brisbane on Sunday evening (October 11) if living outside of Brisbane.

Cost

- There is no cost to attend the workshop, and refreshments (including morning and afternoon teas and lunch) will be provided.
- For people attending the 5-day workshop, travel and accommodation expenses (if living outside of Brisbane) will be covered by Autism CRC.

To apply for the 1-day or 5-day workshop, please complete and submit the Expression of Interest form, available at austismcrc.com.au/researchacademy. Please note: submitting an Expression of Interest Form does not guarantee a place at the workshop. Due to limited spaces, selection will be made by a panel that will assess all forms equitably.

For more information, view the Frequently Asked Questions available at autismcrc.com.au/researchacademy

Alternatively, contact Olivia Gatfield on ogatfield@autismcrc.com.au

Researching Autism Together: Frequently Asked Questions

What is the Autism CRC?

The Cooperative Research Centre for Living with Autism Spectrum Disorder (also called the Autism CRC) is the world's first national, cooperative research effort focused on autism. Our researchers work to better support those living with autism during diagnosis, education and adult life. To do so, Autism CRC researchers are working with the autism community to provide practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

For information about the Autism CRC, please visit our website www.autismcrc.com.au.

What is peer research and why do it?

Peer research, sometimes called research co-production, involves researchers and people on the autism spectrum working together as 'peers' to ensure that what is being researched and how it is being researched is relevant to and appropriate for people on the autism spectrum. Peer research recognises and equally values the skills of researchers and the expertise that people on the autism spectrum have gained through their lived experience.

Evidence suggests that the benefits of peer research include: improved research processes and better targeted measures and interventions; better community engagement and knowledge translation; improved trust of, and communication with, researchers; and better directed research funding.

What is the aim of the workshop?

We aim to increase the ability of researchers and adults on the autism spectrum to work together as peers who contribute to what questions are asked, how research is carried out, ensuring that questionnaires and interview questions are "autism friendly" and, helping to interpret research findings.

Should I attend the 5-day workshop or the 1-day workshop?

The 5-day workshop (October 12-16) is designed for adults on the autism spectrum who want to gain knowledge about the research process and learn the skills to participate in peer research. The 1-day workshop (October 15) is intended for people who work as researchers and want to learn the skills to undertake peer research.

Continued on the next page.

We acknowledge that a number of people who are researchers also identify as an adult on the autism spectrum. Please read through the below section entitled 'what will I learn at the workshop' to help you decide whether the 1-day or 5-day workshop would best suit you. If you would like support to make a decision as to whether to apply for the 1-day or 5-day workshop, please contact Olivia via email on ogatfield@autismcrc.com.au. Olivia will reply to your email within 3 working days.

What will I learn at the workshop?

By attending the workshop you will learn the basic skills to engage in peer research, and network with others who wish to engage in peer research. Topics will include:

- Ensuring equal engagement
- Managing risk
- Participatory methodologies.

Those who attend the 5-day workshop will also learn about the research process, to enable them to provide input into research. Topics will include:

- Research design, such as qualitative and quantitative designs
- Research techniques, such as surveys and focus groups
- Analysis of data
- Ethics
- Distributing and publicising research findings.

All participants will also have the option to practice the skills for peer research, in a non-threatening and flexible atmosphere. Specific details of how the skills will be practiced will be sent to you by September 21, 2015.

What will I be able to do with the skills learned at the workshop?

The skills learned at the workshop will enable you to work as a peer researcher. As an adult with the lived experience of autism spectrum, this may mean providing advice to researchers or being part of a committee or panel that gives feedback on research. As a researcher, this involves appropriately engaging with people on the autism spectrum to facilitate appropriate and relevant research.

In addition, by attending the workshop you will become a member of the Autism CRC Research Academy. The Research Academy will network researchers and adults on the autism spectrum to provide opportunities for peer research.

What costs will be covered by Autism CRC?

For people attending the 1-day workshop. Autism CRC will cover the cost of attendance and refreshments (including morning tea, afternoon tea and lunch). *This is continued on the next page.*

AutismCRC
Research Academy

NATIONAL WORKSHOP 2015

For people attending the 5-day workshop who live in Brisbane or surrounding areas. Autism CRC will pay for the cost of your transport to and from the venue and morning tea, afternoon tea and lunch. If you are unsure whether you live in the surrounding areas of Brisbane, please contact Olivia via email on ogatfield@autismcrc.com.

For people attending the 5-day workshop who do not live in Brisbane or surrounding areas. Autism CRC will pay for the cost of your flights, transport to and from airports and accommodation. We will organise your travel and accommodation, and recommend you arrive late Sunday October 11 to give you an evening to settle in. You are welcome to bring a support person but we will not be able to pay for their expenses. We will provide morning tea, afternoon tea and lunch from Monday to Friday, but you will need to cover the costs of other meals.

Who will be there?

One of the purposes of the workshop is to network adults on the autism spectrum with researchers. We anticipate that about 10 people will attend the 5-day workshop and 20 people will attend the 1-day workshop. We will let you know exactly how many people will be coming to the workshop and provide you with information about them, including photos, by September 21, 2015.

Will the venue suit my needs?

We will select a venue that is comfortable and meets the sensory needs of as many participants as possible. If you are selected to participate in the workshop, we will discuss your specific needs with you.

What would I be required to do?

For people attending the 1-day workshop. Pre-reading of modules developed by the Autism CRC (approximately 4-5 hours), completion of pre-workshop assessment, and attend the face-to-face workshop in Brisbane, Queensland on October 15 (8.45am to 5pm).

For people attending the 5-day workshop. Attend the workshop in Brisbane for the 5 days (Monday, October 12 to Friday October 16, 2015). We will seek to accommodate your individual preferences for travel, accommodation/ facilities, and learning style. We will provide you with detailed information about the venue, the plan for the week, the content for each of the sessions, and expectations (such as not having to attend all sessions, wearing comfortable clothing etc.) by September 21, 2015.

How will you choose which applicants will have a place at the workshop?

A selection committee from Autism CRC will meet and make a selection based on: applicant responses to questions; the number of places available; and, national representation where possible. All applicants will be notified via email as to whether they have been given a place at the workshop by 5.00pm June 30, 2015.

For more information, contact Olivia Gatfield on ogatfield@autismcrc.com.au
To download a copy of the Expression of Interest form, visit autismcrc.com.au/researchacademy

Researching Autism Together: Expression of Interest

Instructions:

To complete and submit an expression of interest-

- ☐ Read the Frequently Asked Questions
- ☐ Copy and paste all of the questions below into a new Microsoft Word document
- ☐ You may format the document however you like
- ☐ Answer each of the questions
- ☐ Save your document as ResearchEOI
- ☐ Email your document to Olivia Gatfield ogatfield@autismcrc.com.au

All applicants will be informed about whether they have been chosen to attend the workshop by 5.00 pm on June 30, 2015. After you submit your expression of interest, you will receive an email within 2 working days to let you know your application has been received.

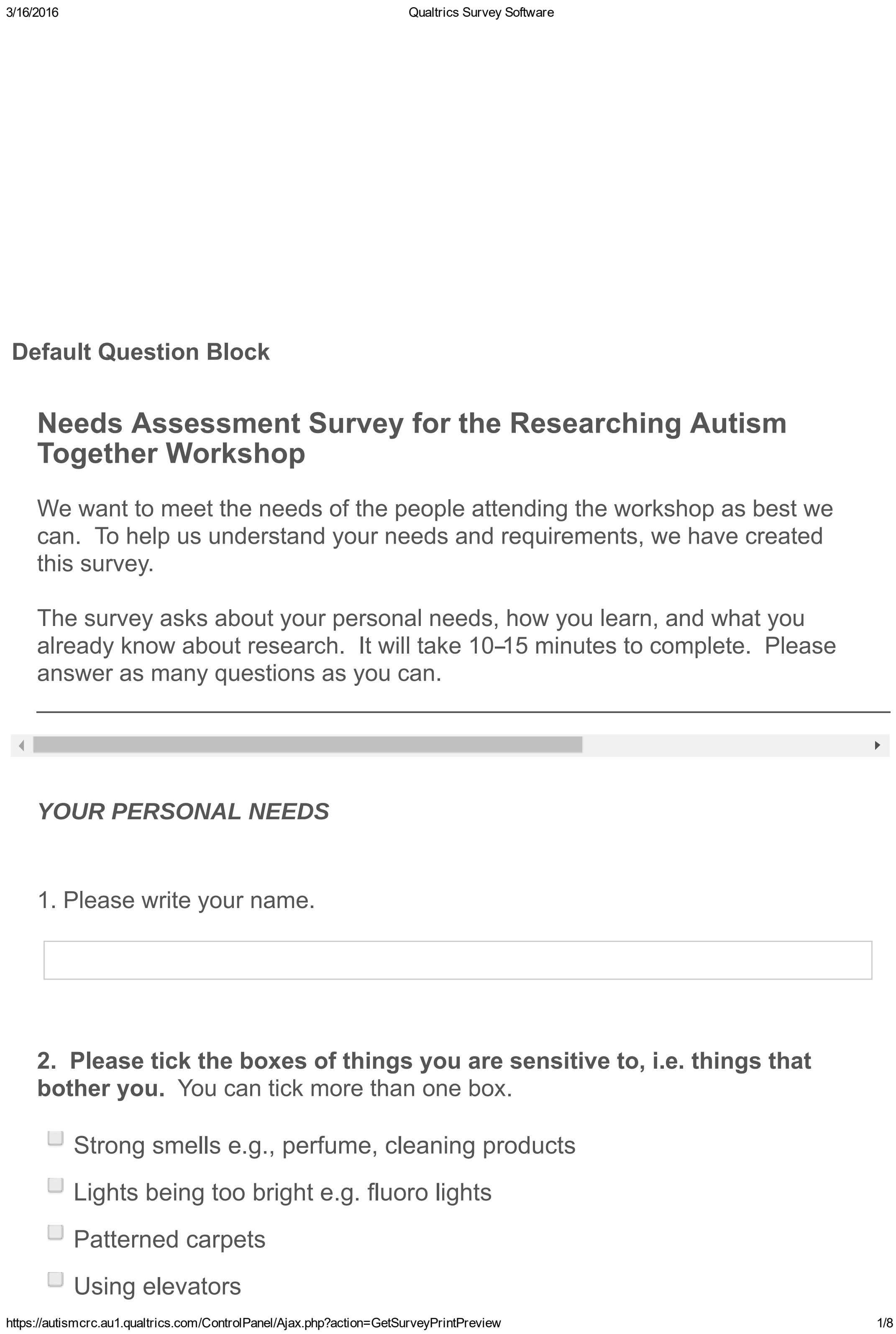
Questions:

1. Write whether you would you like to apply for the 1-day or 5-day workshop.
2. Write your name and postal address.
3. Write your preferred method of contact (e.g. email or phone) and this contact address or phone number.
4. List any formal qualifications and education that you have. (Formal qualifications are not a requirement of this workshop).
5. Write if you are currently working (Yes or No). If yes, please list your current position and employer.
6. List any paid or unpaid work history (e.g. what was your position and who did you work for).
7. Would you like to nominate a person to speak on your behalf about your application? If yes, please write how we can contact them, including: their name, relationship to you and their contact number during office hours or email address.
8. State whether you are already an Autism CRC researcher, PhD scholar or Postdoctoral fellow? (Write 'yes' or 'no').
9. In less than 300 words, tell us why you would like to attend the Research Academy workshop.
10. In less than 300 words, tell us any other relevant information (e.g. current or past membership of reference groups or participation in research).

For more information, view the Frequently Asked Questions available at autismcrc.com.au/researchacademy

Alternatively, contact Olivia Gatfield on ogatfield@autismcrc.com.au

APPENDIX B: PARTICIPANT NEEDS ASSESSMENT SURVEY



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Needs Assessment Survey for the Researching Autism Together Workshop

We want to meet the needs of the people attending the workshop as best we can. To help us understand your needs and requirements, we have created this survey.

The survey asks about your personal needs, how you learn, and what you already know about research. It will take 10–15 minutes to complete. Please answer as many questions as you can.

YOUR PERSONAL NEEDS

1. Please write your name.

2. Please tick the boxes of things you are sensitive to, i.e. things that bother you. You can tick more than one box.

☐ Strong smells e.g., perfume, cleaning products

☐ Lights being too bright e.g. fluoro lights

☐ Patterned carpets

☐ Using elevators

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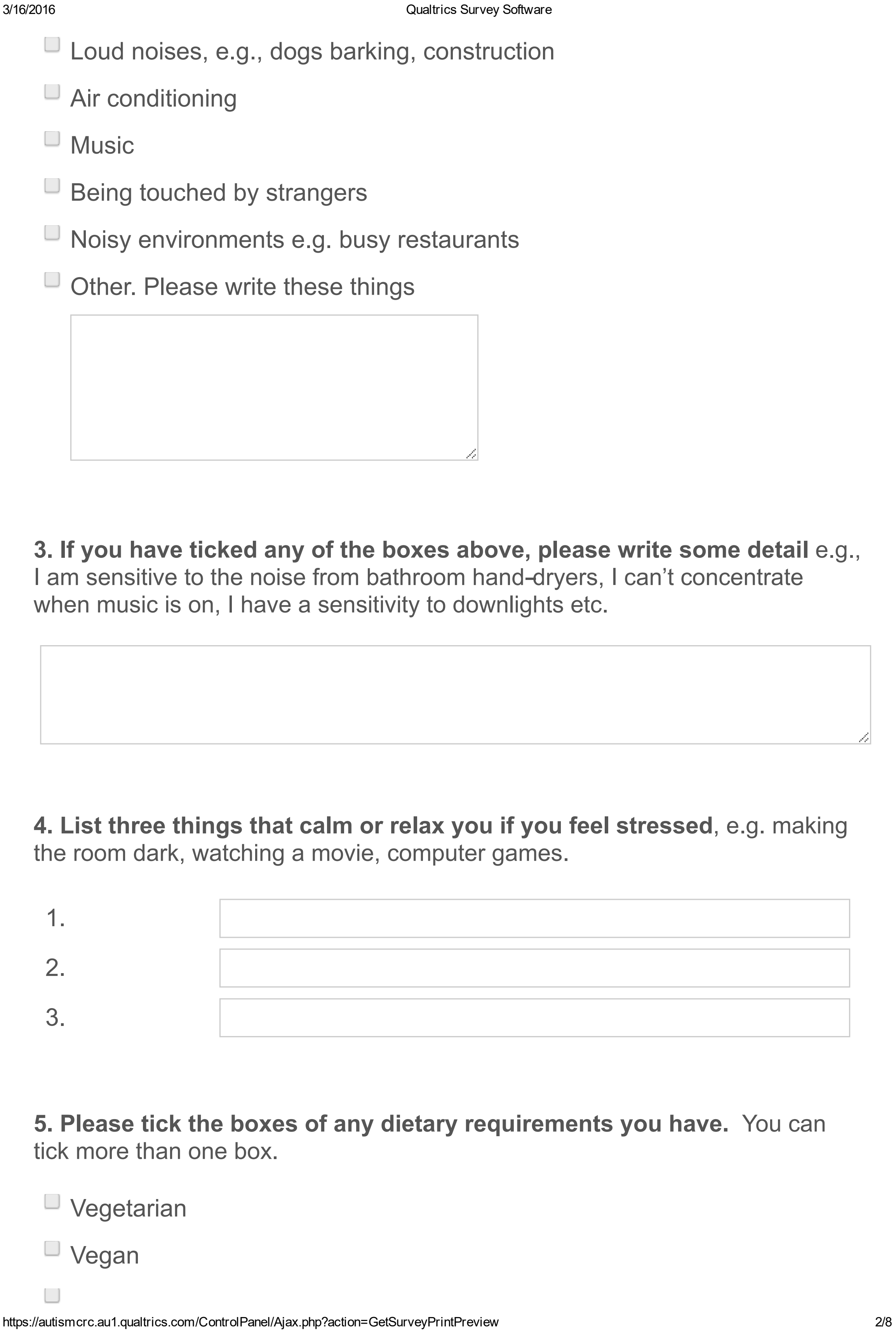


☐ Loud noises, e.g., dogs barking, construction

☐ Air conditioning

☐ Music

☐ Being touched by strangers

☐ Noisy environments e.g. busy restaurants

☐ Other. Please write these things

3. If you have ticked any of the boxes above, please write some detail e.g., I am sensitive to the noise from bathroom hand-dryers, I can't concentrate when music is on, I have a sensitivity to downlights etc.

4. List three things that calm or relax you if you feel stressed, e.g. making the room dark, watching a movie, computer games.

1.

2.

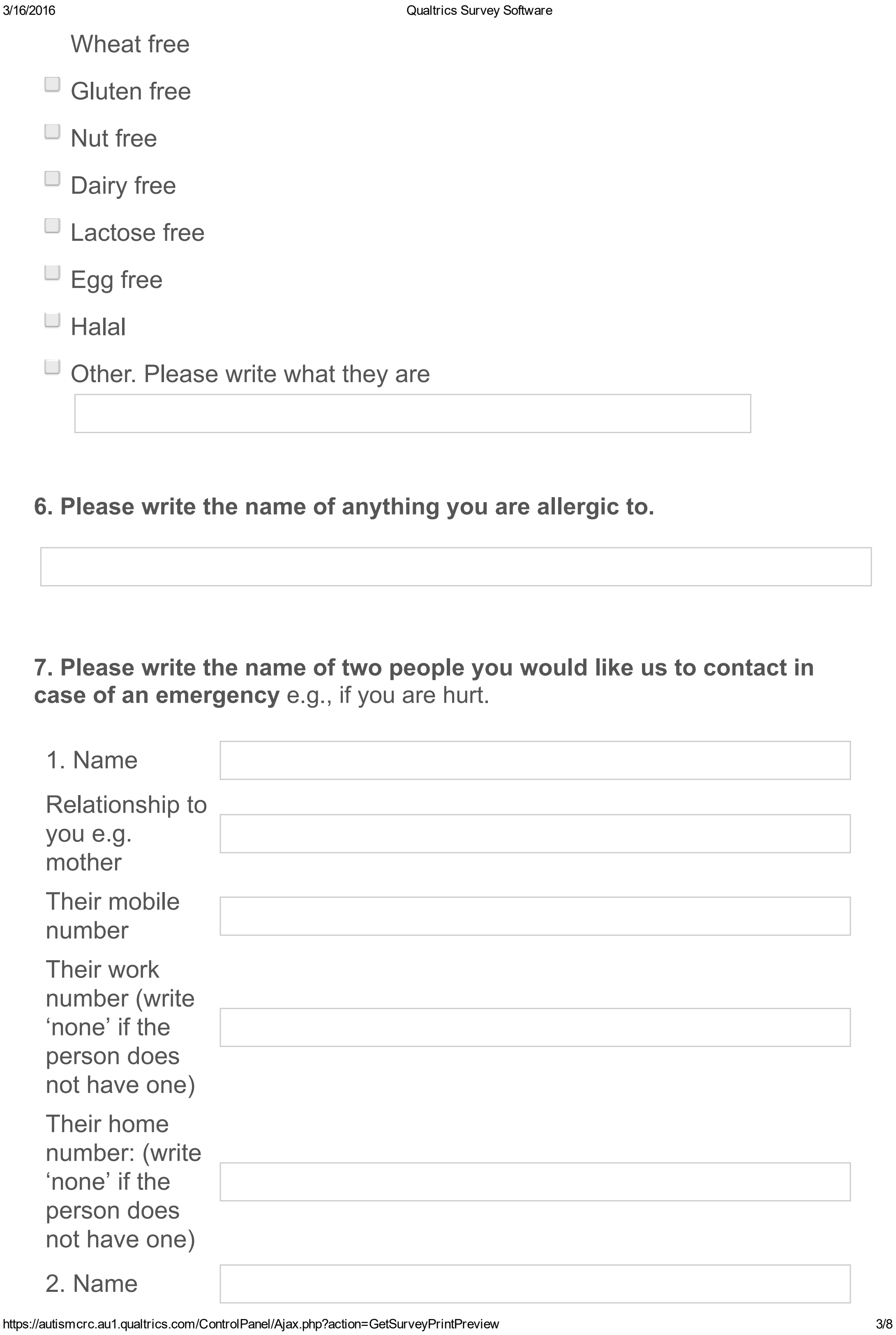
3.

5. Please tick the boxes of any dietary requirements you have. You can tick more than one box.

☐ Vegetarian

☐ Vegan

☐



Wheat free

☐ Gluten free

☐ Nut free

☐ Dairy free

☐ Lactose free

☐ Egg free

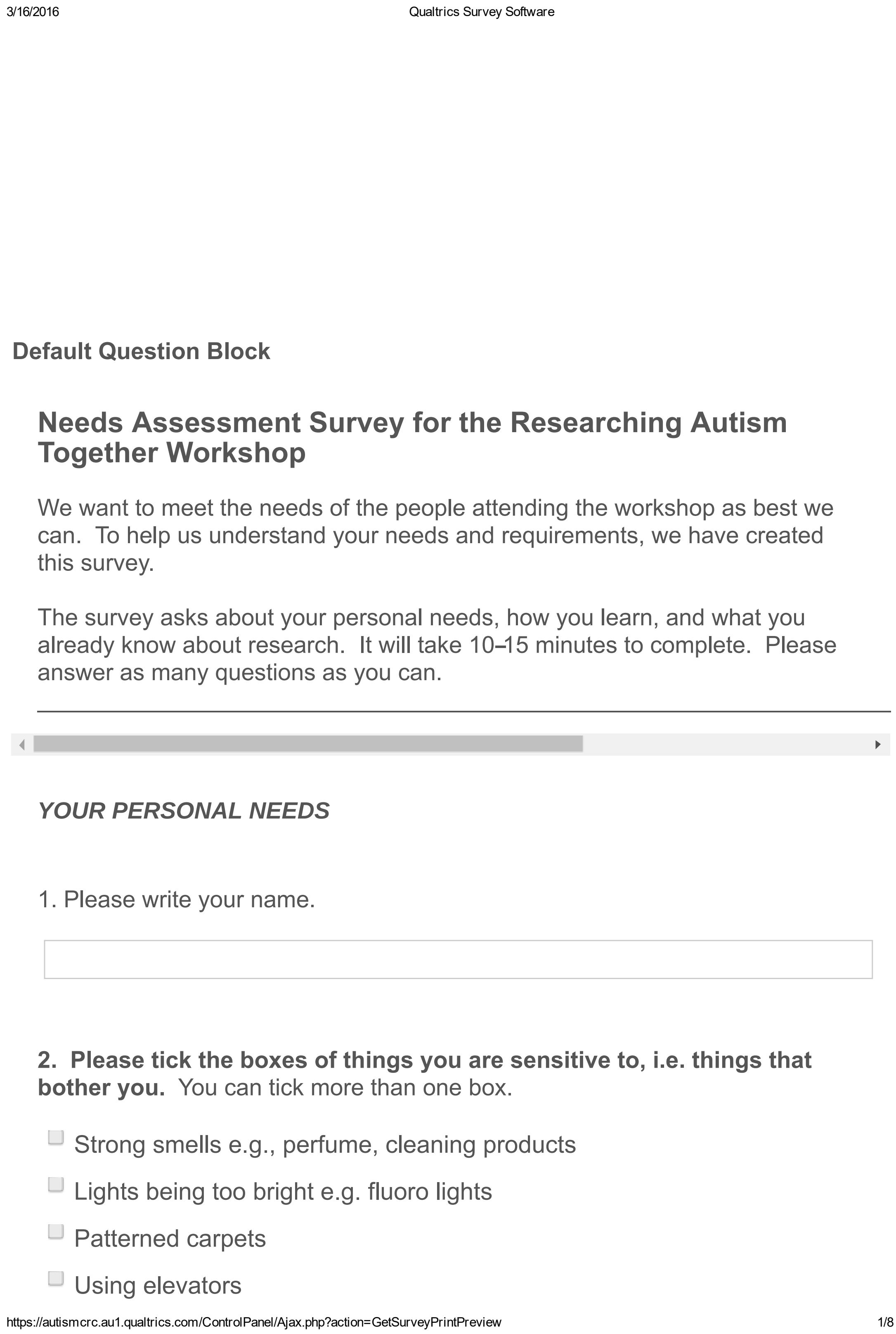
☐ Halal

☐ Other. Please write what they are

6. Please write the name of anything you are allergic to.

7. Please write the name of two people you would like us to contact in case of an emergency e.g., if you are hurt.

1. Name	
Relationship to you e.g. mother	
Their mobile number	
Their work number (write ‘none’ if the person does not have one)	
Their home number: (write ‘none’ if the person does not have one)	
2. Name	



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Needs Assessment Survey for the Researching Autism Together Workshop

We want to meet the needs of the people attending the workshop as best we can. To help us understand your needs and requirements, we have created this survey.

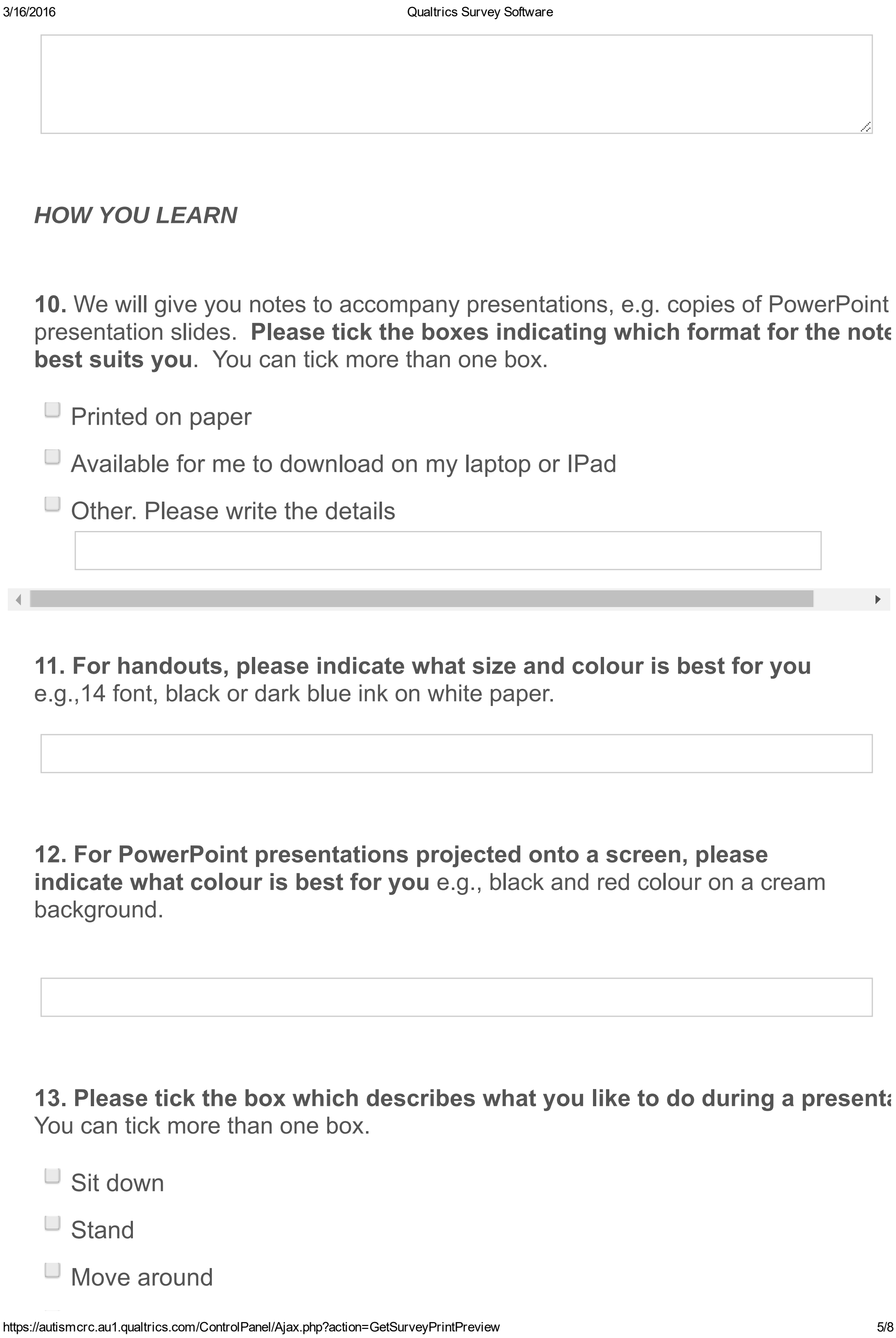
The survey asks about your personal needs, how you learn, and what you already know about research. It will take 10–15 minutes to complete. Please answer as many questions as you can.

YOUR PERSONAL NEEDS

1. Please write your name.

2. Please tick the boxes of things you are sensitive to, i.e. things that bother you. You can tick more than one box.

☐ Strong smells e.g., perfume, cleaning products
☐ Lights being too bright e.g. fluoro lights
☐ Patterned carpets
☐ Using elevators



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HOW YOU LEARN

10. We will give you notes to accompany presentations, e.g. copies of PowerPoint presentation slides. **Please tick the boxes indicating which format for the note best suits you**. You can tick more than one box.

☐ Printed on paper

☐ Available for me to download on my laptop or IPad

☐ Other. Please write the details

11. For handouts, please indicate what size and colour is best for you e.g.,14 font, black or dark blue ink on white paper.

12. For PowerPoint presentations projected onto a screen, please indicate what colour is best for you e.g., black and red colour on a cream background.

13. Please tick the box which describes what you like to do during a presenta You can tick more than one box.

☐ Sit down

☐ Stand

☐ Move around

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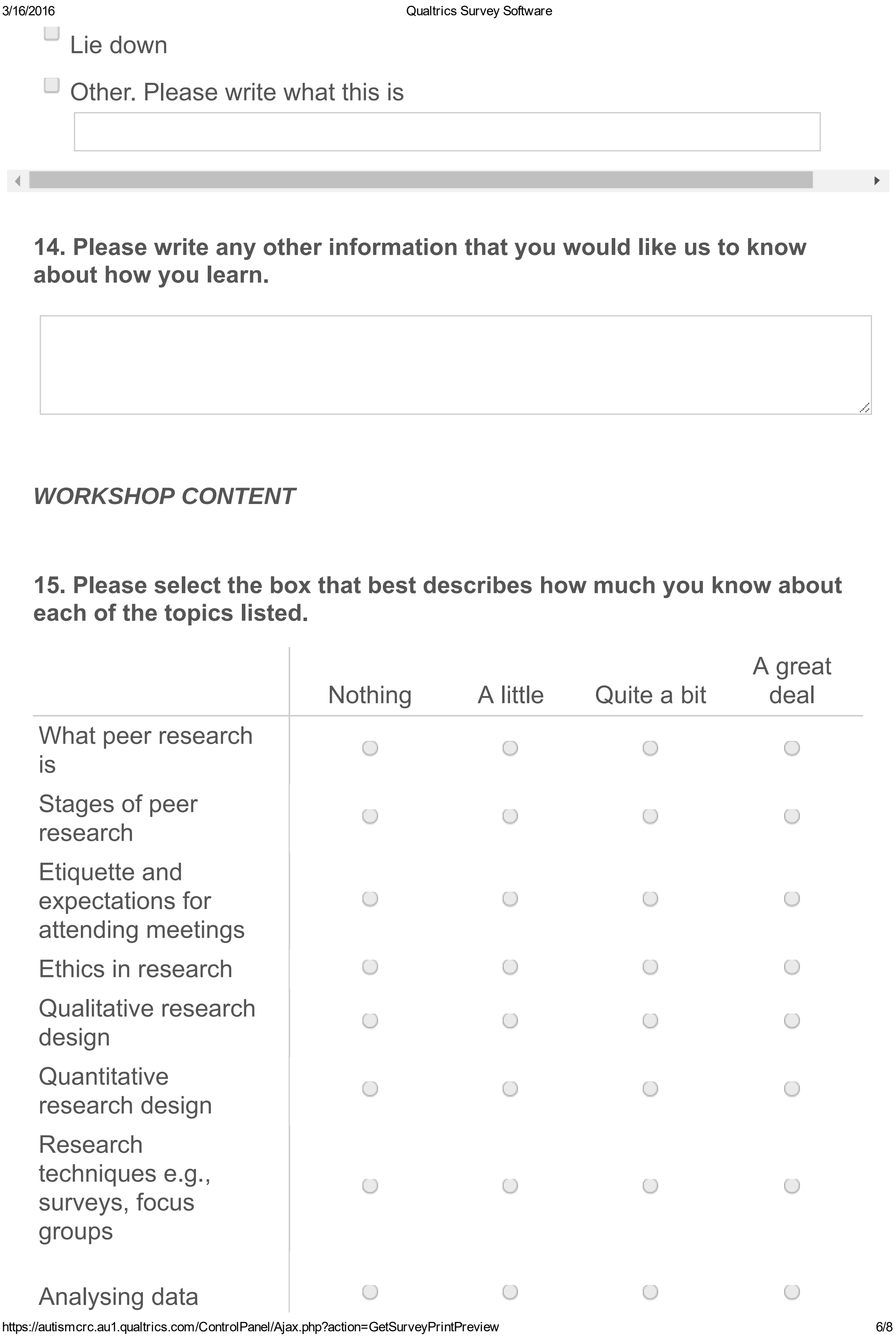


☐ Lie down

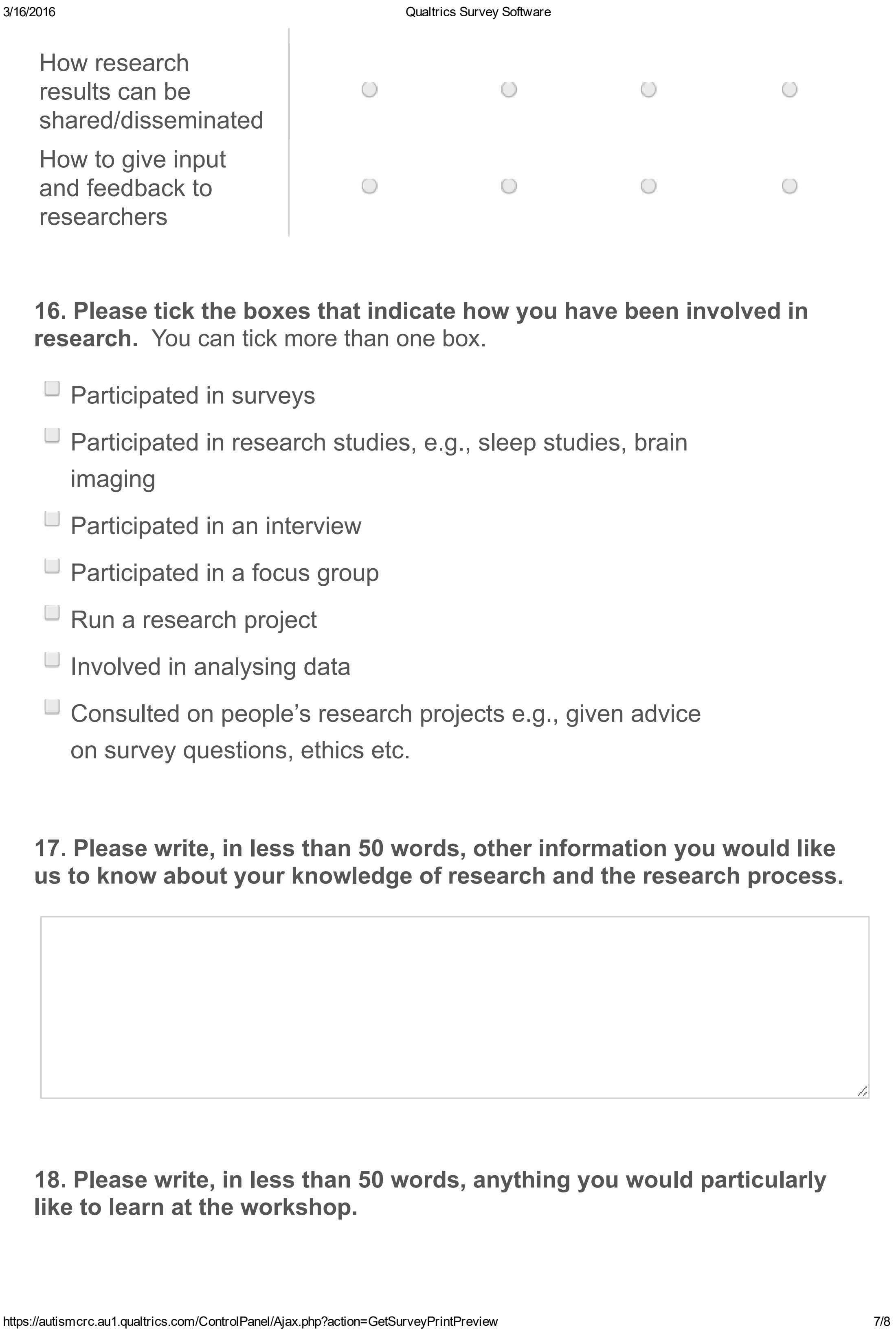
☐ Other. Please write what this is

14. Please write any other information that you would like us to know about how you learn.

WORKSHOP CONTENT

15. Please select the box that best describes how much you know about each of the topics listed.

	Nothing	A little	Quite a bit	A great deal
What peer research is	○	○	○	○
Stages of peer research	○	○	○	○
Etiquette and expectations for attending meetings	○	○	○	○
Ethics in research	○	○	○	○
Qualitative research design	○	○	○	○
Quantitative research design	○	○	○	○
Research techniques e.g., surveys, focus groups	○	○	○	○
Analysing data	○	○	○	○



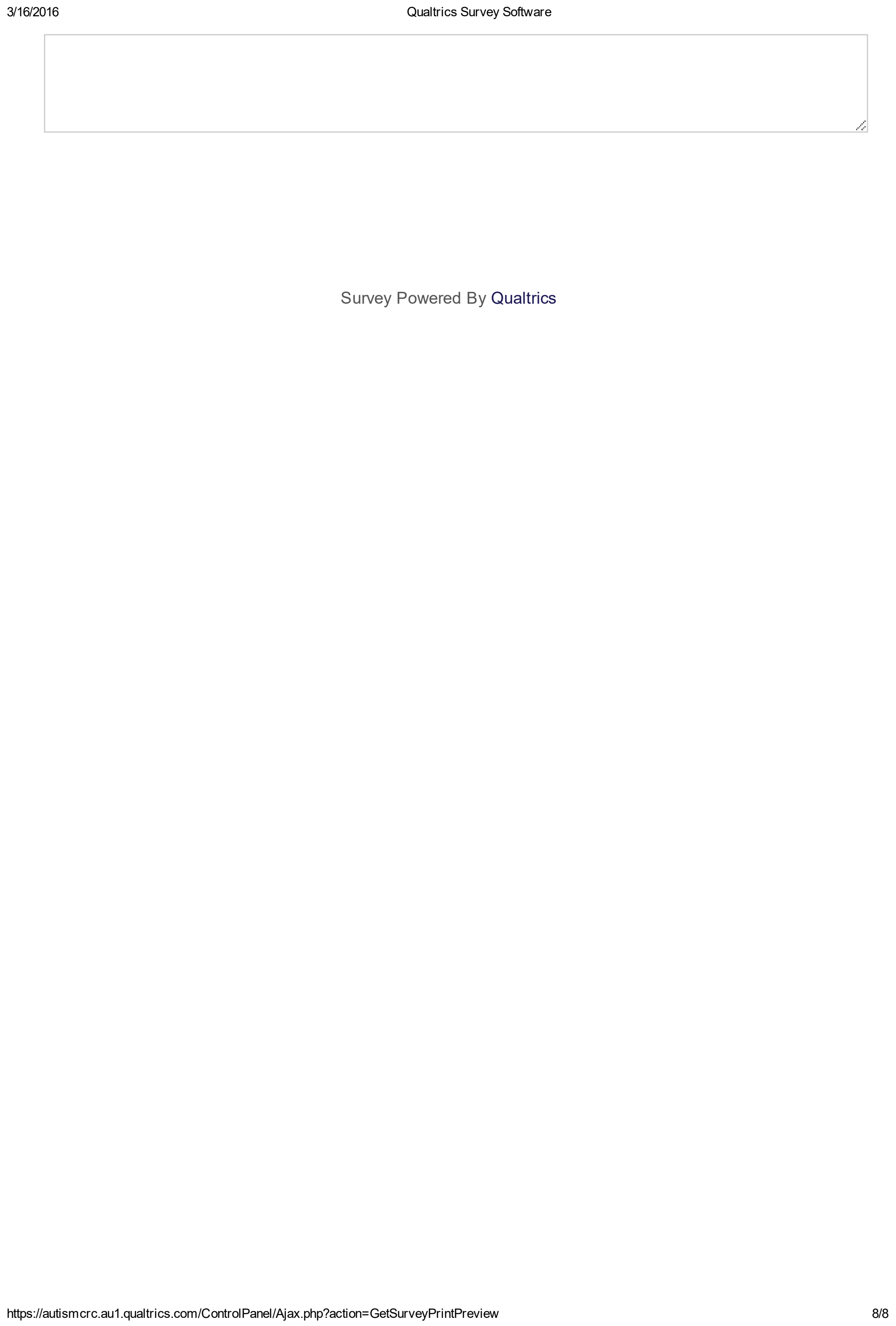
How research results can be shared/disseminated	○	○	○	○
How to give input and feedback to researchers	○	○	○	○

16. Please tick the boxes that indicate how you have been involved in research. You can tick more than one box.

- ☐ Participated in surveys
- ☐ Participated in research studies, e.g., sleep studies, brain imaging
- ☐ Participated in an interview
- ☐ Participated in a focus group
- ☐ Run a research project
- ☐ Involved in analysing data
- ☐ Consulted on people’s research projects e.g., given advice on survey questions, ethics etc.

17. Please write, in less than 50 words, other information you would like us to know about your knowledge of research and the research process.

18. Please write, in less than 50 words, anything you would particularly like to learn at the workshop.



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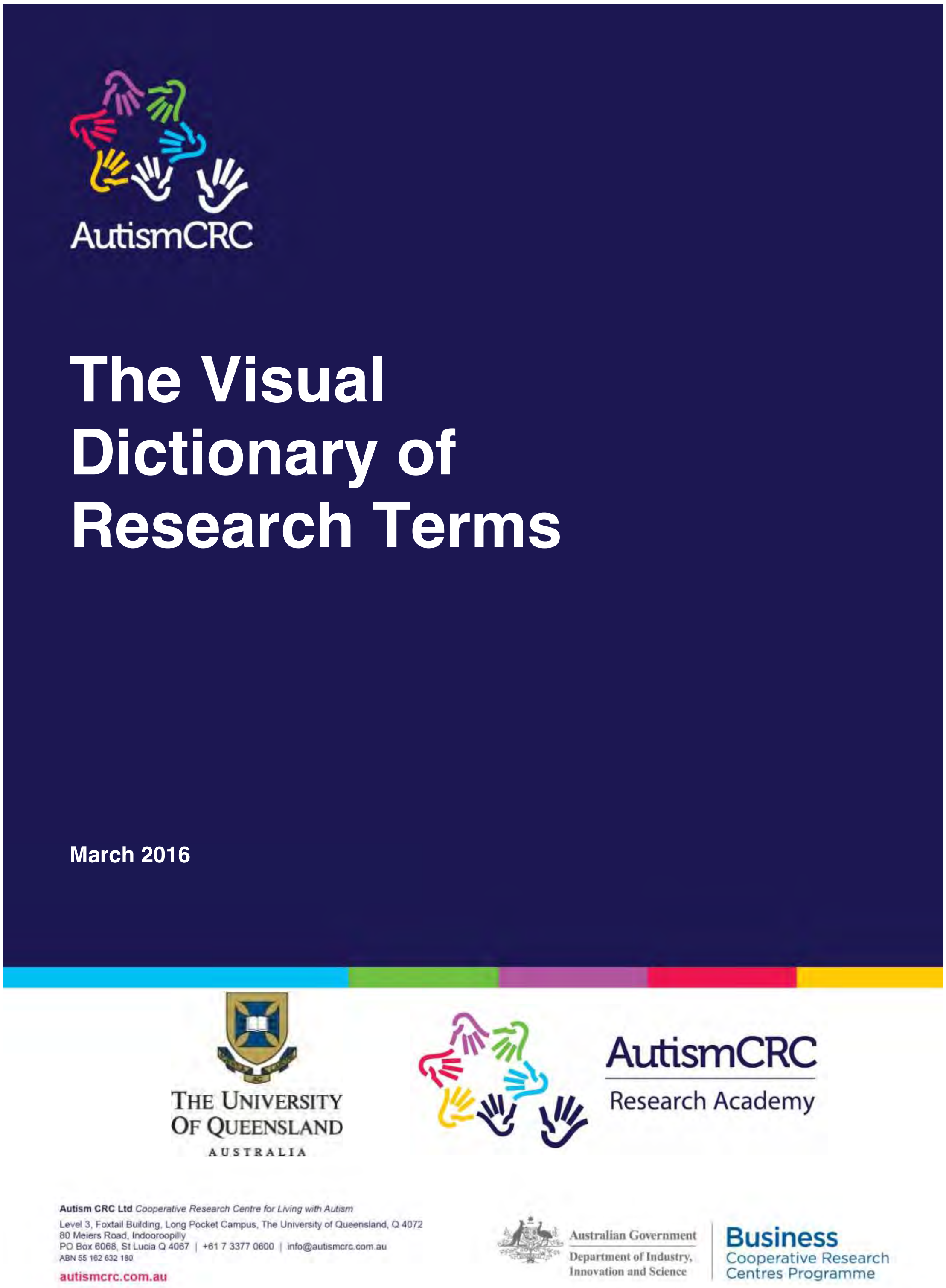
APPENDIX C: CO-PRODUCED VISUAL DICTIONARY OF RESEARCH TERMS



AutismCRC

The Visual Dictionary of Research Terms

March 2016

The University of Queensland
Australia

AutismCRC
Research Academy

Autism CRC Ltd *Cooperative Research Centre for Living with Autism*
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Australian Government
Department of Industry, Innovation and Science

Business
Cooperative Research Centres Programme

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Copyright and Disclaimer

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Katy Fowle
Tori Haar
Julianne Higgins
Abbie Kinniburgh
Chris Lovell
Tracy Regan
Maz Strong
Joel Wilson

Illustrations were provided by Angus Ewin, contactable at angopops@live.com.au.

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 with autism.

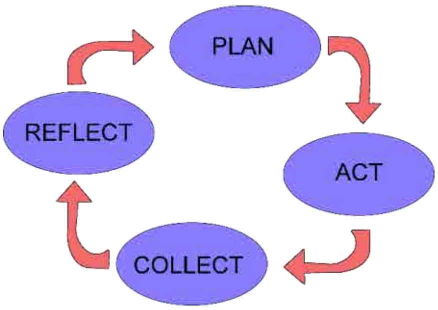
autismcrc.com.au

A

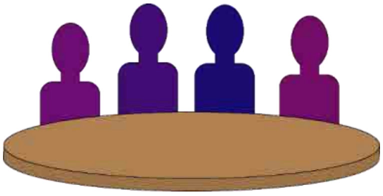
Abstain: refrain from participation**.** Example**:** to abstain from voting means that you decline to vote.

Action: possible activity after a research project.

Action research: research that involves the participants and the researchers alike, which is compiled during the research process.

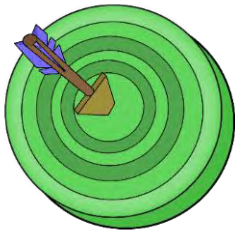


Advisory group: a small group of people who are skilled in their area and who can advise a larger group, Board, or researchers of issues and opinions pertinent to the item of interest.



Aim/ Aims: what we are trying to do. Aims are objectives, predictions, or descriptions that directly explore, propose, or point to the main thing we wish to explore.

Example: our main aim is to explore the impact of exercise on weight loss.



Analysis: information (**data**) is collected, collated and then explored (analysed). Analysing the information helps to understand the data so researchers can draw conclusions and reach outcomes.

Anonymity: Keeping the personal details of participants private and not disclosing or making available these to the public. Allowing the person to anonymously take part in the study.

Area undergoing research: the focus of interest or specific issue that the research will look at.

Example: We looked at the impact of drinking coffee after 5pm on adult female sleeping patterns.

Assent: approval or agreement. In research assent refers to a person's willingness to participate in research. Providing assent is not the same as **informed consent**.

At-risk: describing individuals or groups who are vulnerable.

Autism Spectrum (AS): adults and children 'on the autism spectrum'. The idea that autistic people are as different and varied to each other as non-autistic people are from each other.

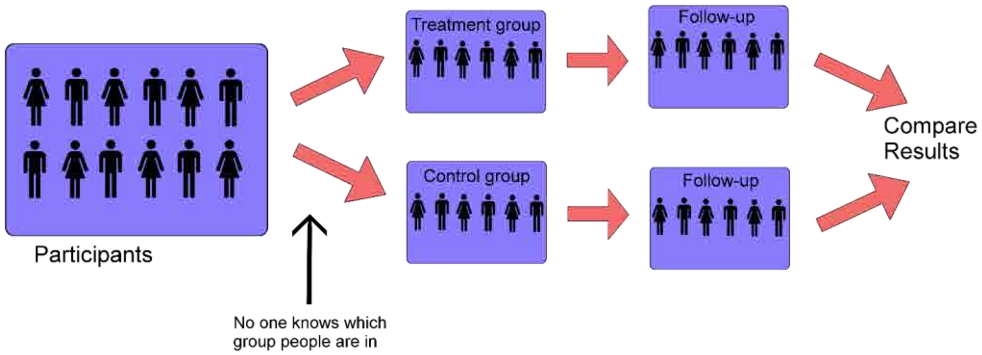
B

Baseline: the starting point for measurement of something, such as before an intervention is provided to see what is happening at the beginning/outset.

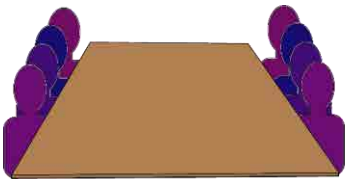
Bias: a particular tendency, trend, inclination, feeling or opinion- usually one that is preconceived or unreasoned. Researchers may unknowingly influence study results due to bias.

Example: illegal bias against older job applicants; the newspaper is biased towards a certain political party, type of illustration or story.

Blindedness/ double blind: an experimental procedure in which neither the participants of the experiment nor the researchers know the critical aspects of the experiment such as which participants are in the control group and which are in the experimental group. A double-blind procedure is used to guard against experimenter bias and placebo effects.



Board: elected or appointed members of a committee managing the business of an organisation, according to its rules of governance.



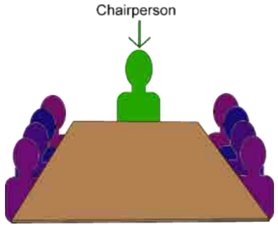
Budget: the measured amount of money or other limited resources available to fund, spend or work with.
Call out: an invitation to submit articles for publication or a conference.

C

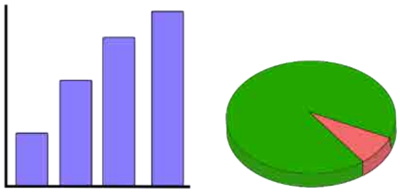
Case Study: a research method involving a detailed examination of the subject of study (the case).

CAQDAS (Computer Assisted Qualitative Data Analysis): software programs that analyse qualitative data.

Chairperson: the person who leads the meetings of a group or organisation.



Charts: a visual representation of data and information.

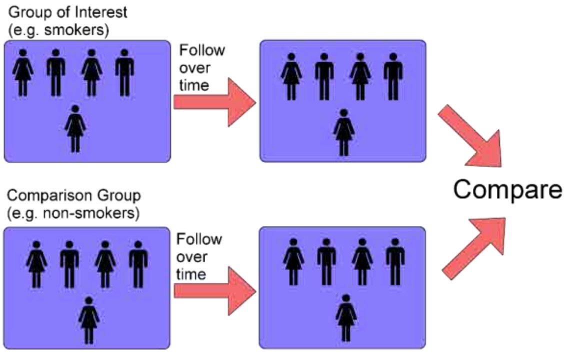


Chatham House Rule: a rule or principle according to which information disclosed during a meeting may be reported by those present but must not reveal the identity or affiliation of the speaker or any other participants.

Cite: to give reference details within the article or text of any author who has been quoted or whose work has informed the writing of that article. To attribute the information used to its author within the text of the work.

Clinical significance: the effect of a treatment or intervention. Is the effect enough to make a difference?

Cohort Study: a study over time, usually following a group of people (a cohort) who have been exposed to a treatment or risk factor (**experimental group**) and another group who have not (**control group**). The outcomes of both groups are compared allowing assessment of relationships between the exposure or treatment and the outcome.



Conclusion: what the research means. The final result or judgement of the topic researched.

Example: after collecting all the **data** (information), looking at what it implies, we reach our conclusion or end result.

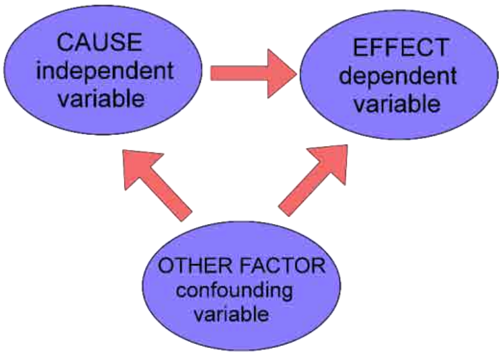
Confidentiality: personal information given to researchers will not be inappropriately shared. It usually means only the researcher, supervisor and individual concerned may know personal information.

Conflict of Interest (COI): where a person has another position or interest that may **bias** the project or discussion. A COI usually must be declared openly beforehand.

Example: An entrant in a competition being on the judging panel.

Confounding Variable: a variable that must be considered because it can distort (confound) the true effect of the other variables or intervention.

Example**:** an experiment looking at the effects of exercise on health may need to consider whether or not participants smoke. Smoking could confound (distort) the results.



Consent form: a written, formal document to be read, completed and signed. This gives permission or consent, such as to take part in a study.

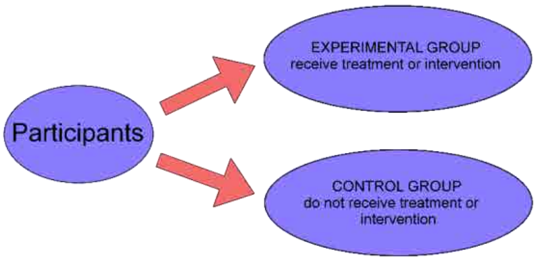
Constructivism: an approach in research which emphasises that people create their realities. Constructivism is often used in qualitative research in exploring various participant's realities.

Consent: to agree or give permission to be included or participate. Informed consent is when an individual fully understands what he/she is agreeing to. Sometimes parents give consent on behalf of children who are considered too young to give their own consent.

Content analysis: a systematic method of describing written, spoken or visual communication or data. Content analysis may provide a quantitative (numerical) description of written data (words). Typically, content analysis uses qualitative codes or themes which capture the essence of what is meant by the written words.

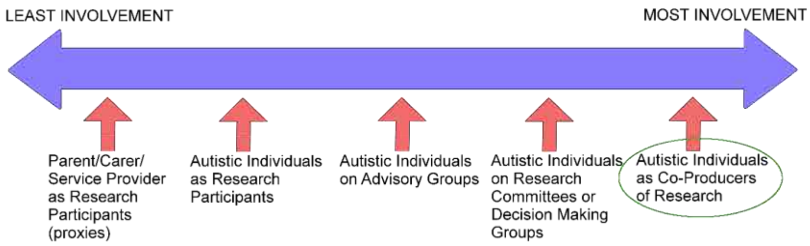
Example: responses to the open-ended survey question were coded as 1 where participants wrote about childhood and 2 where they wrote about adult years.

Control group: A group of subjects (people) who are used as the group to compare to. They are the group that *don't* receive treatment or intervention in
a **Case Control Trial.**



Co-production: a partnership which involves sharing view-points, information and ideas as equal partners; a venture where members of are working together on an equal basis.

Continuum of Research Involvement



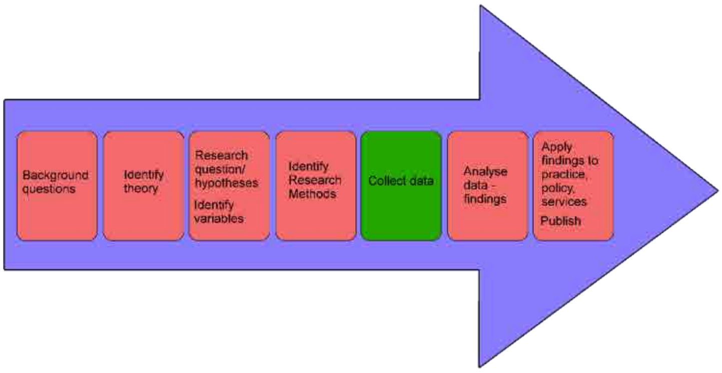
Creative Commons: a type of licensing that allows reproduction and expansion upon creative works, with varying levels of acknowledgment and payment dependent upon the use.

Critical appraisal: the process of systematically identifying the strengths and weaknesses of a research article, in order to assess the validity (whether it does what is says it does), usefulness and relevance.

Curriculum Vitae (CV)/ Resume: a neatly laid out concise summary of an individual’s educational qualifications and work history. Usually includes their name, date of birth and address at the top of the first page before the rest of the outline.

D

Data: research information that may be collected by way of interviews, observations, surveys, reports from literature reviewed, computer generated or all of the above. Data may be obtained directly from sources such as through telephone interview, in person, the internet or direct studies. It may also be obtained indirectly such as through comparisons of a variety of research already undertaken.

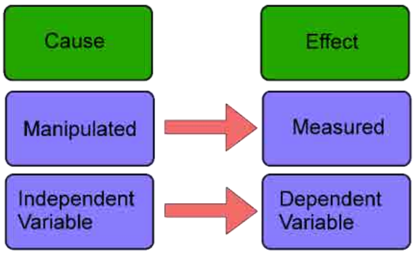


Data analysis: the process of transforming raw data into useable information. Methods of data analysis include statistical analysis and thematic analysis.

Data synthesis: combining results from a number of studies. See also meta analysis.

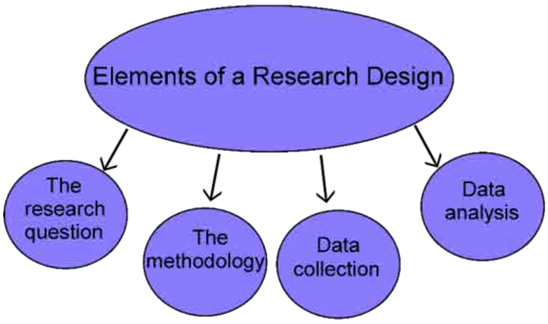
Degree: a qualification for successful completion of a course of study. Usually refers to undergraduate (first university study) education at a university. At the end of 3-4 years fulltime study students obtain a bachelor degree (Example: a Bachelor of Arts). This period of study may sometimes be undertaken part-time or by distance education.

Dependent Variable: what you measure in the experiment and what is effected during the experiment. This is the outcome of the experiment/study- for example, reading ability, length of employment, autistic characteristics.



Descriptive statistics: analysis of data in which numbers are used to summarise or describe data.

Design: the model for how the research will be conducted.



There are many types of design models for research. Some use information (**data**) of a statistical nature (maths), tables, calculations and measurements, this is called a **Quantitative research design**. The **Qualitative research design** looks at the data in a non-statistical manner, or via observation (such as watching **participants** interact with others or within their environment and making observational notes on what the researcher sees).   The **Methodology** or way the research will be conducted may involve other aspects of looking at the research.

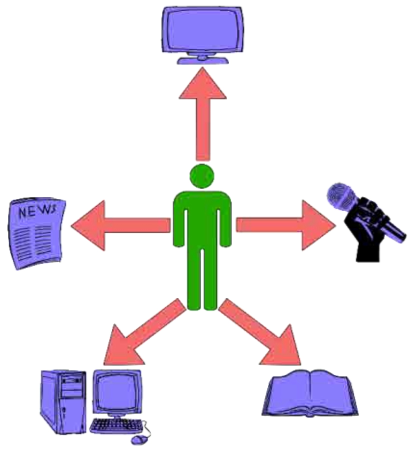
There are **methods** that use both the **Quantitative** (statistical analysis) and the **Qualitative** design; these are called **‘mixed methods/design’**.

Dichotomy: divided into two mutually exclusive, opposed, or contradictory groups.

Diploma: A course of study/training undertaken at TAFE or similar institutes in a specific area of study leading to a certified qualification called a diploma. Sometimes after a **degree** has been awarded students may choose to do further study at a higher level, called a ‘post degree’ or ‘graduate diploma’ which is usually taken at a university.

Dissemination: distribute, pass knowledge around and share information in a variety of ways.

Example: through speaking, writing, illustrating)



E

Editor: the person or persons who check over the written work and checks (edits) it for any grammatical or spelling errors in readiness for publication.

e.g.: from the Latin, *exempli gratia* which means “for example.”

Efficacy: effectiveness. Example: researchers often study the efficacy of one intervention over another to see which one works best.

Empirically tested/informed: The work is based upon evidence which can be reproduced and replicated, often collected through research means.

End Users: the ultimate consumer (users) of a product, especially the one for whom the product has been designed. Example: the person on the spectrum who will use the augmented adaptive communication device.

Essential Participants: participants without whom the agency cannot function.

Et al.: abbreviation for the Latin phrase *et alia* which means "and others’’.

Ethics: a set of principles of right or appropriate conduct, such as of a person or profession, or to protect the rights of others.

Example: ‘The ethical thing to do is to ensure the parent or named person is present during the interview’. What is the accepted, usual etiquette for this? ‘Is it ethical to only accept middle class white males into a study exploring intelligence?’ ‘Are the ethics of autism research being facilitated by only researching autism’s impact upon parents;„ or should we ask autistic individual’s themselves?’ ‘Is it ethical to only ask verbal children with autism how autism colours their lives, or should we find a way to ask non-verbal autistic children too?’

Ethnography: the study of people, sub groups, or cultures.

Etic: the perspective of an outsider.

Evaluation: to give feedback about your experiences.

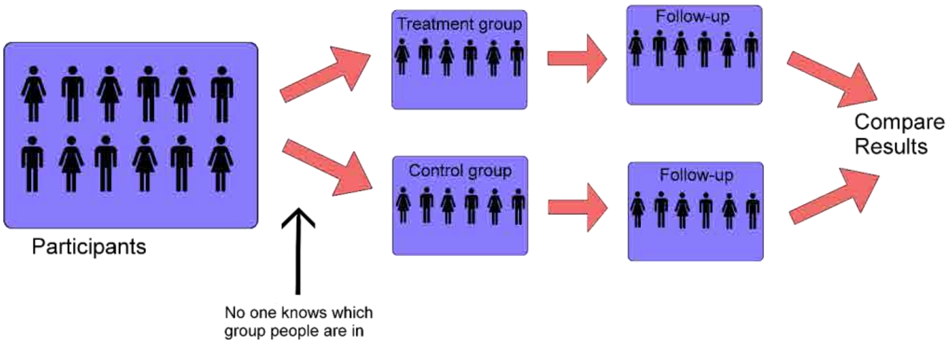
Event: a specific action, occasion or situation being recorded or measured. Example: brain response.

Event-related potential (ERP): the measured brain response that is the direct result of a specific sensory, cognitive, or motor event. Example: electrical activity recorded from the brain.

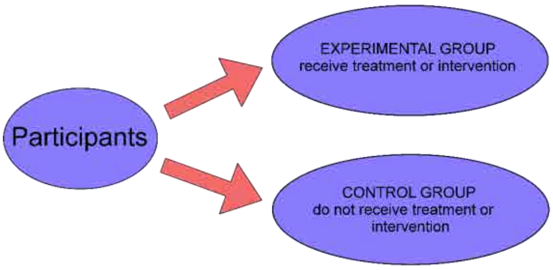
Evidence-based: indicates that the work, intervention or action is based upon research showing its efficacy (or lack of).

Experimental design: experimental and quasi-experimental (meaning not truly experimental) examine the effect of a variable that the researcher manipulates on other variables.

Example: an experimental or quasi-experimental study might examine the effect of telling stories on children's literacy skills. The researcher will "manipulate" the variable of telling stories by placing half of the children in a treatment group that listens to stories and the other half of children in a control group that gets the ordinary literacy instruction. In a quasi-experimental design, participants are not randomly allocated to groups.



Experimental group: The group exposed to, or participating in, the experimental conditions.



Expression of Interest (EOI): an individual's or agency's level of interest in wanting to be involved or considered for the project.

F and G

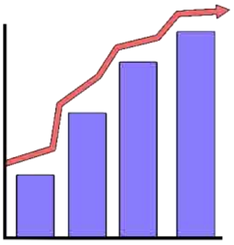
Factor: see **variable.**

Feedback: when individuals give their views, opinions and comments. It may be spoken, in written form, using a diagram or picture, or by an action or activity.

Focus group: a qualitative research method in which a group of people are asked their ideas, attitudes, experience, beliefs etc.

Free: not bound or committed; free to leave the research study.

Graphs: A graph (or a **chart**) are visual forms or ways to illustrate the results, the trend, the evidence and/or outcome of the research. They help us 'see' our results clearly.



Grounded theory: a research methodology sometimes used in qualitative research where the researcher does not have a theory but develops one through data collection.

H and I

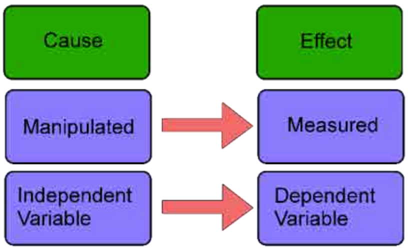
Honours: typically a twelve month program of study undertaken alongside a **bachelor degree** (in the final year for four year degrees) or as a twelve month period after a **bachelor degree** (for three year degrees). Often involves the writing of an extended paper or minor thesis and provides a preparation for further research study such as Masters or PhD.

Human Research Ethics Committee (HREC): a group of individuals who are responsible for evaluating research proposals to make sure that researchers and participants are protected and that they pass ethical guidelines for working with vulnerable people and humans in general.

Hypothesis: a prediction of what the research will show.

Independent Variable: represent the inputs or causes which may be tested to see to see if they 'cause' the outcome or effect (**dependent variable**).

Example : a researcher might look to see if gender (male or female) impacts on strength or running speed or autistic characteristics.



Information: facts and knowledge which give us understanding and appreciation of the meaning, enabling us to stay informed and be aware. This points us towards what we need to know.

Informed Consent: consent given by people before they participate in research.   People, from whom consent is sought, are to be fully informed of the research aims, methods and what they will need to do to participate.

Intellectual Property: work/study/research/writing/digital content that an individual has completed and to whom that work belongs. Sometimes if we study at a university, that institution ‘owns’ the work we do, meaning that the university has the right to the ‘intellectual property’ rather than the individual who completed the work.

Intervention: treatment or action that may promote or improve mental and physical health, wellbeing, behaviour, communication, social skills as well as school, employment and other desired outcomes.

J and K

Juxtaposition: two ways of looking at something by placing or dealing with them close together for contrasting effect.

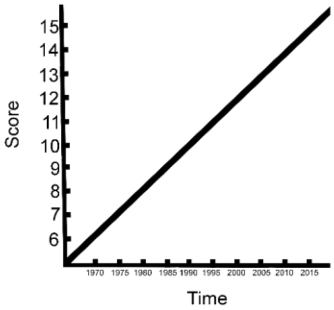
Key Terms: the technical terms of an industry or field. Single words or phrases that unpack more than the literal definition of that word or phrase.

L and M

Likert scale: a scale, commonly used on surveys, where a number or statements are issued and the **participant** specifies their level of agreement or disagreement.

Longitudinal Study: a research study that involves repeated observations of the same variables over long periods of time. Example: in the television series called 7-Up, the same group of participants were videoed about their lives every 7 years.

Linear: in a line or across sequential time. Sometimes we use linear graphs or studies to show changes across time in a linear fashion.



Major project: the key work of the research. Sometimes there are lesser projects, which are minor projects.

Masters: a period of study undertaken after a bachelor degree which can be either coursework or a research project. Masters usually takes 2 years.

Material governance: set procedures and processes that govern the relevant practice.

Medical model of disability: attributes disability to a medical diagnosis meaning that if you are medically compromised you are disabled by your medical condition. See also **social model of disability.**

Memorandum of understanding (MOU): A written document outlaying the guidelines and principles of the understanding between the parties involved.

Medical Research Ethics Committee (MREC): a group of individuals who assess the ethical qualities of the medical practice or medical interventions prescription.

Meta analysis: the process of combining results from a number of studies.

Example: combining the results from a number of different research studies which assessed the same early intervention program.

Methodology: specific philosophical and methods used in a research project. It describes the way the research is to be completed.

Morbidity: refers to disease, illness or injury. Sometimes we refer to people having co-morbid conditions.

Example: many adults on the spectrum experience comorbid anxiety. The anxiety co-exists alongside the autism.

Mortality: A term used to refer to dying**.** A medical study may report the mortality (death rate) for people in the control (treatment as usual) versus the experimental condition (new drug).

N and O

Narrative enquiry: a form of qualitative research where data, such as interviews, letters, stories or photos are used to understand people's experiences and they way they create meaning.

National Ethics Application Form (NEAF): a form used when applying to an appointed national body (group of people) for ethics clearance at the national level.

National Health and Medical Research Council (NHMRC): a group of individuals who are responsible for granting or not granting funding for various projects.

Null and Void: ceases to apply. Typically means that a contract or agreement is no longer valid or enforceable.

Observation: an approach to data collection where researchers examine participants in their natural settings.

Example: the researcher observed the children in the playground to see how they interacted with others.

Operation: the action or the work being done.

Other participants: individuals or an agency who directly support the workings of an organisation by donating time or funds to the work of that organisation**.**

Outcome: the end result of the research.

P

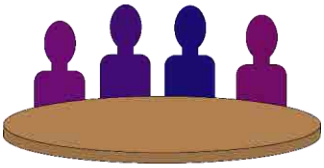
Participant: someone who joins with others in a venture. In research, a person who takes part in a research study or experiment.

Participatory Research: research that shares equal access and value amongst its participants and researchers.

Peer Review: a formal process of validating research prior to its publication. This is done by peers in the same field.

PhD: Doctor of Philosophy. It usually requires a three year full time research program undertaken by a student and supervised by one or two academics thus enabling the student to become an independent researcher in their own right.

Project Advisory Group: a small group of people who are skilled in their area and who can advise a larger group, Board, or researchers of issues and opinions pertinent to the item of interest.



Post Doctoral Fellow: person who has completed a **PhD** and is working with a mentor to develop his/her research career and independence as a researcher. Typically these fellowships are funded by universities or specific research grants.

Post-test: an attempt to measure the effectiveness of the intervention; measurement or testing of a **variable** (factor) after **an intervention or treatment** is provided.

Example: researchers would retest social competency after a social skills training intervention.

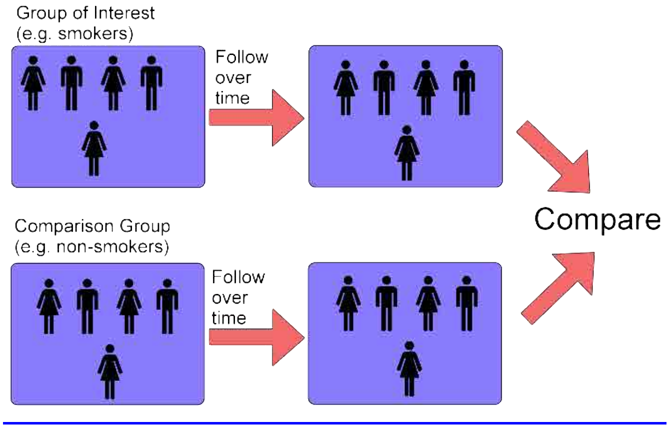
Power: statistical power is a value given to the numeric strength of a study. It shows how robust the study’s findings are. If the research is robust and has strong power it may be more meaningful than a project of weak power.

Pre-test: A method of discovering the starting point; measurement or testing of a variable/factor before an intervention or treatment is provided. Example: researchers might look at a child’s reading age before a literacy intervention occurs.

Pre-verbal: Before an individual uses spoken language.

Private: Information not available to people.

Prospective Study: a longitudinal study that looks forward in time.



Purposive sampling: where a research chooses certain people to be participants in their research study who can best answer the question.

Example: the researcher asked school principals to participate in research about the barriers to schools using evidence-based practices.

Q

Qualitative Research: methods used rely on observations, or interviews, either individual or in groups (focus groups) that typically result in words (transcript) typed out from recording of interviews or researcher notes. These words are then analysed using a range of methods to determine the key themes that emerge. The emphasis is on words and generating theories.

Qualitative	Quantitative
Confusing Timeing Art Good Ambiguous Efficient Repetitive Annoying Old Digital Slow	6.022×10^{23} 44% 20mm 2163.48 18.5 x 51mm 69$ .357 inch

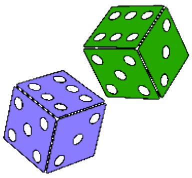
Quantitative Research: methods that result in numerical data such as numbers that can be analysed using statistics which might be as simple as percentages or more complex statistical tests to find a difference between groups. The emphasis is on numbers and testing theories.

Questions: surveys and interviews asking questions that require answers are the chosen method to gather information in qualitative research. In quantitative research, questions are asked that require such answers as ticking a box or selecting a level on a graded scale like a Likert Scale.

R

R and D: Research and development.

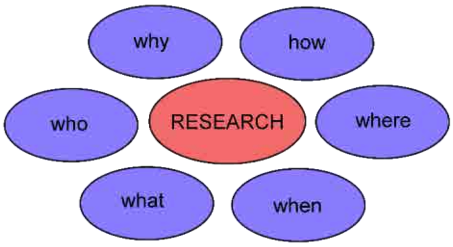
Random: chosen in no particular order or a lack of pattern. Example: drawing names out of a barrel.



Randomised Control Trial (RCT): a type of experiment where the people being studied are randomly allocated to different groups (experimental or control). RCTs are often used to test the effectiveness of various types of intervention and the random allocation minimises bias.

Reliability: the trustworthiness of the tests or the assessment tools. It is the extent which measure shows dependability, stability and consistency when repeated under the same conditions/

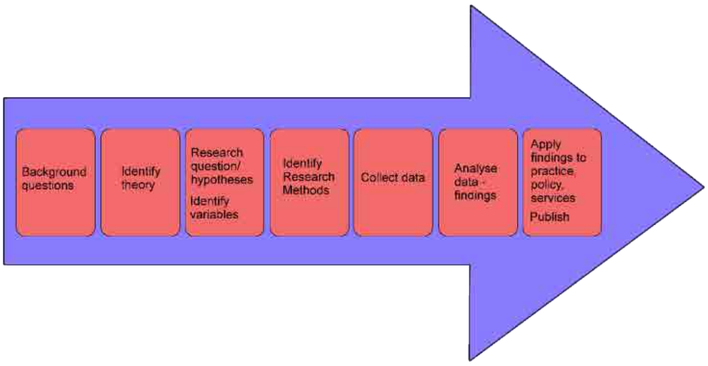
Research: to access, compare and assess various sources of information; to explore, look at, investigate, find reasons for or answers to. To work in a particular way to understand or find a reason for something, or to answer a questions.



Research based practice: everyday teaching/ therapy or health activities that are informed by or based on research findings.

Research Methods: how the research will be conducted; the strategies and techniques that researchers use to collect data**.** Research methods include participant observation, questionnaires, focus groups, case studies etc.

Research Process: steps undertaken to reach the goal of the research. This process is to produce new knowledge or deepen understanding of a topic or issue. The research process is shown in the illustration below.

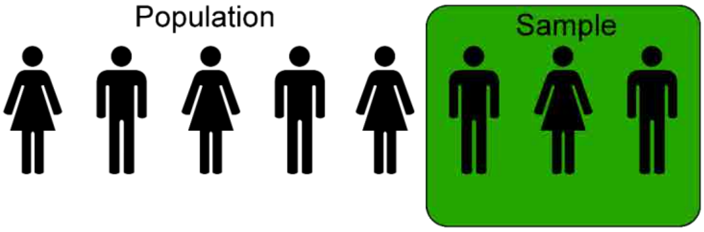


Retrospective Study: a longitudinal study that looks back in or over time. Example: researching adults on the spectrums experiences of bullying in childhood.

Rigour: the extent to which the research will stand up to investigation by future researchers and critiques.

S

Sample: a group of people, chosen from the population of interest, to participate in research or an experiment. It may also mean the product being tested. Example: '… a sample was chosen to test for drugs.'



Social model of disability: attributes the experience of disability to society and the environment rather than an in built impairment in the person. For example, not having a wheelchair ramp to a building is disabling, as are negative societal attitudes.

Statistical significance: the result is likely to be attributable to a specific cause, rather than having occurred by change alone. A p-value is statistically calculated and if this is below 0.05, or sometimes 0.001, then the results are considered statistically significant. In this instance, the **hypothesis** is supported.

Subject: may refer to the idea, heading, concept or matter under discussion: example, the subject for the research. It may also be used to label the research participants for the research, example: the subjects were assigned to either the experimental group or the control group.

Summary: the condensed form; a shortened version; to sum up or put a conclusion to the work.

Supervisor: person with a PhD who oversees and advises students undertaking Honours, Masters by research, or PhD study.

Survey: a method of data collection in which participants respond to a series of questions. Surveys may include check boxes, rating

Symposium or conference: a gathering for academic sharing or a coming together to hear the work presented.

Systematic review: a type of literature review that evaluates and synthesis results of multiple studies that meet specific inclusion criteria.

T and V

Theme: group of alike data. See **thematic analysis.**

T scores: standardised statistical scores used to compare two means (averages) to establish whether there are any statistically significant differences between them.

Terms of Reference (TOR): the terms of the agreement that refer to the expectations, boundaries and other procedures that are laid out in a contract or document.

Thematic analysis: a categorizing strategy for analyzing qualitative data.
Researchers review their data, make notes sort it into categories or **themes.**

Validity: an indication of how sound the research is. Applies to the research methods and design.

Variable(s): the characteristic or attribute of an individual, group, system or the environment that is of interest in a research study. All research projects are based around variables, which can also be called **factors**.

Example, a variable in an education program may be the individual teacher presenting the material to be learned.

Verbal: Able to use spoken language.

W, X, Y and Z

Window: a defined period of time; a view or opportunity to take a clear look at a behaviour or event. Example: there was a window of opportunity each day to observe teachers reading to students.

X: typically the horizontal and axis on a graph.

Y: typically the vertical axis on a graph.

Z-scores: a standardised statistical measurement used to show how far and in what direction an item deviates from its distribution's mean. It is expressed in units of its distribution's standard deviation.

Glossary of Metaphors

Beer and skittles: a common expression used to imply something is or isn’t fun. For example, ‘it takes a lot of work; it’s not all fun and games

Gangbusters: originally meant with great initial excitement, speedily, with a strong start, or with immediate success. The idiom originally came from the midcentury American radio program *Gang Busters*, which began each episode with great excitement and vigor (i.e., with lots of loud sound effects).

Guinea Pig: a generic term that implies an individual is consenting to take part in an experiment; a test case. Based on the fact that animals such as guinea pigs were used a lot for experimental testing. Example: “i need some guinea pigs to eat this special dietary food for a week and tell me if it made them feel better’’. Also used to describe times when you feel you are being experimented on without consent.

Hell for leather: going as hard and fast as one can manage. Example: driving your car as fast as it can go, dancing with as much exuberance as possible.

Housekeeping: information provided at the start of a conference or session that relates not to the content but to the management of the session. Example: instructions for responding to a fire alarm; pointing out where the toilets are, giving of general information that people need to have to keep safe and comfortable.

Ice breaker: a term used to denote a game or activity designed to facilitate people who have just met getting to know something about each other.
In a nutshell: term used to state the summary of events or circumstances but in a concise manner**.**

In the deep end: implying a person will be moving into a situation they are not prepared for and won't know what to expect. Can also mean willingly trying something new and giving it your best effort even though it is unfamiliar.

In the same boat: used to imply 'we are in this together' and that whatever affects one affects all. Also can mean a separate group or person who is involved in a similar situation. Example: another person in a different company also lost their employment and so are in the same boat as you.
Jump in boots and all: used to suggest a person chooses to take on a challenge, whatever it may bring.

Lab rat: implies an individual has offered to allow themselves to be the test case for a venture (see also **guinea pig**) Example: agreeing to test a new system in the workplace.

Lone soldier: someone who takes on the work, the fight, the battle on their own and doesn't call on support from others.

Nitty gritty: the possible uncomfortable and mundane details of an event, project or task that may not be glamorous but needs to be done.

Out of the blue: a term used when an unexpected thing that happens.

Pear shaped: when plans or events don't work out as hoped. When it all goes wrong.

Reinvent the wheel: used to suggest this has been done before and doesn't need doing again. In other words, there is no need to create a new way to do something when the current way is perfectly satisfactory.

Role play: to act out and/or demonstrate a scenario.

Sounding them out: testing to ascertain how someone feels about taking part in a task or taking on some responsibility. May also refer to testing out how an idea or a speech or a plan etc. sounds to another person.

Straw man: a term used to suggest something isn't very strong or not up to the job. Straw man is also common form of argument and is an informal fallacy based on giving the impression of refuting an opponent's argument, while actually refuting an argument which was not advanced by that opponent.

Talk to the paper: when a person or persons explain the information, analogies, diagrams and so on, that are written down on a paper or poster. The paper or poster might be on show at a conference.

Top and tail (topping and tailing): an expression used when a researcher gives information about the introduction and conclusion of a project but leaves the middle details out.

Win/win: a term used when all stake holders win, whatever side they are on. A positive outcome for all involved.

Winging it: meaning to pass or get by without full access to the whole story. For example: to make a presentation without preparation.

APPENDIX D: CO-PRODUCED OPEN LETTER TO RESEARCHERS

AutismCRC
Research Academy

January 2016

Dear Autism Researchers,

At the Inaugural Research Academy held in October 2015, fourteen autistic adults met to learn with and from each other and researchers about the processes involved in engaging in peer research. At this workshop, it became evident that many of us had previously had a range of experiences with research projects and researchers. The group felt quite strongly about these experiences, hence we have decided to write an open letter to researchers in this regard.

Our experiences of participating in autism research to date have been more negative than positive.

The positive aspects of participating in research have included:

- the experience of being interviewed; and,
- generally positive interactions with researchers.

However the negative aspects of participating in research have often outweighed the positive and have included:

- difficulty in obtaining information about the research and getting in contact with researchers when needed;
- not receiving reports on the research/findings/our individual results when researchers have promised to distribute them;
- a sense of being clinically examined during research session;
- researchers not asking for feedback regarding how my results were interpreted;
- feeling pressure to participate in research for “the greater good”; and,
- feelings of coercion regarding the use of experimental drugs and subsequent post-traumatic experiences.

In an effort to improve engagement with the autistic and autism community, we brainstormed a number of ways that researchers could enhance our experiences and support effective participation by autistic adults in research projects and processes.

To increase positive experiences of research participation we need:

- communication on ***both*** sides – a willingness to really understand what we are saying and a willingness to adapt communication strategies to meet our needs;
- explanations that ***we*** can understand in a format that makes sense to ***us*;**
- to be treated individually and flexibly, not based on a stereotypic view of autism; and,
- to know how to give researchers' feedback and be honest about our experiences.

To help ensure our effective participation we need researchers to:

- ask us questions instead of assuming what we might mean (e.g. asking "what do you mean by that?");
- understand that we may need support, such as from an advocate/ buddy/ mentor to help us get our message across during interviews or research sessions;
- enable us to have something written to help us respond to questions so we can read or use this if necessary, this can be facilitated by providing questions ahead of time, so that we can consider our responses rather than being put on the spot.

As a result of attending the Research Academy, we are keen to engage as peers with autism researchers, to be involved in research teams, advisory groups and provide feedback on research tools and approaches.

APPENDIX E: CO-PRODUCED INCLUSIVE RESEARCH PRACTICE GUIDES AND CHECKLISTS

Inclusive Research Practice Guide 8:

Evaluation of Research Outcomes and Impact

> *We will use processes that ensure people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*
>
> *We will ensure that people on the spectrum and their families play a central role as both research participants and where appropriate as co-researchers, and that their input is respected and their voices validated throughout the research process.*

Consistent with the *Autism CRC Statement on Inclusive Research Practices* (practices 1 and 4), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum (taking into account their strengths as well as areas in which they may require more support) in the evaluation of research outcomes and impact. Evaluation of research outcomes and impact is an important but sometimes forgotten stage of the research process.

This process involves comparing the results achieved by the project and the predetermined objectives. It also involves drawing conclusions and evaluating the relative success of the activity, what it might mean for Autism CRC partners, stakeholders (including end-users on the spectrum) and all involved. The process of measuring and evaluating various elements of a research project should be ongoing, providing information and insight that enables the research team to monitor, track, assess, modify, improve and report on the value of their efforts in the short and longer term.

It is useful to develop a monitoring and evaluation plan from the outset of the research project, as a way of tracking whether key project milestones are delivered on time and on budget. This plan can be reviewed at regular research team meetings as a way of keeping the team focused and on track. Additionally there is a specific focus of evaluation at the end of the project that focuses on the research outcomes. At a later stage, research impact can be addressed as it is translated into everyday practice, policy, processes or services; but this takes time. It is, however, useful for the team to consider research impact and how it might be measured/addressed from the outset.

Monitoring and Evaluation Plans

These plans (1) describe how project achievements are to be measured, (2) document consensus to enable transparency, accountability and responsibility, (3) guide implementation, and (4) preserve team memory. In developing a monitoring and evaluation plan, these should be useful (assist with decision making, resource allocation, assessment of performance), feasible (realistic and practical), ethically sound, and accurate.

Key components that should be discussed by the team with input from those on the spectrum include:

- What does the research project want to change and how?
- What are the specific objectives leading to change?
- What are the indicators (of change) and how are they measured?
- What will project success look like?

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- How will the monitoring and evaluation data be collected and analysed?
- What will be the impact of the research on end-users?

Steps in Developing a Monitoring and Evaluation Plan

1. Engaging with end-users and stakeholders

Stakeholder and end-user consultation is critical and their participation should be regular, relevant and timely. See Inclusive Research Practice Guides 2, 3, and 4 for assistance here. It is critical to understand various perspectives and integrate these into the plan. The authentic needs of the end-user groups and what impact will look like for these groups must be articulated. What will be better? Changed? And How? Promoting participation of individuals on the spectrum, and where relevant carers/parents, helps to clarify expectations and provides a sense of involvement, ownership, and responsibility.

2. Developing the plan

It is important to identify project inputs, outputs, outcomes and impact.

Project inputs refer to the elements that team members and partners bring to a research project, such as financing, in-kind support (e.g., data bases, access to schools, research labs) and the lived experience of being on the spectrum. These are used within the project in order to carry it out.

Research activities are those activities undertaken within research projects including education, communication and engagement activities.

Research outputs are products, training packages, educational outputs (PhD students or teachers trained) or activities resulting from the CRC research. Sometimes these are referred to as deliverables. What is to be produced or undertaken? What is to be delivered?

Research usage refers to how the research is utilised, for example, how many students trained, teachers undertaking professional development, GPs who access health resources developed by a CRC project, adults engaged in employment who used our vocational/educational tools. Who and how many ‘used’ our products?

Research outcomes refers to what happened as a result of the research outputs and activities. These may include changes in behaviours, attitudes, policies, school practices and funding systems.

Research impact describes the effects and outcomes of the research in terms of value and benefit as a result of research outputs/products. These may include health gains, productivity gains, increased school or employment success and the monetary (economic) and social value/benefit of these outcomes. Each project will have its own way of specifying likely research impacts. Those on the autism spectrum have a special role to play in identifying research impact and its measurement within the autistic community.

Consensus should be reached among the research team based on input from advisory groups and the consultations undertaken regarding the project objectives, what is expected to change, and what impact this will have. This will enable identification of the elements that need to be measured and how these will be measured.

3. Determine the methodology

This requires consideration of the theoretical framework, appropriate methods for data collection and analysis, and how information will be recorded, analysed and reported. Resource availability, cost and time also need to be considered. Individuals on the spectrum are able to provide researchers important perspectives and critique on measurement of research outcomes and their utility, from the perspective of the lived experience. Also on methods of data collection that are suitable within the autistic community and interpretation of findings that seek to understand the autistic perspective. As the outcomes Autism CRC seek may relate to transforming the lives of people on the spectrum, theirs is the ultimate perspective on which our research rests in order to determine success regarding efficacy and impact. Our research must not only include but value highly the perspective/s of those on the autism spectrum in evaluating success. Other Inclusive Research Practice Guides provide assistance with this- particularly Guides 2, 3, and 6.

4. Assign responsibilities for implementation

The roles and responsibilities of various stakeholders need to be described for accountability and reporting.

5. Setting targets

Targets set with stakeholders enable everyone to understand what the plan is expected to achieve. These need to be realistic however there may need to be flexibility regarding change in direction over time. There may be a need to respond to new events, opportunities and issues over time.

6. Defining reporting, dissemination and utilisation of results

End-users information and learning needs must be addressed throughout to ensure utilization of findings from the research project. Preliminary findings can be presented at strategically timed user meetings/workshops, such that they are tailored to specific stakeholders' interests and needs. Content and format will need to vary with end-user needs and the audience- keeping a careful eye on technical language and complexity. As discussed in Inclusive Research Practice Guide 9, identification of appropriate outlets and means of dissemination will be important- enhanced by the views of those on the spectrum informing researchers or as peer researchers on teams.

Measuring the Impact of Research

Examples of impact outcomes include indicators that demonstrate:

- Change in understanding of autism, subtypes, schooling, adult life etc.
- Enhancement of health and well-being in autistic community members as a result of research outputs/activities
- Contribution to the knowledge base for both the autistic community as well as researchers
- Change in clinical, diagnostic, educational, employment or research practice
- Implementation of policy or legislation in areas such as education, employment, health, disability
- Extent of interdisciplinary research
- Scientific impact
- Collaboration patterns

- Research productivity
- Publication practices
- Economic benefits
- Citation impact (number of times researchers are cited in other publications)

The Becker Medical Library Model for Assessment of Research Impact provides a list of indicators to document evidence of research impact:

- Advancement of knowledge
- Clinical implementation
- Implementation (community, relevant services, school based implementation)
- Community benefit
- Legislation and Policy
- Economic benefit

How to Build Pathways to Impact

- Build relationships and networks including those with individuals on the autism spectrum
- Cultivate champions within your team including individuals on the spectrum Ideas travel through networks and relationships – foster these
- Ensure the pathways to impact are active before and during a research project and soon after
- Develop expertise in your field and be a trustworthy source of evidence
- Address areas of policy interest
- Get decision makers involved in the research
- Join relevant committees and insert your findings into decision making
- Consider Action Research designs
- Don’t wait for publication. Disseminate early (See Inclusive Research Practice Guide 9)
- Be opportunistic
- Present, present, present the research findings

References

World Health Organisation (2014). Monitoring and Evaluating an Implementation Research Project. Module 6. http://www.who.int/tdr/publications/year/2014/participant-workbook6_030414.pdf

https://becker.wustl.edu/sites/default/files/becker_model-reference.pdf

Useful Resources

University of Kansas (2015) Toolkit on Evaluation. http://ctb.ku.edu/en/evaluating-initiative#node_toolkits_full_group_outline

The Community Tool Box is a public service of the University of Kansas. It is developed and managed by the KU Work Group for Community Health and Development and partners nationally and internationally. The Community Tool Box is a part of the KU Work Group's role as a designated World Health Organization Collaborating Centre for Community Health and Development

Section 1. Measuring Success: Evaluating Comprehensive Community Initiatives Sections 1-8

http://ctb.ku.edu/en/table-of-contents/evaluate/evaluate-community-initiatives/measure-success/main

See Checklist 7: Practices that Support Evaluation of Research Outcomes and Impact co-developed by Sylvia Rodger, Wenn Lawson, Olivia Gatfield, Julianne Higgins and Joel Wilson.

Checklist 7:
Practices that Support Evaluation of Research Outcomes and Impact

Autism CRC aims to support the participation of individuals on the spectrum and their families in research evaluation. This checklist will help peer researchers to check that they are considering key aspects which can increase the voice of the lived experience in project evaluation.

1. Considerations prior to commencing the project

Prior to commencement the team should consider questions related to the project outcomes, likely impact, and evaluation.

Questions	Yes	No	Unsure
What do you want to change and how?			
What are the specific project objectives leading to change?			
What are the indicators of change and how are they measured?			
What will project success look like?			
How will the monitoring and evaluation data be analysed?			
What will be the impact of the research on the lives of those on the spectrum?			

2. Developing a monitoring and evaluation plan

2.1 Engaging with end-users and stakeholders

Questions	Yes	No	Unsure
Have you planned for regular, relevant and timely engagement with end-users and stakeholders?			
Have you asked what project impact will look like for these groups?			
Have you considered the authentic needs of the end-users who will benefit from the project?			

2.2 Developing the Plan

Questions	Yes	No	Unsure
Have you identified project inputs (the elements that team members and partners bring to the project including the lived experience of being on the spectrum)?			
Have you identified the research activities undertaken within the project, such as education and communication?			
Have you identified research outputs, sometimes called deliverables, such as products, training packages, educational outputs?			
Have you identified how the research will be utilised, such as whom and how many people will use the outputs?			
Have you identified research outcomes which are what happened as a result of the research activities and outputs (e.g. change in behaviour, attitudes, policies, school practices)?			
Have you considered research impact- that is, the effects or outcomes of the research in terms of value and benefit as a result of the outputs?			
Have you ensured that individuals with the lived experience have provided input into the research impacts and their measurement?			

2.3 Determine the methodology

Questions	None	Some	The majority
Have you agreed on methods of data collection, analysis and reporting?			
Have those with the lived experience provided input into the research outcomes and their utility?			
In analysis of findings have you sought to understand the autistic perspective?			

2.4 Assign responsibility and set targets

Questions	None	Some	The majority
Are expectations of all involved clear?			
Have roles and responsibilities been described and agreed?			
Have you set targets /timeframe milestones with end-users and stakeholders so all are clear on expected progress?			

2.5 Reporting, dissemination and utilisation of results

Questions	Yes	No	Unsure
Have you addressed end-users information and learning needs throughout to ensure utilisation of findings?			
Have appropriate dissemination avenues been considered to meet end-users needs and those of other stakeholders?			
Have you varied language, style and format to meet various end-user and stakeholder needs rather than researcher needs?			
Have you considered technical language and complexity, and adjusted where required?			

See Inclusive Research Practice Guide 8: Evaluation of Research Outcomes and Impact, co-developed by Sylvia Rodger, Wenn Lawson, Olivia Gatfield, Julianne Higgins and Joel Wilson.

Inclusive Research Practice Guide 9:

Disseminating and Utilising Findings

> *We will use processes that ensure people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*
>
> *We will ensure that people on the spectrum and their families play a central role as both research participants and where appropriate as co-researchers, and that their input is respected and their voices validated throughout the research process.*

Consistent with the *Autism CRC Statement on Inclusive Research Practices* (practices 1 and 4), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the autism spectrum in the dissemination and utilisation of findings. The Guide takes into account individuals' strengths and areas in which more support may be required. Dissemination, utilisation of findings and translation of these into practice is an important but sometimes forgotten stage of the research process. Dissemination is a key responsibility of all researchers as it is particularly important in 'closing the loop' for research participants and funding agencies. Essentially, dissemination refers to sharing the research findings with target audiences who will benefit from the study. These target audiences reach beyond the traditionally narrow realms of academia: researchers, conference attendees, and peers who read research journals. Whilst these are important audiences, responsible dissemination demands that a wider audience/demographic receives these research findings. It is vital that access to the findings is promoted and facilitated particularly to those on the autism spectrum, research participants, families/carers, service providers, Government policy makers, employers, and depending on the focus of the study- education and health professionals. Dissemination is a condition of some funding bodies and is critical within the Autism CRC as knowledge translation and utilisation are key outputs/ deliverables. Findings cannot be used or translated into practice if they are not made public.

Planning for Dissemination

Dissemination works best when it is considered and planned for from the outset. Therefore, it is wise to develop a publication plan or strategy with the whole research team.

This plan needs to be reviewed regularly, as the research being undertaken is modified.

Various publication avenues need to be considered, not only for the technical findings (scientific journals) and conferences, but also for the autistic community and whatever agencies, government, schools or other bodies might benefit from the findings.

It is prudent to consider and document the people assigned responsibility for various aspects of the dissemination strategy.

It is critical that input from peer researchers and/or advisory group members on the autism spectrum is sought in order to ascertain the most efficient and successful means of accessing the autistic community and providing feedback to research participants.

It is always best to start early.

What are the Components of a Dissemination Plan?

Developing a dissemination plan can facilitate translation of the research into practice. A plan involves the following elements:

1. Research findings and products – what is to be disseminated?
2. End-users – who will it apply to or who will apply it in practice?
3. Dissemination partners – through which individuals, organisations and networks can end-users be reached? Peer researchers or advisory group members have a really important role to play here.
4. Communication – how will research outcomes be conveyed?
5. Evaluation – how will what worked be determined?
6. Dissemination work plan – where will we start?

Some useful tools to help develop a dissemination plan can be found at:

> Carpenter, D., Nieva, V., Albaghal, T., & Sorra, J. (2005). Development of a planning tool to guide research dissemination. *Advances in Patient Safety: From Research to Implementation, 4,* 83-91. Retrieved from http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/advances-in-patient-safety/vol4/planningtool.html
>
> http://www.ahrq.gov/qual/advances/planningtool.htm

Forms of Dissemination

There are many forms of dissemination as seen in the table below.

Written	**Oral / Audio Visual**	**Visual**	**Other**
Journal articles/papers	Conference posters	Posters	Poetry
Reports	Public talks/lectures	Visual summaries	Plays
Books/chapters	Conference presentations	Exhibitions	Art work
Executive summaries	Talks for special groups	Videos	Dance
Newsletters (mail/email)	Radio	Photo-voice galleries	Music
Newspaper articles – press releases	Television	Power-point slide shows	
Online media articles	You Tube clips		
Websites	Video/films/documentaries		

Facebook	Websites		
Twitter	Seminars		
Blogs			
Policy briefs			

Who is the Audience? Are there Different Audiences for Different Components of Research Findings?

It is really important to firstly identify the audience/s and the messages appropriate for each demographic/group, then consider how the messages might best be conveyed. Audiences might include researchers, professionals/ clinicians across health, education, employment, early intervention, school sectors, government departments, service provider organisations, individuals on the spectrum, parents/carers of those on the spectrum, and the lay public to name a few.

Being clear about the audience and their needs, abilities, and interests is critical. Those with the lived experience, such as individuals on the spectrum and parents/carers of those on the spectrum will provide significant insights regarding understanding the specific demographic/audience and the key messages and dissemination strategies they feel will be most suitable for the audience with whom they identify.

How to Choose the Right Form of Dissemination for Research Findings?

- Know the audience/s
- Consider audience needs, abilities, interests
- Identify key messages for specific audiences – it is likely that there will be slightly different messages for different audiences
- What will make the most impact?
- Engage with peer researchers to determine messages and the right form of dissemination
- Consider age/stage of audience, literacy levels, preferred modalities and level of knowledge likely in that community to date

Faster Routes

Given the time taken from submitting papers to academic journals to publication can be between 3 and 24 months or longer, this contributes significantly to the research-practice gap. Final reports may also be embargoed until publication is approved (and manuscripts are in press). Hence faster routes for dissemination may need to be sought. Some of these include:

- Blogs
- Tweets
- Facebook
- Mobile phone texts
- Websites

- You Tube
- Newsletter updates
- Conferences
- Public talks/ presentations
- Workshops

When considering using faster routes, it is important to consider the impact of using these on future publication in journals, chapters, formal written reports and so on.

Dissemination Approaches

Dissemination or knowledge translation activities essentially fall into two types, end-of-grant and integrated knowledge translation activities.

- **End-of-grant** activities are focused on translating knowledge into effective communication tools and disseminating those to a particular audience and present completed findings. These come after the research.
- **Integrated** approaches allow for more innovation and are effective in providing timely solutions and release of findings. They are more dynamic and involvement of stakeholders (particularly those on the spectrum or other target groups such as professionals/clinicians) is crucial.

  In all of the research team's considerations it is important to determine the extent of the resources at your disposal as some dissemination avenues can be expensive and require specific expertise (videos, films, exhibitions) and ensure you can work within your budget. Importantly it is worth considering timing and windows of opportunity which may be strategic for your findings to reach the widest possible audiences (e.g., book launches at conferences, media releases aligned with Autism Awareness week, workshops at events, policy briefings at a time particular discussions are happening at a government level).

  End-users on the spectrum can be of assistance with writing and reviewing the key research messages for their community. They may also provide ideas for dissemination by informing the team about forthcoming events and activities within the autistic community, the release date of various advocacy group newsletters, and the means of accessing the particular organisations such as autism group/advocacy network email lists. Apart from access, those on the autism spectrum will also provide valuable insights into the culture of specific groups, based upon their intimate knowledge and their lived experience, as to what has the best chance of being mutually beneficial and what might be best avoided.

References

World Health Organisation, (2014). Toolkit for Research and Training in Tropical Diseases. Module 5 Disseminating Research Findings. http://www.who.int/tdr/publications/year/2014/participant-workbook5_030414.pdf

See Checklist 8: Practices that Support Evaluation of Research Outcomes and Impact, co-developed by Sylvia Rodger, Wenn Lawson, Olivia Gatfield, Julianne Higgins and Joel Wilson.

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Checklist 8:
Practices that Support Evaluation of Research Outcomes and Impact

Autism CRC aims to support the participation of individuals on the spectrum and their families in research dissemination and utilisation. This checklist will help peer researchers to check that they are considering key aspects which can increase the voice of those with the lived experience in disseminating, translating and utilising findings. Those on the spectrum will have specific insights into how best to engage with the autistic community and the appropriate messaging.

1. Planning for dissemination

Making research findings public is the only way to ensure that they can be translated into practice, however, translation of knowledge requires more than just making findings public.

Questions	Yes	No	Unsure
Are you considering dissemination from the outset of the project?			
Are you clear about the likely avenues for dissemination for this project?			
As well as considering scientific journals and conferences, have you identified other avenues for dissemination?			
Are you planning opportunities for co-presenting findings/outcomes with people on the spectrum?			
Have you considered what agencies, systems, government departments or other bodies might benefit from the findings?			
Have you developed with your peer researchers/advisors, a strategy for engaging with the autistic community?			

2. Components of dissemination

2.1 Forms of dissemination

Questions	Yes	No	Unsure
Have you considered written forms of communication and who they might suit best?			
Have you considered oral/audio visual means of communication and who they might suit best?			
Have you considered visual means of disseminating findings (e.g. posters, exhibitions, visual summaries)?			
Are there other means of dissemination (e.g. poetry, plays, art, dance, music) that might be best for a particular audience?			

2.2. Considering the audience/s

Questions	Yes	No	Unsure
Have you identified your audience/s?			
Have you identified which findings/outcomes are best suited for which audience?			
Have you considered the needs, interests, and abilities of your various audience/s and how best to engage with them?			
Have you considered which key messages need to be addressed with which audiences (where relevant)?			
Have you considered who is best to present to which audiences? Has co-presenting been considered?			
Have you ensured that individuals with the lived experience have provided input into the dissemination strategy and key messages for various audiences?			

2.3 Dissemination approaches

Questions	None	Some	The majority
Have you considered social media, blogs, tweets, Facebook and/or YouTube videos including potential risks and their management?			
Have those with the lived experience provided input into the dissemination strategy?			
Have you considered integrated (as you go) as well as end of grant activities?			
Have you realistically considered the resources (e.g. budget and human resources) available?			

2.4 Reporting, dissemination and utilisation of results

Questions	Yes	No	Unsure
Have you addressed end-users information and learning needs throughout to ensure utilisation of findings?			
Have appropriate dissemination avenues been considered to meet end-users needs and those of other stakeholders?			
Have you varied language, style and format to meet various end-user and stakeholder needs rather than researcher needs?			
Have you considered technical language and complexity, and adjusted where required?			

See Inclusive Research Practice Guide 9: Disseminating and Utilising Findings, co-developed by Sylvia Rodger, Wenn Lawson, Olivia Gatfield, Julianne Higgins and Joel Wilson.